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ALZHEIMER EUROPE NEWSLETTER

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WELCOME



We are following the situation in Ukraine with great concern and are in disbelief that Europe is again facing war. Our Chairperson, Iva Holmerová, who is in the Czech Republic, has written a letter with her personal thoughts about

the situation, addressed to our members, which we have shared on page two of this newsletter. People with dementia will of course be negatively impacted during this crisis and we have shared two resources, one from the World Health Organization and one from Alzheimer's Disease International, to help support them. These can also be found on page two.

In much happier news, we are delighted and relieved to have signed our new operating grant with the EU's Disability Programme, allowing us to continue giving a voice to people with dementia in Europe. This has also allowed us to finally look at a much-needed expansion of the Alzheimer Europe team, to help us contribute to European research projects and to support people with dementia to be involved in research.

Elsewhere in the field of disability, the European Disability Forum has contributed a report to the second review of the EU's implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Covering the period since the first review by the UNCRPD Committee in 2015, this report highlights that whilst progress has been made in some areas, the primary objective, to ensure the full and equal enjoyment of all human rights

and fundamental freedoms by all persons with disabilities, has not been fully realised.

On the publications front, we have had a busy few weeks, culminating in the launch of our 2021 report on sex, gender and sexuality in the context of dementia, and the 38th edition of our Dementia in Europe magazine. Our 2021 Yearbook on dementia-inclusive initiatives and communities, is set to launch during March. I also co-authored an article, "What Matters to Patients with Alzheimer's Disease and Their Care Partners?", published in The Journal of Prevention of Alzheimer's Disease.

Looking to our members, I would like to say happy anniversary to our colleagues at the Czech Alzheimer Society, who celebrate 25 years of supporting people with dementia and their families. A fantastic achievement! I would also like to welcome Mariló Almagro, who is the new President of the Confederación Española de Alzheimer.

The members of the European Working Group of People with Dementia never cease to amaze us with their tireless advocacy work, and this month was no exception. Helen Rochford-Brennan appeared on national Irish television, speaking about living with dementia and about her campaigning work. The Alzheimer Society of Ireland received a hugely positive response to Helen's appearance on the show. Tomaž Gržinič took part in a Slovenian TV documentary on dementia; and in Finland, Petri Lampinen received a merit award for patient and customer safety. Congratulations to all three of them!

Stay safe and healthy.

Jean Georges
Executive Director

A FEW PERSONAL WORDS FROM OUR CHAIRPERSON ABOUT THE SITUATION IN UKRAINE

Dear colleagues, friends,

We have been watching the war live for several days. A war in Europe that threatens to be the biggest since the Second World War, threatening not only the entire continent but also the civilised world. A peaceful European country has been invaded by an aggressor. By an aggressor that has never given up its expansionist tendencies for many decades, systematically and, unfortunately, largely undetected, has been building up its intelligence networks in all European countries and across the Atlantic, significantly influencing major political events, elections and otherwise doing all sorts of damage in order to consolidate its power and connect its malicious networks.



How damaging they are was perhaps not something we wanted to believe until the first invasion of Ukraine in 2014, the murders on UK soil or the attack on ammunition depots in my country (Czech Republic). This undoubted international influence, together with a sense of unlimited power in their own realm, but also complete isolation from normal people, undoubtedly accentuated by fear during a pandemic, led a psychopathic individual, gradually consolidating his power and dreaming of unlimited world domination, to make the unprecedented and insane decision to launch an unprecedented aggression. I live in a country that experienced aggression in 1968, when the Soviet occupation isolated us from the countries of democratic Europe for the next decades. When Russian tanks were shuffling along our borders, we did not believe then that occupation was possible either. It happened, and afterwards we lived in an environment of fear, unfreedom, suppression of opinions, restriction of all activities, not only political ones, but also cultural and simple civic ones, when the totalitarian power supervised everything that was taught even in schools, what people could and could not say, what and who could be in the media.

Even thirty years after the fall of the Iron Curtain in Europe, these devastating effects of decades of totalitarianism are still evident throughout the former Soviet bloc. I am always aware of this when I present the new version of the European Dementia Monitor. The Central and Eastern countries have integrated into Europe in many respects, especially politically and economically. But there are areas where traces of the division of Europe are still evident. These include not only the success of scientists and their participation in European research cooperation, but also, for example, the care of people living with dementia. The traces of the Iron Curtain are still evident in the provision of care for people with dementia, but that is no cause for regret. On the contrary: I would like to thank our member organisations in these countries for doing everything they can to improve the care of people with dementia and the quality of life of people living with dementia and their families.

