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## ALZHEIMER EUROPE NEWSLETTER

# HIGHLIGHTS IN THIS ISSUE 6 January: Global dementia numbers set to triple by 2050 13 18 January: EAA members elected to senior Parliament positions 8 26 January: Innovative Health Initiative is launched 10 27 January: EASPD event looks at social impact of dementia 2

#### WELCOME



Kicking the year off with a disability focus, we were delighted to speak at an EASPD (European Association of Service providers for Persons with Disabilities) "Knowledge Café" on the topic of the social Impact of Alzheimer's

dementia. I presented the work and campaigns of Alzheimer Europe; Chris Roberts, Chair of the European Working Group of People with Dementia shared his experiences of dementia and expectations regarding dementia-inclusive services; and Dianne Gove, Director for Projects, gave a presentation about dementia as a disability, focusing on the ethical challenges linked to supporting people with dementia, particularly with regard to personal identity and hidden disability.

We were also invited to contribute to Health Europa Quarterly, with an article outlining the need for dementia to be prioritised as a policy matter, which focused on areas such as prevalence, practice and prevention. We highlighted that significant also improvements are needed in dementia care. The urgency of these points is starkly illustrated by a new demographic analysis in the January issue of the Lancet Public Health journal which, similarly to Alzheimer Europe's 2019 Yearbook on dementia prevalence, forecasts that current numbers will triple by 2050.

January saw the launch of the new Innovative Health Initiative (IHI) which aims to build on the successes of the Innovative Medicines Initiative. The IHI is still a European publicprivate partnership dedicated to advancing health research and innovation, but working across a broader range of sectors, with new partners and an updated governance structure. The launch event, which I attended together with other members of the team, was highly informative and we look forward to continuing our work on current and future projects supported by the IHI.

Members of the European Alzheimer's Alliance have been elected to senior positions within the European Parliament. Roberta Metsola MEP (Malta) was elected as President of the European Parliament, Dimitrios Papadimoulis MEP (Greece) and Heidi Haultala (Finland) were elected as Vice-Presidents, and Christophe Hansen MEP (Luxembourg) and Anne Sander MEP (France) were elected as Quaestors. I offer my warm congratulations to them all and look forward to our continued collaboration. Also at the European level, the Commission

has formally adopted the EU4Health Work Programme 2022, while the Council of the EU has adopted the Regulation enhancing the mandate of the European Medicines Agency, strengthening its role in crisis preparedness and management for medicinal products and medical devices. The latter will come into force on 1 March 2022.

Finally, I want to give a special mention to Alzheimer Europe Board member Pat McLoughlin, who is stepping down from his position as CEO at The Alzheimer Society of Ireland. We wish Pat all the very best in his retirement and a speedy recovery and are grateful that he will be able to remain on the Board of Alzheimer Europe.

Jean Georges
Executive Director



## Help us give a voice to people with dementia

### **Donate**



#### **ALZHEIMER EUROPE**

### 18 January: AE adds new trials to its Clinical Trials Watch



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

that are investigating drugs for the prevention and/or treatment of dementia and/or Alzheimer's disease. In January 2022, five new Phase III trials have been added to the service:

- EVOKE (Novo Nordisk A/S)
- EVOKE Plus (Novo Nordisk A/S)
- APOLLOE4 (Alzheon Inc.)
- GREEN MEMORY (Green Valley (Shanghai) Pharmaceuticals
   Co)
- AHEAD 3-45 (Eisai).

Further information about the CTW is available on:

https://www.alzheimer-europe.org/research/clinical-trials

### 20 January: Alzheimer Europe article featured on Health Europa website

Alzheimer Europe has contributed to Health Europa Quarterly, outlining the need for dementia to be prioritised as a policy matter. Written by Alzheimer Europe Policy Officer, Owen Miller, the article includes a focus on areas including

prevalence, practice and prevention, as well explaining that significant improvements are needed in dementia care.

The article is focused around four key questions:

- What is the significance of early diagnosis in treating and ensuring support for people living with dementia?
- What are the key symptoms or indications of Alzheimer's disease and other dementias? What treatments are recommended?
- With ageing populations projected to cause significant increases in dementia, what should be done at a policy level to mitigate the effect of Alzheimer's disease, and other dementias on patients and the healthcare system as a whole?
- Are there any notable developments or current issues in research or treatment of Alzheimer's disease which you would like to highlight?

In addition, the article addresses a range of subjects including the increasing prevalence of the condition, the need for a greater focus on prevention and the recent European Medicines Agency (EMA) decision around aducanumab.

The full article is available at:

https://www.healtheuropa.eu/enhancing-brain-health-throughoptimising-dementia-care-and-diagnosis/112934/

### 27 January: EASPD Knowledge Café looks at the social impact of dementia



On 27 January, the EASPD (European Association of Service providers for Persons with Disabilities) Knowledge Café addressed the topic of the social Impact of Alzheimer's dementia. The webinar was opened by Maya Doneva (the Secretary General of EASPD) and followed by a presentation by the Coordinator of the Co-Care project. Jean Georges, Executive Director of Alzheimer Europe, then gave a presentation about Alzheimer Europe and its campaign to make dementia an EU policy priority in which he described various policy challenges, Alzheimer Europe's various campaigns to bring about change,



key reports produced by Alzheimer Europe on policy and ethical issues, and the focus of EU presidencies in relation to dementia as well as EU Joint Action programmes and funding for dementia research. This was followed by a speech by Chris Roberts, Chair of the European Working Group of People with Dementia, who talked about his personal experience of dementia and his expectations regarding dementia-inclusive services. Finally, Dianne Gove, Director for Projects of

Alzheimer Europe, gave a presentation about dementia as a disability, focusing on the ethical challenges linked to supporting people with dementia, particularly with regard to personal identity and hidden disability. Over 30 people attended the virtual Knowledge Café and there was an interesting dialogue between the participants and presenters at the end about a range of related issues such as legal capacity, guardianship measures, institutional care and inequity.



### **Alzheimer Europe networking (online)**

- On 12 January, Angela participated in a meeting of the EMA raw data advisory group.
- On 13 January, Ana and Dianne attended the RADAR-AD Steering Committee meeting.
- On 17 January, Ana attended the INTERDEM task force meeting on prevention.
- On 17 January, Jean and Dianne had a meeting with the European Association for Service Providers for People with Disabilities.
- On 19 January, Jean attended the Biogen Patient Advisory Group meeting.
- On 19 January, Cindy attended the Al-Mind Executive Board meeting.
- On 20 January, Ana and Dianne participated in the RADAR-AD qualification advice meeting.
- On 20 January, Jean and Owen attended a meeting of the EU4Health Civil Society Alliance.
- On 20 January, Jean attended an information meeting of DG SANTE on operating grants under the health programme.
- On 21 January, Jean had a meeting with the European Public Health Alliance.
- On 24 January, Chris attended a Financial Times webinar on supporting Pharma Innovation in Europe, jointly organised with EFPIA.
- On 24 January, Angela attended a webinar on obesity & mental health for the PRIME project.
- On 24 January, Cindy participated in an EPAD communications meeting.
- On 25 January, Cindy attended the PRODEMOS WP leads meeting.
- On 25 January, Dianne, Ana and Angela participated in an EWGPWD meeting.
- On 25 January, Owen attended an ENSA webinar on "Quality of life: post Covid challenges and opportunities for seniors, professionals and persons with disabilities".



On 26 January, Dianne and Ana attended an INTERDEM task force on technology and Covid.

On 26 January, Jean, Owen and Chris attended the launch of the Innovative Health Initiative.

On 26 January, Jean met with Biogen and Roche.

On 26 January, Ange, Chris and Jean attended an IHI/Neuronet meeting.

On 27 January, Chris attended the Brain Health meeting "How European research can join forces".

On 27 January, Angela participated in the period 2 review meeting for the VirtualBrainCloud project.

On 27 January, Angela participated in the EPND Management Board meeting.

On 27 January, Dianne attended the MinD network meeting.

On 27 January, Jean and Dianne attended the EASPD knowledge café.

On 27 January, Gwladys attended a demo at the European Convention Center Luxembourg.

On 27 January, Jean attended the Management Board of the Dementia Panel of the European Academy of Neurology.

On 27 January, Chris attended the Brain Health meeting "How European research can join forces".

On 28 January, Angela participated in an EPND communications meeting with ADDI.

On 28 January, Gwladys had a meeting with Lufthansa Group.

On 28 January, Gwladys had meetings with suppliers for the 32<sup>nd</sup> Alzheimer Europe Conference.

### Sponsors of the month

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

Read more about sponsorship opportunities here: https://www.alzheimer-europe.org/aboutus/governance/finances/2021-sponsorship-opportunities







### **EU PROJECTS**

14 January: ERA PerMed awards funding to 22 projects on personalised medicine, including the AE partner project Pattern-Cog

The results of the 2022 ERA-Net Cofund action on Personalised Medicine (ERA PerMed) funding call have just been published, heralding the launch of 22 projects which will develop clinical support tools for the implementation of personalised medicine.

Alzheimer Europe is a partner on the funded Pattern-Cog project, which is coordinated by Prof. Jussi Tokha (University of Eastern Finland) and also involves partners at Karolinska Institutet (Sweden), Charité — Universitätsmedizin Berlin, Jena University Hospital (Germany) and the Carlos III Madrid Health Institute (Spain).

Pattern-Cog stands for "Personalised aging pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals" and aims to improve dementia prevention strategies by developing and validating an Al-based framework that can detect the earliest signs of impending cognitive decline.

Findings from multidomain lifestyle trials have emphasised the importance of accurately identifying at-risk individuals who are most likely to benefit from interventions such as improved diet, structured exercise programmes and cognitive training. Pattern-Cog, which is funded for a period of 3 years from 2022, will develop methods for predicting future cognitive decline based on clinical data, identifying older adults who might be at higher risk for developing mild cognitive impairment and dementia in the future. This methodology will be tested in ongoing dementia prevention trials. Alzheimer Europe will carry





out public involvement work to explore the perspectives and views of people with cognitive impairment in relation to Albased tools for risk prediction, also supporting the communication activities of the project.

https://erapermed.isciii.es/newsletter-7/

### 17 January: RADAR-AD smart home study has kicked off

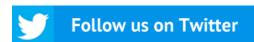


The RADAR-AD smart home study recently began. The first participant in the RADAR-AD tier 3 study was included on 25 November 2021 in Thessaloniki, Greece. The tier 3 study is a pioneer study in which participants visit RADAR-AD's smart home that utilises remote measurement technologies (RMTs) to detect and capture performance ranging from activities of daily living to physiological measurements and sleep. This is employed in a realistic domestic smart home environment to validate its efficiency and effectiveness.

The outcomes of the tier 3 study will provide RADAR-AD researchers with an insight into the potential of technological solutions to be incorporated into the daily activity of people living with more advanced stages of cognitive impairment with the goal to explain cognitive decline over time in an unobtrusive and objective way.

Read the full news story here.

RADAR-AD is a collaborative research initiative that explores the potential of mobile and digital technologies to improve the assessment of Alzheimer's disease (AD). The AD terminology in the RADAR-AD project reflects the recent conceptualisation of AD as covering the full spectrum of the disease, including both pre-dementia (preclinical and prodromal AD) and dementia phases (mild to severe AD dementia). This project builds on the knowledge and experience gained in a sister project called RADAR-CNS (Remote Assessment of Disease and Relapse – Central Nervous System), which was launched in 2016 to explore remote monitoring in people living with multiple sclerosis, epilepsy and depression.



## 19 January: EPAD project publishes interviews results with its participants on the affordances of clinical research participation

A new article entitled "Lived time and the affordances of clinical research participation" has recently been published in the journal Sociology of Health &



Illness. In this article, both authors Natassia Brenman and Richard Milne address the problem of participation and the dominant focus on motivations in clinical research. They explore participation as a relational mode of 'being in time' in Alzheimer's dementia prevention—a field profoundly shaped by changing bodies through time, as well as promissory trends towards future-oriented preventative medicine.

The authors conducted interviews with participants in the EPAD cohort study as part of a sub-study known as SPEAR: the 'Study of participant Experience in Alzheimer's disease Research'. The SPEAR sub-study aimed to better understand participation in Alzheimer's disease research, in order to improve study experience, informing future approaches to recruitment and retention and provide evidence for the assessment of ethical questions related to study participation. This was a mixedmethods study that included a survey as well as six months ethnographic fieldwork in four research facilities across the UK. Analysis of interviews with older adults in the clinical trial platform demonstrated that what research 'does' or might (not) 'do' for participants emerges as temporalities of participants' everyday lives, becomes entangled with the possibilities, constraints and demands of biomedical 'research time'. As well as consistent desires to help (future) others, authors identified incidental possibilities for care that emerged from continued research participation.

https://doi.org/10.1111/1467-9566.13374

### 21 January: LETHE project releases brochure in Italian, Finnish, German Greek and English

On 21 January, the LETHE project which aims to develop a personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning



released a project brochure. The brochure introduces the project background, the intervention technologies that will be developed to empower people to develop or maintain an active and health lifestyle as well as project partners. The brochures can be accessed here:

https://www.lethe-project.eu/media-kit/



### 24 January: LETHE project publishes its first newsletter

On 24 January, the LETHE project (A personalized prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning) released its first external newsletter and reported the important advances that have been made during the past quarter.

The newsletter covers introductions to the Advisory Board, composed of people at higher risk of developing dementia and members of the public with an interest in brain health. Apart from interesting news about the first in-person project meeting, the issue also features video interviews with Early Career researchers and the latest project updates. You can read and subscribe to the newsletter here.

## 26 January: INDUCT updates its "Best Practice Guidance - Human Interaction with Technology in Dementia" with first recommendations from DISTINCT



**INDUCT** (European Interdisciplinary Network Dementia Using Current Technology) has published an updated version of its Best Practice Guidance Human Interaction with Technology in Dementia. This is a comprehensive

#### **Best Practice Guidance**

set of recommendations on improvement of technology for people with dementia in three areas: everyday life, meaningful activities and healthcare. It also provides evidence to show how technology can improve the lives of people with dementia.

This Best Practice Guidance originally results from literature studies and field research conducted within INDUCT (2016-2020), a Marie Sklodowska Curie funded Innovative Training Network (ITN) of researchers at eight Universities in six European countries. The web-based version of the Best Practice Guidance was launched in autumn 2019 and a year later a first update was published.

In the update of the Best Practice Guidance of December 2021, the first recommendations of a second Marie Sklodowska Curie funded ITN on Technology and dementia, called DISTINCT (2019-2023) are included. The main aim of DISTINCT is to provide the evidence to show how technology can improve the social health of people living with dementia by enabling them to 1) fulfil their potential on a societal level, 2) manage their own lives and 3) participate in social and meaningful activities.

The recommendations for improving the usability, effectiveness and implementation of technology in dementia, which are presented in this Best Practice Guidance, are meant to be helpful for different target groups: People with dementia; their formal and informal carers; health care and welfare providers;

policymakers; designers; and researchers. For this reason, representatives of these target groups were consulted and involved throughout the INDUCT and DISTINCT projects.