Most of the refugees from Ukraine are and will be heading to these countries, and there has been a huge wave of solidarity, of all-out efforts to help. However, this is far from enough, and it is necessary to stop the aggression, to hold the guilty to account and to persist in supporting Ukraine not only in military operations, but also in those that will lead to its reconstruction, including all the important civic activities, the care of society for its members, including people with dementia. Therefore, I would like to thank you for the support that members of our Alzheimer's organisations are already providing to the people of Ukraine and to believe that, in these difficult times something very valuable can begin as a basis for future cooperation and belonging.

Iva Holmerová, Chairperson, Alzheimer Europe

RESOURCES TO HELP SUPPORT PEOPLE WITH DEMENTIA DURING WAR AND HUMANITARIAN CRISES

The World Health Organization is following the situation very closely, especially how the war affects elderly people in general and people with dementia in particular. The IASC MHPSS Reference Group (network of UN agencies and partner organisations working in humanitarian settings to coordinate large-scale emergency responses on the ground and develop new guidance/tools, has written a summary document with materials and resources available in relevant languages for the immediate response when setting up humanitarian support: <https://interagencystandingcommittee.org/iasc-reference-group-mental-health-and-psychosocial-support-emergency-settings/mental-health-and-psychosocial-support-humanitarian-response-ukraine-and-neighbouring-countries>

Alzheimer's Disease International has produced a really useful report entitled "Forgotten in a crisis" which highlights how dementia should be prioritised during humanitarian crises: <https://www.alzint.org/resource/forgotten-in-a-crisis-addressing-dementia-in-humanitarian-response/>

**Help us give a voice to people
with dementia**

Donate



COVID-19 SITUATION

9 February: Scottish Government publishes analysis of excess death statistics, identifying dementia as the most common pre-existing condition in COVID-19 deaths

On 9 February, the Scottish Government published their long-awaited report entitled “Excess deaths from all causes, involving and with dementia as the underlying cause: Scotland 2020/2021”. The report paints a stark picture, showing the devastating effect of the COVID-19 pandemic on people with dementia, which was the main pre-existing medical condition in deaths involving COVID-19 during this period.

The report is based on a secondary analysis of weekly statistics published by National Records of Scotland (NRS) on deaths involving dementia, or with dementia as an underlying cause. Looking at the period between 16 March to 31 December, 2020, figures show that 28% of all deaths involving COVID-19 had dementia mentioned on the death certificate. This makes dementia the leading pre-existing condition in all COVID-19 deaths. In comparison, 14% of deaths involving COVID-19 also mention ischaemic heart disease, the next most prevalent pre-existing condition.

The Scottish Government analysis also shows that residential setting had a huge impact on COVID-19 deaths of people with dementia. In 2020, there were 1,638 excess deaths involving dementia in care homes, 26% higher than previous years. The vast majority of these excess deaths involved COVID-19, highlighting the inadequacy of measures for reducing infection in the care home setting during the early months of the pandemic.

Commenting on the report, Alzheimer Scotland called for re-evaluation of the large Care Home Model, where numerous people live together and are cared for by a small, dedicated team, as it presents a high risk of virus transmission for people with dementia: “We need to radically transform our approach, and develop a smaller scale approach to residential and nursing care. One that is not based on large scale but designed to meet the high care needs of individuals, and one which can withstand the ongoing threats of future pandemics without the unbearable consequences that those we have lost and their loved ones had to endure....We must have care environments which are not built on economies of scale but designed to tackle the rigours of a world learning to live with COVID-19 in as safe, humane and caring way as possible.”

<https://www.gov.scot/publications/excess-deaths-causes-dementia-setting-scotland-2020-2021/>

<https://www.alzscot.org/news/the-scottish-governments-excess-deaths-from-all-causes-and-dementia-report>

ALZHEIMER EUROPE

7 February: Check out the new Alzheimer Europe website flyover video



Alzheimer Europe has a brand-new website. The new-look, updated and more user-friendly site can be reached at the same address as before: www.alzheimer-europe.org

We have streamlined the content and made navigation easier and more accessible. The look is clean and modern and the site is adapted to mobile devices as well.