Have a look at the website and easily navigate to the recommendations relevant to you:

https://www.dementiainduct.eu/guidance/

### 26 January: PRIME project organises a webinar on obesity and mental health

The PRIME project (Prevention and Remediation of Insulin Multimorbidity in Europe) was launched in early 2020, aiming to unravel the insulin-dependent mechanisms that link diseases such as type 2 diabetes with brain disorders, including



Alzheimer's disease (AD) and compulsivity disorders. Including 17 partners from academia, SMEs and NGOs, PRIME is using a broad range of preclinical, clinical and data-driven approaches to understand how insulin signalling might be involved in these brain disorders.

On 26 January, PRIME organised a webinar for the consortium, entitled "Mental health and obesity: addressing a double epidemic". Prof. Monica Bullo of the Nutrition and Mental Health Research Group of the Institute of Health Pere Vigili at the University Rovira y Virgili in Barcelona presented the webinar, which was chaired by Jeanette Mostert of Radboud University Medical Center. During her presentation, Monica explained that obesity and type 2 diabetes share many of the same risk factors, and themselves risk factors for cognitive impairment and dementia. There are also direct connections between obesity and type 2 diabetes: people who are obese account for 65-80% of new diagnoses of type 2 diabetes. Focusing on mental health, depression and anxiety are both linked to obesity, type 2 diabetes and dementia, with people who have depression and anxiety being at increased risk of developing these conditions. Monica explained that late-life depression is associated with a 1.85x higher risk of dementia, but that mid-life obesity is much more predictive of dementia than late-life obesity, emphasising that there are ways that people can reduce their risk of dementia in mid-life, by adopting healthier lifestyles and improving their mental health.

The next PRIME webinar will be held on 16 February, with a presentation from Prof. Henrik Larsson of Orebro University in Sweden.

https://prime-study.eu/

### 27 January: FINGER-NL has started: a study on the effects of lifestyle interventions on cognition

On 27 January, the FINGER-NL study - a two-year long intervention study researching the effect of a combination of lifestyle interventions on the cognitive abilities of elderly people - has officially started. In the FINGER-NL study, which is part of





the overarching national MOCIA project, five Dutch research institutes join forces to one multi domain lifestyle intervention. Wageningen University and Research Centre, Maastricht University, Radboud University Medical Centre Nijmegen, University Medical Centre Groningen, and Alzheimer

Centre Amsterdam will jointly research how lifestyle interventions can contribute to improving brain health of an elderly population.

Previous scientific research found that there are factors that can be linked to cognitive decline. Some of these risk factors can be influenced by making adjustments in lifestyle. A previous study conducted in Finland, with the name FINGER, found that a combination of physical exercise, healthy diet, monitoring cardiovascular health and memory training can improve the cognitive abilities in an elderly population. Recent research shows that other lifestyle factors, such as adequate sleep and relaxation may also have a positive effect on cognition. Inspired by the positive results of the FINGER study, a global initiative FINGERS (WW-FINGERS) called World-Wide established to expand the findings globally while optimizing the intervention. EU-FINGERS, a JPND project where Alzheimer Europe in involved in, is part of the global WW-FINGERS network of multidomain trials for dementia risk reduction and prevention.

In the Netherlands, the lifestyle intervention is called FINGER-NL. The personalised lifestyle programme in this study will take two years and is focused on different factors related to brain health, such as physical exercise, memory training, diet, monitoring cardiovascular health and adequate sleep and relaxation. Participants for this study are between 60-79 years old. The results of this study can be used for more specific lifestyle advice, with the goal of preventing cognitive decline amongst elderly. More information:

https://mocia.nl/scientific/research/work-package-1-finger-nl-lifestyle-intervention/

## 27 January: Take the INTERDEM survey on the uptake of technology among people with dementia during the COVID-19 pandemic!

A special INTERDEM interest group on assistive technology runs a project to explore the uptake of technology among people with dementia during the COVID-19 pandemic.



As part of this, Dr Duygu Sezgin, Prof. Dympna Casey (School of Nursing and Midwifery, National University of Ireland Galway) and Dr Laila Øksnebjerg (Danish Dementia Research Centre) are currently leading a pan-European mapping exercise. They aim to collect information from as many perspectives as possible, so they encourage professionals who have knowledge about past and current activities, initiatives and research projects addressing people with dementia's use of various kinds of digital technologies during the COVID-19 pandemic to participate in this mapping exercise.

Access:: https://interdemmappingexercise2021.questionpro.eu The deadline is **14 March 2022**.

#### EU project acknowledgements







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

**EPAD** – grant agreement 115736 **LETHE** – grant agreement 101017405 **PRIME** – grant agreement 847879 **RADAR-AD** – grant agreement 806999





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



### Members of the European Alzheimer's Alliance



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

Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). Belgium: Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). Bulgaria: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei 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 Spyraki (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); Clàudia 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 Estaräs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). Sweden: Jytte Guteland (S&D); Peter Lundgren (ECR).



## EUROPEAN ALZHEIMER'S ALLIANCE

## 18 January: EAA members elected to senior positions in the European Parliament

On 18 January 2022, a number of members of the European Alzheimer's Alliance (EAA) were elected to senior positions within the European Parliament. This included:

- EAA member Roberta Metsola MEP (Malta) who was elected as President of the European Parliament
- EAA members Dimitrios Papadimoulis MEP (Greece) and Heidi Haultala (Finland) who were elected as Vice-Presidents of the European Parliament
- EAA Vice-Chairperson, Christophe Hansen MEP (Luxembourg) and member Anne Sander MEP (France) who were elected as Quaestors of the European Parliament.

Alzheimer Europe offers its congratulations to these members in their new roles and looks forward to continued collaboration with them to help prioritise dementia at a European level.

Further information on the 2022 Work Programme can be found at:

https://ec.europa.eu/assets/sante/health/funding/wp2022\_en.pdf



#### **EU DEVELOPMENTS**

January: **Joint Programme** on Neurodegenerative Disease Research (JPND) opens 2022 call on understanding mechanisms of non-pharmacological interventions

Neurodegenerative diseases (NDs) are debilitating and largely untreatable conditions that are strongly linked with age. Worldwide, there are estimated to be 50 million people with Alzheimer's disease and related disorders, the most common class of neurodegenerative diseases. This figure is expected to double every 20 years as the population ages. The total direct and informal care costs of Alzheimer's, Parkinson's and related disorders are expected to surpass EUR 350 billion per year across the European Union. Existing treatments for





neurodegenerative diseases are limited in effect and mainly address the symptoms rather than the cause or the progressive course. With this in mind, The EU Joint Programme – Neurodegenerative Disease Research (JPND) has identified a pressing need for investment aimed at enabling research projects on understanding the mechanisms of non-pharmacological interventions, and on 4 January 2022, launched a transnational call for proposals.

Several non-pharmacological interventions have been shown to be effective and accepted by people living with NDs, e. g. from existing cohort data. Such interventions may include, among others, psychosocial interventions, neuromodulation, nutrition or exercise. Although NDs are recognised as multifactorial syndromes, there is little interaction between biomedical and psychosocial approaches. One rationale for integrating biomedical and psychosocial research is the discordance between neuropathology and cognitive functioning. However, there is yet little knowledge about the mechanisms of non-pharmacological interventions, e. g. at the molecular or cellular levels.

This transnational call invites proposals for ambitious, innovative, multinational and multidisciplinary collaborative research projects with a view to promoting research aimed at improving the understanding of the mechanisms and biological substrates that underlie non-pharmacological interventions, in order to tailor a holistic personalised treatment approach.

The total funding made available for this call is about EUR 19 million.

The pre-proposal submission deadline is 1 March 2022 and full proposals must be submitted no later than 12:00h C.E.S.T. on 28 June 2022, via the electronic submission tool.

For more information about the call, see:

https://www.neurodegenerationresearch.eu/initiatives/annual-callsfor-proposals/understanding-the-mechanisms-of-nonpharmacological-interventions/

## 14 January: European Commission adopts EU4Health Work Programme 2022

The European Commission has adopted the EU4Health Work Programme 2022, outlining how the EUR 835 million budget for 2022 will be invested, as part of the ongoing work towards the European Health Union.

The level of funding is unprecedented and focuses on four areas: crisis preparedness, disease prevention, health systems and healthcare workforce, and digitalisation. In



addition, the funding will support work around COVID-19 pandemic responses, Europe's Beating Cancer Plan, the Pharmaceutical Strategy for Europe, and the European Health Emergency Preparedness and Response Authority (HERA).

The programme will provide funding to eligible entities from Member States, associated third countries, international organisations, NGOs and the private sector in the form of grants or procurement of specific services.

Following the campaign from a coalition of NGOs (including Alzheimer Europe), EUR 9 million has been allocated to allow NGOs to apply for operating grants, as well as additional funding for action grants on various topics.

The European Commission and the Health and Digital Executive Agency (HaDEA) will manage the programme. Further information on the 2022 Work Programme can be found at: https://ec.europa.eu/assets/sante/health/funding/wp2022 en.pdf

## 25 January: Council of the EU and European Parliament agree enhanced mandate for the European Medicines Agency

The Council of the EU has adopted the Regulation enhancing the mandate of the European Medicines Agency (EMA), strengthening the EMA's role in crisis preparedness and management for medicinal products and medical devices.



The new mandate will allow the EMA to facilitate coordinated EU-level responses to health crises by:

- Monitoring and mitigating the risk of shortages of critical medicines and medical devices
- Providing scientific advice on medicines that may have the potential to treat, prevent or diagnose the diseases causing those crises
- Coordinating studies to monitor the effectiveness and safety of medicinal products intended to treat, prevent or diagnose diseases related to the public health crisis
- Coordinating clinical trials for medicinal products intended to treat, prevent or diagnose diseases related to the public health crisis
- Transferring the expert panels of the Medical Device Regulation to the Agency.

The legislation also formally establishes the Medicines and Medical Devices Shortages Steering Group and the Emergency Task Force, working on the above tasks.

Following the formal signing of the Regulation by the European Parliament and the Council, it will be published in the Official



Journal. The Regulation will enter into force on the day following its publication and will apply from 1 March 2022. The Regulation's provisions on shortages monitoring of medical devices, except for the transfer of the expert panels, will apply 12 months after the entry into force of the Regulation.

## 25 January: New European clinical trials regulation is under way to harmonise and streamline the processes for application and supervision of clinical trials in the EU

On 25 January, the European Medicines Agency (EMA) published a press release on the new Clinical Trials Regulation (Regulation (EU) No 536/2014), coming into application on 31 January 2022. This Regulation will replace the existing EU Clinical Trials Directive 2001/20/EC and national legislation that was put in place to implement the Directive. It will also apply to trials authorised under the previous legislation if they are still ongoing three years after the Regulation has come into operation.

The new Regulation harmonises the assessment and supervision processes for clinical trials throughout the EU via a Clinical Trials Information System (CTIS). This new portal will be the single-entry point for the submission of data and information relating to clinical trials in the EU. EMA sets up and maintains CTIS, in collaboration with the Member States and the European Commission. Information stored in CTIS will be publicly available for transparency.

In the past, sponsors had to submit clinical trial applications separately to national competent authorities and ethics committees in each country to gain regulatory approval to run a clinical trial, and registration and posting of results were also separate processes. With CTIS, sponsors can now apply for authorisations in up to 30 EU countries at the same time and with the same documentation.

The application of the Clinical Trials Regulation and the go live of CTIS will strengthen Europe's position as an attractive location for clinical research.

https://www.ema.europa.eu/en/news/regulatory-harmonisationclinical-trials-eu-clinical-trials-regulation-enter-application-new

## 26 January: Innovative Health Initiative (IHI) replaces Innovative Medicines Initiative (IMI)



The Innovative Health Initiative (IHI) held its launch event online, on 26 January 2022. It aims to build on the successes of the Innovative Medicines Initiative (IMI). The IHI is still a European public-private partnership dedicated to advancing health research and innovation, but working across a broader range of sectors, with new partners and an updated governance

structure. Meanwhile it will keep supporting the projects launched under IMI.

The IMI started life in 2008 as a public-private partnership (PPP) between the European Union and the European pharmaceutical industry. The initiative proved successful, and in 2014 the IMI2 programme was launched. The IMI1 and IMI2 programmes resulted in almost 200 projects covering a wide range of disease areas and addressing challenges across all areas of medical research and drug development.

Meanwhile science is driving new avenues of research and development often spanning different sectors within the life-science community, and it is clear that future breakthroughs in medical science will involve cross-sectoral discoveries, such as medical device / drug combinations or diagnostics based on artificial intelligence.

With the end of the IMI2 programme in sight, and aware of the growing importance of cross-sectoral cooperation, the European Commission decided to launch a new PPP in health. In February 2021, the Commission released its proposal to create the IHI. The proposal was formally approved by Council of the European Union, which represents EU Member States, in November 2021.

The IHI is designed to build on what worked well in IMI, address the lessons learnt, and leverage the benefits of cross-sectoral collaboration in research and innovation to better respond to current and emerging health needs.

In practice, all of this means that while some elements will stay while other things are changing significantly. Here are some of the main similarities and differences:

- As was the case in IMI, the 'public' member in the partnership is the European Union, represented by the European Commission.
- The industry members are COCIR, EFPIA (including Vaccines Europe), EuropaBio and MedTech Europe, taking IHI beyond the pharmaceutical industry and bringing on board the medical technology, biotechnology, digital health and vaccine industries.
- As in IMI, the EU will provide 50 % of the funding for IHI, and the industry members will contribute the other 50%, primarily through 'in-kind' contributions.
- IMI started with a strong focus on the pharmaceutical sector, but with growing numbers of projects in fields such as digital health, big data and imaging, the IHI plans to support truly cross-sectoral projects involving the biopharmaceutical, biotechnology and medical technology sectors, including companies active in the digital area.
- Like IMI, IHI has a Governing Board made up of equal numbers of representatives from the European Commission and the industry partners, plus a States Representatives Group (SRG) comprising representatives of EU Member States plus countries associated to Horizon Europe.



- New under IHI is the Science and Innovation Panel, an advisory body that will bring together representatives of the scientific community and the wider health sector.
- Like IMI, IHI will work by running open, competitive Calls for proposals, and will continue to publish draft topic texts before the Call launch, to give applicants additional time to work on their proposals.
- As in IMI, IHI will bring together diverse stakeholders (universities, ,large and small companies, and other health stakeholders) in collaborative projects that address disease areas where there is a big impact on patients and/or society. However, IHI expects to launch a larger proportion of truly cross-sectoral projects involving new stakeholders representing the other industry sectors.

It was also made clear at the launch, and on the IHI website, that the IHI Programme Office will continue to manage the IMI projects, many of which still have years to run.

Executive Director Jean Georges and Project Communications Officer Chris Bintener represented Alzheimer Europe at the IHI launch event.

Find out more, on the IHI website: https://www.ihi.europa.eu/

## 28 January: European Economic and Social Committee adopts care model opinion



### European Economic and Social Committee

The European Economic and Social Committee (EESC) has adopted and published an "own-initiative" opinion entitled "Towards a New Care Model for the Elderly: learning from the Covid-19 pandemic".

The opinion analyses various models of long-term care for people over the age of 65 who

have lost their autonomy or who are dependent, particularly in institutional care settings, as well as assessing the impact of the COVID-19 pandemic on the different models of care.

The opinion highlights the context of longer life-expectancies across Europe, noting the challenges and opportunities this presents, as well as related issues around autonomous, active and healthy ageing. Furthermore, the insufficient funding for care was identified as a significant issue, with Member State investment ranging from 0.3% to 3.7% of GDP. Whilst it was noted that this is linked to the individual care models themselves, it is also connected to the impact of policies resulting from the pandemic.

In addition to welcoming the European Commission's announcement on the development of a European Care Strategy, the opinion makes a number of recommendations, including:

 Advocating for greater attention to be given to care for dependent older people with long-term care needs, with this mainstreamed into EU policymaking (in view of the ageing demographics)

- Proposing the establishment of a European Observatory for care for older people, to collect statistical data, compare good practices, identify structural weaknesses in national systems, as well as provision of technical support
- Urging the European Commission and the Member States to develop principles relating to care for older people within the European Pillar of Social Rights Action Plan
- Calling for Member States to use EU Structural Funds and the Recovery Fund to provide funding to adapt housing, create cohabitation units, redevelop the various types of care home and invest in labour and services.

#### **POLICY WATCH**

28 January: Taskforce of the Beneluxa Initiative publishes Pharmaceutical Developments on Alzheimer's Disease report

On 28 January, the Taskforce of the Beneluxa Initiative entitled "Domain Taskforce Horizon



Scanning" published a report on pharmaceutical developments on Alzheimer's disease (AD) for Austria, Belgium, Ireland, Luxembourg and the Netherlands.

The aim of the Beneluxa Initiative is to ensure sustainable access to innovative medicine at affordable cost for patients in the represented countries.

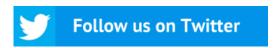
The report gives an overview of new pharmaceutical developments, lists the current treatment options, gives an overview of the estimates of the prevalence of dementia as well as the available guidelines and an estimation of the current pharmaceutical costs for this disease in the Beneluxa countries.

The main focus of the report is on the new pharmaceuticals that could enter the market between 2022 and 2027. The setup of the clinical trials, including the used biomarkers, are summarised. Also, the possible challenges, both on HTA level as on Health care level, are described.

With this report, Beneluxa aims to timely inform policy makers, healthcare organizations, payers and the general public on upcoming new pharmaceuticals and possible challenges.

The report can be downloaded here:

https://beneluxa.org/sites/beneluxa.org/files/2022-01/Beneluxa\_Alzheimer%27s\_Disease\_Jan2022.pdf







### **SCIENCE WATCH**

## 22 December: Vivoryon Therapeutics receives FDA Fast Track Designation for varoglutamstat in AD



On 22 December, Vivoryon Therapeutics N.V., a clinical stage company focused on developing innovative small molecule-based medicines, announced that the US Food and Drug Administration (FDA) has granted Fast Track designation for its lead product candidate varoglutamstat for

Alzheimer's disease (AD). Fast Track designation is a process designed to facilitate the development, and expedite the review of drugs with the potential to treat serious conditions and fill an unmet medical need, aiming to bring important new drugs to the patient earlier.

Varoglutamstat, also named PQ912, is an investigational oral small molecule medicine for the potential treatment of early AD. Varoglutamstat is currently being investigated in two Phase II clinical trials with early and mild AD: the European VIVIAD study and the recently initiated US VIVA-MIND study. The VIVIAD clinical trial remains on track for an interim safety readout in mid-2022 with anticipated final data in the second half of 2023.

https://www.vivoryon.com/vivoryon-therapeutics-receives-fda-fast-track-designation-for-varoglutamstat-in-early-alzheimers-disease/

## 23 December: Study suggests a link between non-mutated ApoE and dementia



Genetic mutations in the ε4 allele of apolipoprotein E (APOE) have been associated clinically with increased dementia risk and pathologically with increased Aβ plaque load. A new study, led by researchers from the University of Kentucky, detected the ApoE protein in dementia brains from

participants with and without the APOE ε4 risk allele. Findings were published in the American Journal of Pathology.

Researchers analysed several proteins from the amygdalae of 40 participants from the University of Kentucky Alzheimer's Disease Center autopsy cohort. The amygdala is a brain region vulnerable to mis-aggregated proteins associated with

dementia. Participants ranged from cognitively normal to severe dementia.

As expected, people with dementia had significantly higher Tau and A $\beta$  protein levels than the normal and mild cognitive impairment group. The data also revealed a close correlation between dementia diagnosis and the detection of ApoE peptides in the brain, including from people lacking the APOE  $\epsilon 4$  risk allele. Overall, the correlation for ApoE peptides with dementia was even stronger than that seen for Tau or A $\beta$ . In the present study, researchers suggested a link between the non-mutated Apolipoprotein E and dementia in the aging brain.

https://doi.org/10.1016/j.ajpath.2021.11.013

### 6 January: SciSparc starts a new Phase 2 trial with SCI-110 in AD

On 6 January, SciSparc Ltd., a clinical-stage pharmaceutical company focusing on the development of cannabinoid-based treatments, announced the recruitment of the first participant in a new Phase IIa clinical trial in Alzheimer's disease (AD).

Conducted at the Israeli Alzheimer's Medical Center, the clinical trial is evaluating the safety, tolerability and efficacy of SCI-110 in people with AD and agitation. The primary objective of the study is the safety of SCI-110 and the secondary objective is the ability of the drug candidate to ameliorate agitation and other behavioural disturbances in people with AD.

The drug candidate SCI-110 contains Dronabinol and the endocannabinoid palmitoylethanolamide, and is designed to stimulate cannabinoid receptors across the Central Nervous System.

https://www.prnewswire.com/news-releases/scisparc-announcesrecruitment-of-first-patient-for-its-phase-iia-clinical-trial-inalzheimers-disease-301455472.html#

### 6 January: Researchers show that cannabinol may protect ageing brain cells from damage

A new laboratory research study, published on 6 January in the Free Radical Biology and Medicine journal, has found how cannabinol can protect aging brain cells from damage caused by oxidative stress.

Cannabinol is a cannabinoid compound produced by



cannabis plants, similar to the compounds THC and CBD, but without their psychoactive properties. A team of researchers from the Salk Institute for Biological Studies had previously observed that brain cells treated with cannabinol were protected from damage caused by oxidative stress. This type of damage is thought to be involved in the development of Alzheimer's disease. In their new study, they identify the biological mechanism behind the protective properties of cannabinol, also known as CBN.



Analysing the behaviour and function of brain cells that were treated with CBN, they noticed that the mitochondria of cells that weren't treated with CBN became dysfunctional in the presence of agents that cause oxidative stress. Mitochondria are known as the powerhouses of cells, generating energy that is necessary for many processes that keep cells healthy and functioning. However, when brain cells were treated with CBN, their mitochondria retained their function in the presence of oxidative stress. Further experiments confirmed that the protection of mitochondria by CBN allowed brain cells to remain healthy in oxidative stress conditions, and also showed that CBN was not psychoactive. The researchers are continuing their studies in animal models of disease, to see if the protective effects on brain cells translate to cognitive or functional benefits.

https://www.sciencedirect.com/science/article/abs/pii/S0891584922 000016

## 6 January: New study estimates that the number of people with dementia worldwide will reach 153 million by 2050



Current prevalence estimates indicate that there are almost 60 million people, worldwide, with dementia. A new demographic analysis has forecast that this number will triple by 2050, underlining the critical need to redouble efforts for improved prevention, management and care.

The Global Burden of Disease, Injuries and Risk factors (GBD) study is a comprehensive, global study that analyses over 260 causes of death, 369 diseases and injuries, and 87 risk factors across over 200 countries. In the January issue of the Lancet Public Health journal, collaborators on the GBD Dementia Forecasting team published their latest results on the prevalence and incidence of dementia worldwide.

In their article, they developed dementia forecasting estimates for adults aged 40 and over for 195 countries, using figures on relative risk and forecasted risk prevalence to estimate the prevalence of dementia in different countries by 2050. Their

findings indicate that the number of people with dementia will increase in all countries, with the largest proportionate increases found in Africa and the Middle East (367%). In comparison, a rise of 53% is projected in the high-income Asia-Pacific region, and 74% in Europe. In total, they estimate that the number of people with dementia worldwide will reach 153 million by 2050, tripling relative to the prevalence figures for 2019.

According to the researchers, most of the increases are attributable to population ageing and population growth. Although they found some increases in certain countries linked to risk factors such as smoking and obesity, in many cases these were counterbalanced by the reduction of dementia risk thanks to increased projected educational attainment. Consistent with previous reports, the GBD study estimates that there will still be more women than men with dementia in 2050, with an average female-to-male ratio of 1.67.

Together, these data underscore the need for public health planning and policy efforts to meet the needs of people with dementia, now and in the future.

https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(21)00249-8/fulltext

## 13 January: Amsterdam UMC POLAR project study indicates less psychosocial problems in people with dementia during the second lockdown

The POLAR project (Psychosocial effects of COVID-19 in Alzheimer's disease) is a research project of Alzheimer Center Amsterdam of Amsterdam UMC, Pharos, and Alzheimer Nederland, with the aim of making people with dementia more resilient to the consequences of the COVID-19 measures by developing



applicable information. A team of researchers working on this project has completed a study on "Psychosocial Effects of COVID-19 Measures on (Pre-)Dementia Patients During Second Lockdown" which was published online in the Journal of Alzheimer's Disease on 13 January 2022.

The COVID-19 pandemic poses enormous social challenges. People with cognitive impairments (problems with, for example, memory and concentration) and dementia are doubly affected by the pandemic. On the one hand, they have a direct risk of severe COVID-19 symptoms, and on the other hand, the restrictive measures hit them extra hard. As a result of disrupted formal care, such as home care, informal carers and supporters were heavily impacted too.

The new study showed, however, that people with dementia and their loved ones have adapted to the challenges of the COVID-19 lockdown. They reported fewer psychosocial problems, such as anxiety, during the second lockdown. They also experienced more social support compared to the first lockdown. Finally, the researchers found an important



protective factor against negative feelings during the lockdown. Patients and loved ones who experienced support from family and friends reported fewer negative feelings, such as loneliness and sadness.

https://www.amsterdamumc.org/en/research/institutes/amsterdamneuroscience/news/-less-psychosocial-problems-in-patients-withdementia-during-the-second-lockdown-.htm

## 19 January: Eisai enrols its first participant in the Phase 2/3 Tau NexGen study for dominantly inherited AD



On 19 January, Eisai announced that the Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU), led by Washington University School of Medicine in St. Louis, has enrolled their first participant in the Tau NexGen study. The DIAN is an international research effort focused on dominantly inherited

Alzheimer's disease (DIAD), which is a rare form of Alzheimer's disease (AD) that causes memory loss and dementia in people -typically while they are in their 30s to 50s.

The Tau NexGen Phase II/III study will evaluate the investigational tau antibody E2814 in pre-symptomatic or symptomatic participants who have an AD-causing gene mutation. DIAN-TU selected E2814 as the first investigational therapy among anti-tau drugs for the trial in March last year. With increasing evidence showing that targeting amyloid can reduce biomarkers of AD, the Tau NexGen clinical trial leaders selected lecanemab (BAN2401), an investigational anti-A $\beta$  antibody, as the background anti-amyloid therapy.

In the study, symptomatic participants will be administered lecanemab for six months before being randomly assigned to also receive E2814 or a placebo. Pre-symptomatic participants will be randomly assigned to receive E2814 or a placebo for a year before beginning lecanemab administration. Researchers would like to evaluate the effects of the anti-tau drug E2814 alone before assessing the effects of the two drugs together.

The trial's primary endpoint is the slowing of tau accumulation in the brain in symptomatic people. The secondary endpoint will be the evaluation of the therapies' effect on the levels of a type of tau in the cerebrospinal fluid, the liquid that surrounds the brain and spinal cord, of pre-symptomatic patients.

https://www.eisai.com/news/2022/news202205.html

## 24 January: New study shows the benefit of continuity of care for people with dementia

According to a new study, people with dementia who were consistently seen by the same doctor over the course of one year had an increased quality of care with safer prescribing and lower rates of major adverse events. Findings were published in the British Journal of General Practice on 24 January 2022.

Researchers, from the University of Exeter, analysed anonymised data from 9324 people with dementia aged 65 and older living in England, who were followed up for a maximum of one year. The study included people who had at least visited three times a doctor in the previous year.



The team found that people with dementia who had a higher continuity of care by consulting the same doctor consistently were less likely to be given medicines deemed potentially inappropriate and had lower medication burden. They were associated with a reduction in incidence of delirium (35%), incontinence (58%), and emergency hospital admission (10%). Researchers suggested that increasing continuity of care for people with dementia may help improve treatment and outcomes.

https://doi.org/10.3399/BJGP.2021.0413

## 26 January: European Researchers invited to apply to European Crucible programme which builds new interdisciplinary research collaborations between Scotland and Europe

The European Crucible is a leadership and development programme for early/mid-career researchers that offers opportunities to build new interdisciplinary research collaborations between Scotland and Europe.

The Call for Applications to European Crucible 2022 is open to applicants from Scottish institutions (deadline closed) as well as to applicants from European institutions. The deadline for European applicants is **21 February 2022**, 17:00 (GMT).

The first European Crucible, held in partnership with the University of Luxembourg, created a cohort of 50 researchers; 25 from Scottish institutions, and 25 from institutions across 12 European countries. The Cruciblists engaged with senior leaders from government, finance, media and academia, and participated in virtual pitching and networking activities. 28 of the "Cruciblists" have since gone on to win funding for 7 collaborative projects, exploring research ideas generated in the European Crucible workshops.

The 2022 European Crucible will once again be run as a virtual programme and is supported by the Scottish Government via the Scottish Funding Council.

The call to apply has closed for Scottish researchers, but is still open to early/mid-career researchers employed in Europe, and carrying out research in science, engineering, technology, medicine, healthcare, arts, design, humanities, business, or social and political science. Ambitious university Lecturers and Readers (i.e. Assistant and Associate Professors), Research Fellows and equivalents in research institutes and industry with experience of managing their own research, are encouraged to apply.





#### **European Crucible 2022**

Invitation to apply

The European Crucible is a leadership and development programme for early/midcareer researchers from Scotland and Europe, that offers opportunities to build new interdisciplinary research collaborations between Scotland and Europe.

The call is open to early/mid-career researchers employed in Scotland or Europe. Ambitious university Lecturers and Readers (i.e. Assistant and Associate Professors), Research Fellows and equivalents in research institutes and industry with experience of managing their own research, are encouraged to apply.

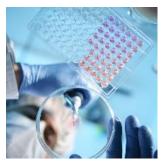
We are particularly looking for individuals with ambitions to develop novel research ideas across the interfaces of different disciplines and/or sectors, and who wish to see their research having wider impact in society internationally.

The European Crucible 2022 is particularly looking for individuals with ambitions to develop novel research ideas across the interfaces of different disciplines and/or sectors, and who wish to see their research having a wider impact in society, internationally.

Once awarded a place on the European Crucible Event, all training, networking and administration costs for participants will be covered. You can find out more, and apply, here:

https://scottishcrucible.org.uk/european-crucible/

## 26 January: Cortexyme announces clinical trial hold on Atuzaginstat's investigational new drug application



On 26 January, Cortexyme, a clinical-stage pharmaceutical developing company novel treatments for altering the course of Alzheimer's disease (AD) and other neurodegenerative disorders, announced that the Food and Drug Administration (FDA) has placed a clinical hold

Atuzaginstat's (COR388) investigational new drug application. The notification to stop testing Atuzaginstat has been received in a letter on 25 January. The company plans to provide a full update on its development plans and additional updates pending continued engagement with FDA.

The hold applies to Atuzaginstat, which recently failed to show a benefit in the large Phase II/III GAIN trial. This trial was a randomised, double-blind and placebo-controlled study assessing the efficacy, safety and tolerability of two dose levels of Atuzaginstat oral capsules in people with mild to moderate AD. Cortexyme announced top-line results in October 2021, showing that the study failed to meet its co-primary endpoints as measured by ADAS-Cog11 and ADCS-ADL at end of the

treatment period (48 weeks) in the overall population. The most common adverse events were gastrointestinal, such as diarrhoea and nausea.

https://www.cortexyme.com/cortexyme-announces-clinical-hold-on-atuzaginstats-investigational-new-drug-application/

28 January: touchNEUROLOGY Editorial Board member Jeffrey Cummings explores the use of lecanemab (BAN2401) for the treatment of early Alzheimer's disease

During 2021, Eisai and Biogen announced that the US Food and Drug Administration (FDA) had



granted Breakthrough Therapy designation for lecanemab (also known as BAN2401), an investigational antibody targeting amyloid beta, for the treatment of Alzheimer's disease (AD). In November, new data on lecanemab were presented at the 14<sup>th</sup> Clinical Trials on Alzheimer's Disease (CTAD) conference.

touchNEUROLOGY Editorial Board member Jeffrey Cummings has published an article examining the trial results and discussing the use of lecanemab for early AD. You can read the article, here:

https://touchneurology.com/alzheimers-disease-dementia/journalarticles/innovative-therapeutic-development-programme-for-thetreatment-of-early-alzheimers-disease-lecanemab-ban2401/

#### **MEMBERS NEWS**

## 5 January: The Alzheimer Society of Ireland CEO Pat McLoughlin announces his retirement

It is with great regret that The Alzheimer Society of Ireland (ASI) announced, on 5 January 2022, that Pat McLoughlin has decided to step down from his role as CEO, for medical reasons. Mr McLoughlin became CEO in October 2016 and will officially retire from his role in March 2022.



He said: "I am so grateful to have been given the opportunity to lead The Alzheimer Society of Ireland over the past five years. I am honoured to have led this extra-ordinary organisation over this time and represent people living with dementia and their family carers across Ireland. I would like to thank the chairman Eugene McCague, board of directors and all the staff, volunteers, advocates and everyone associated with The ASI. You have been incredible, and I know you will achieve great things in the future."

ASI Chairman Eugene McCague expressed his gratitude to Pat McLoughlin for his leadership of over the past five years.



He said: "On behalf of the board of The ASI, I would like to express my gratitude to Pat for his extraordinary leadership of The Alzheimer Society of Ireland over the past five years. We are very understanding of Pat's decision to step back from his role, and I know you will join me in letting Pat know how grateful we are to him for leading The ASI over this time and supporting the thousands of people living with dementia and their family carers in Ireland. Pat brought so much expertise to this position, and this was clear for everyone to see over the last five years."

The ASI board of directors will take immediate steps to recruit a new CEO. An internal interim CEO will be appointed while a new CEO is being identified.

### 19 January: Facebook Fundraising initiative proves a success for Alzheimer Scotland



Alzheimer Scotland has started 2022 with the introduction of a new fundraising initiative for the charity, Facebook Challenges. Growing in popularity since the pandemic, the Facebook Challenges initiative has opened doors for charities to reach new audiences who consider the social media platform a part of daily life.

Alzheimer Scotland asked participants to complete 90,000 steps over one week in January to represent the 90,000+ people living with dementia in Scotland. Registration was free and supporters could sign up, create a fundraising page and connect with other participants all via one Facebook Group.

Keeping the concept clear, achievable and connected to the charities' cause has proven to be a successful combination for this new digital fundraising format. Return on investment was straightforward to monitor as all paid advertisement ran through Facebook, allowing conversion rates to be measured.

The month-long campaign has exceeded its target by 68% with an income of GBP 13,500 (EUR 16,200 approx.) to date, with one week still to go, at the time of writing.

Alzheimer Scotland has been able to deliver this fundraising method through "GivePanel"; a Facebook giving tool designed to give charities a proven way to thank fundraisers, collect contact details, track results and drive new Facebook fundraisers.

One key campaign benefit has been the ability to use Facebook Groups to connect supporters and allow organic conversation and support to flourish. Evidently, conversation between participants has shown a higher engagement rate than charity-

led posts. This therefore reduces the charities' need to deliver a robust "supporter journey" after the point of sign up. Instead, they provide the tools and support to begin the challenge, and then allow participants to engage with one another and create their own unique supporter experience.

Due to the success of this fundraising format, moving forward the Alzheimer Scotland team aims to include Facebook Challenges within its calendar of events to ensure it continues to adapt and evolve within the growing arena of digital fundraising.

Get in touch if you would like to learn more about the lessons they have learned, about embracing virtual fundraising during the pandemic. Contact them, via: events@alzscot.org

## 27 January: Alzheimer Hellas organises three online events during January, discussing diet and dementia risk-reduction, healthy ageing, and "Smart Homes"

On 13 January 2022, Alzheimer Hellas held on an online event on "What kind of diet protects against dementia?" Prof. Magda Tsolaki, Neurologist-Psychiatrist, Theologian and President of the Panhellenic Federation of Alzheimer's Disease and Related Disorders coordinated the event. Paschalis Devranis, Neurologist,



Military Doctor, PhD Candidate, presented his project.

On 20 January 2022, the Panhellenic Federation of Alzheimer's Disease and Related Disorders in collaboration with Heraklion of Creta coordinated an online event on "Successful Aging" by Magda Tsolaki as well as Ioanna Kortsidaki, the President of Alzheimer of Heraklion. Kounti Zafeiropoulou Fotini, Neuropsychologist, member of the Scientific Board of Alzheimer Association of Heraklion and scientifically responsible for the programme "Promotion of active and healthy Aging" presented the Program for Active and Healthy Aging in the community - with the support of TIMA Public Benefit Foundation. Potouridis Pavlos, Professor of Physical Education, Member of the Scientific Board of Heraklion Alzheimer Association talked about "Age should not be a problem to exercise and entertainment".

Finally, on 27 January, Julietta Lazarou, Psychologist, PhD of the Medical School of AUTh gave a talk called "How the 'Smart Home' contributes to the precise diagnosis of cognitive disorders" and Prof. Magda Tsolaki coordinated the event.





## 28 January: Czech Alzheimer's Society reports on final international conference of the ERASMUS+ SiDeCar project



In late 2021, the International Final Conference of the ERASMUS+ SiDeCar Project took place in Prague. The main topic of the ERASMUS+ SiDeCar project International Meeting was care for people living with dementia and care for their carers. The key area was focused

on psychosocial interventions and their implementation in educational curricula for professionals, with a positive impact on informal carers.

Psychosocial interventions as non-pharmacological treatments are currently held in its various modalities for the evidence-based method, which includes indisputable advantages such as non-invasiveness and efficiency, built on individualised care, "tailor-made" and based on person-oriented care. The basic characteristic of a psychosocial intervention is its holistic nature and complexity.

The one-day conference took place in an online environment, with the first session taking place in the morning. Project manager and the head of non-medical professions department of the Institute of Postgraduate Education (IPVZ) in Prague, Dr Pavla Povolná, opened the session together with the project guarantor, Chairperson of the Czech Alzheimer's Society and the head of the Department of Long-Term Care Medicine IPVZ, Dr Iva Holmerová.

Other invited speakers for the morning part were the creators of educational project videos, Dr Miroslav Barták and Mgr. Monika Čajko Eibicht. An important factor influencing the quality of care provided for people living with dementia is the ability of the health and social care facilities and experts to cooperate, e.g. in the offer and creation of co-housing projects - this was the topic of the presentation of Dr Adéla Mojžíšová and Dr Miroslav Barták, followed by the Coordinator of the National Action Plan for Alzheimer's Disease (NAPAN) Bc. Markéta Švejdová, who presented the possibilities of cooperation and implementation of materials created during the project into the intentions and structure of NAPAN.

The afternoon part of the conference was in the form of lectures and discussions by foreign experts (representatives of partner universities) of the SiDeCar project. The discussion was moderated by Mgr. Tereza Pečánková and Dr Miroslav Barták.

The discussion was opened by Dr Iva Holmerová, who introduced the other speakers: The first was Fania Dassen from the partner university in Maastricht, whose team is led by Prof. Marjolein de Vugt (Netherlands). Fania Dassen's contribution was on "The importance of education about dementia". Then Rabih Chattat from the project's leading university in Bologna (Italy) presented a topic for ongoing discussion: "A systematised channel to transfer knowledge in dementia care". The University of Maastricht took the floor again, this time with a contribution by Niels Janssen who delivered an overview of

various different topics. Last but not least was a summary and celebration of the successful formulation of the psychosocial interventions curriculum by the project leader Dr Giovanni Ottoboni (Italy), who discussed project outcomes from the SIDECAR curriculum. The conference ended with a lively discussion between all the participants in the expert panel.

You can find the SiDeCar project website on IPVZ and videos via

https://www.ipvz.cz/o-ipvz/granty-a-projekty/skills-in-dementia-care-building-psychosocial-knowledge-and-best-practice-in-dementia-care

#### DEMENTIA IN SOCIETY

### 19 January: Family carer support programme piloted in Lithuania

Dementia Lithuania has started a mental health support group for family carers of people living with dementia. The piloted initiative, implemented in partnership with the National Mental Health Centre in Lithuania, is the first step towards developing support services for the families who take care of their loved ones at home.



Officially, there are around 40,000 people living with dementia in Lithuania. While the majority of them live at home, the support services in communities for people living with dementia, as well as support for the carers, are still being developed.

Dementia Lithuania is piloting the peer-support programme as a part of a range of services advocating that mental health support should be available and accessible across the country for everyone who needs it.

The peer support group programme is run remotely and is open for people from all over the country. The association coordinates the participation in these support groups, as well as providing training to use remote meeting tools. The pilot consists of three groups, moderated by mental health professionals. The pilot will enable the creation of a service which could later reach more people in need.

After its launch, registration for the people living with dementia and their carers in this pilot programme is being kept open in order to gauge the demand. The second launch of the groups will start shortly after the pilot ends.

The peer support programme is part of the initiative "Towards a dementia strategy: situation analysis and public awareness", implemented by the association Dementia Lithuania and the NGO Socialiniai meno projektai, and is supported by the Active Citizens Fund.



#### 28 January: Congratulations to Saloua Berdai-Chaouni on completing her PhD on dementia among older labour migrants in Belgium



Congratulations to Saloua Berdai-Chaouni on completing her PhD focusing on dementia among older labour migrants in Belgium and on inclusive research, with an introduction of a new conceptual model for inclusive dementia care. Her PhD is called "Grasping fading memories of a Motherland: Capturing dynamic

care realities of older labor migrants with dementia".

Saloua Berdai-Chaouni was a member of Alzheimer Europe's recent working group on inclusive research. She has also recently published a book together with Ann Claeys, collecting the most important findings of the Diverse Elderly research project. It is the first book on the topic in Belgium and is currently available in Dutch. A French version will follow in the coming months.

Find out more about the book, here:

https://www.maklu.be/MakluEnGarant/BookDetails.aspx?id=978904 4138276

### **NEW PUBLICATIONS & RESOURCES**

#### 13 January: New Oruen CNS journal is published, featuring report on 31st Alzheimer Europe Conference

The new Oruen Journal Publication went live on 13 January 2022, and includes a report on Alzheimer Europe's 31st Annual Conference, which took place in the latter part of 2021.

Oruen is the leading CNS medical publication and multimedia platform committed to improving international communication and medical education for physicians with clinical interests in CNS medicine.



You can read the January 2022 edition of the journal, here:

https://www.oruen.com/Journal/Volume7lssue2/

Please click here to go directly to the Alzheimer Europe article.

#### JOB OPPORTUNITIES

#### 27 January: European Patients' Forum (EPF) seeks Senior Communications Manager

The European Patients' Forum (EPF) is looking for a new Senior Communications Manager. The Communications Manager will be responsible for developing and overseeing communications of EPF's work.



The deadline for applications is 4 European Patients Forum

February 2022, 23:59 CET.

Interview invitations will be extended on a rolling basis. The selected candidate should be prepared to start in late February 2022. Full job description here:

https://www.eupatient.eu/globalassets/library/enewsletter/2021/seniorcommunications-manager---job-ad---17-jan-2022.pdf





#### **Contact Alzheimer Europe:**

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

#### **Alzheimer Europe Board:**

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

#### **Alzheimer Europe Staff:**

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

#### **AE CALENDAR**

Date	Meeting	AE representative
1 February	Neuronet Communication Expert Group meeting	Chris, Ange, Cindy
1 February	Meeting with Gates Ventures	Jean and Angela
2 February	Mobilise-D webinar	Chris
2 February	RADAR AD meeting	Ana and Dianne
2 February	INTERDEM Dementia-friendly design taskforce	Ana, Dianne and Owen
3 February	EU Commission Healthier together webinar	Owen
3 February	Conference debriefing meeting with Live Online Events	Jean and Gwladys
3-4 February	PRIME General Assembly meeting	Angela
4 February	Meeting with Lilly	Jean
8 February	Meeting with EFPIA/AD Platform	Jean
8 February	Meeting with Nutricia	Jean
10 February	European Disability Forum ENGO	Owen
10 February	JAIN attaché meeting	Chris
14 February	NeuroCohort taskforce meeting	Angela
16 February	Mobilise-D webinar	Chris
16 February	PRIME webinar on the TIMESPAN project	Angela
21 February	STUDICODE meeting	Dianne
22 February	Alzheimer Europe Board meeting	Jean
23 February	Meeting with Roche	Jean
23 February	LETHE Advisory Board meeting	Ana
24 February	ImmiDem webinar	Dianne
24 February	Biogen Advisory Board meeting	Jean
25 February	EWGPWD meeting	Ana and Dianne



### **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
28 April	Diagnostik und Früherkennung von Demenzerkrankungen, https://demenz-konferenz.ch/	Bern (Switzerland) and online
7-9 June	7 <sup>th</sup> World Conference on Adult Capacity, https://wcac2022.org/	Edinburgh, Scotland
8-10 June	30 <sup>th</sup> European Social Services Conference, https://essc-eu.org/	Hamburg, Germany
8-10 June	35 <sup>th</sup> Global Conference of Alzheimer's Disease International (ADI 2022),https://adiconference.org/	London and online
25-28 June	8 <sup>th</sup> EAN Congress, https://www.ean.org/congress2022	Vienna, Austria
20-22 September	Dementia Lab Conference - The residue of design, https://www.dementialabconference.com/	Leuven, Belgium
17-19 October	32 <sup>nd</sup> Alzheimer Europe Conference, https://www.alzheimer-europe.org/Conferences	Bucharest, Romania
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



## 32<sup>nd</sup> Alzheimer Europe Conference Building bridges

## Bucharest, Romania 17 to 19 October 2022

www.alzheimer-europe.org/conferences