Watch our short 'flyover' video here:

<https://vimeo.com/674344891/78de8e196d>

8 February: Alzheimer Europe signs new Operating Grant agreement with EU disability programme

On 8 February 2022, Alzheimer Europe signed a Grant Agreement with the European Commission under the Citizens, Equality, Rights and Values (CERV) programme, which will allow the organisation to continue its work making dementia a policy priority in Europe.

Alzheimer Europe expresses its gratitude to the European Commission for recognising that dementia is the leading cause



for disability and dependency in older adults in Europe and for providing vital financial support for the organisation's 2022 activities.

The signing of the agreement marks a slight shift in the future focus of Alzheimer Europe's policy work since the organisation had previously received operating grant funding from the EU's health programme. Building on its previous work promoting a rights-based approach and advocating for the rights of people with dementia and their carers, Alzheimer Europe will now be in a position to place an even greater focus on the citizenship and equal participation of people with dementia in society.

Alzheimer Europe will undertake a number of different strands of work throughout 2022, including:

- Promoting and defending the rights of people with dementia as full EU citizens, giving them a voice in EU and national policies by involving the European Working Group of People with Dementia in all operating grant activities and meetings, as well as publishing a guide on dementia-inclusive language
- Promoting the compliance of national dementia policies and strategies in the field of employment and social protection, in line with the UN Convention on the Rights of Persons with Disabilities (UNCPRD) and the European Strategy on the Rights of Persons with Disabilities (ESRPD), by mapping and analysing national policies, identifying good practices and publishing these in the Dementia in Europe Yearbook 2022
- Improving the capacity of national member organisations to contribute to national and EU disability policies by organising capacity building webinars and workshops
- Ensuring that dementia is recognised as a leading cause of disability and dependency by actively contributing to EU

policy making and supporting the implementation of the ESRPD and European Semester process

- Raising awareness of the ESRPD by effectively communicating EU policies and operating grant results and achievements to its members and the general public.

Alzheimer Europe's Executive Director, Jean Georges stated: "The signing of the Grant Agreement with the European Commission is an important step in securing funding for Alzheimer Europe's work in the coming years. Dementia and related cognitive impairments are not always recognised as disabilities, despite the significant impact they have on the day-to-day lives of individuals, their families and carers. Thanks to this vital support by the European Commission, we will be able to continue our work focused on citizenship and rights and identify measures which will improve the lives of people with dementia, their families and carers."

Alzheimer Europe will receive funding from the European Commission's call for proposals for its CERV-2021-DISA-OG-SGA under the Citizens, Equality, Rights and Values Programme (CERV). The maximum grant amount for 2022 will be EUR 499,200.

Details on Alzheimer Europe's previous and current work can be found here: <https://www.alzheimer-europe.org/our-work>

Details on Alzheimer Europe's finances can be found here: <https://www.alzheimer-europe.org/about-us/governance/finances>

25 February: Alzheimer Europe launches new report on sex, gender and sexuality in the context of dementia

On 25 February 2022, Alzheimer Europe launched a new report: "Sex, gender and sexuality in the context of dementia: a discussion paper".

Sex, gender and sexuality are fundamental aspects of people's lives. Information about people's sex, gender and sexuality is typically considered as socially salient and serves, to some extent, as a basis for how they are perceived and treated, and for all kinds of assumptions about their interests, needs, capacities and wishes. These aspects of personal identity influence self-perception, how people position themselves within society and how they are positioned by society. They are not the sum total of who people are, but may come to the fore and impact on people's lives at certain times and in certain contexts or situations.

Our aim, in this report, was to promote the right of every person with dementia, irrespective of their sex, gender identity and sexual orientation, to be treated with respect and to have access to timely diagnosis, treatment and good quality care and support. We specifically targeted policy makers, health and social care students and health and social care professionals/service providers because they are the people



who can make the necessary changes to improve the lived experience of people with dementia of all sexes, gender identities and sexual orientations.

The report starts with an overview of the terminology and concepts related to this topic and briefly mentions the guiding theoretical framework (covering heteronormativity, intersectionality, micro-aggressions and feminism), which is described in depth in the Appendix, and accompanied by a useful glossary. The rest of the report focuses on seeking and obtaining a diagnosis, living one's sex, gender and sexuality with dementia, accessing and using professional services and support. The authors explore the various issues insofar as they relate to people with dementia, their carers/supporters and health and social care professionals and service providers, always bearing in mind, as well as challenging, broader societal influences and structures.

The emphasis throughout this report was on recognising and challenging prejudice, discrimination and injustice, not only towards marginalised minority groups (such as LGBT* people, people from minority ethnic groups etc.) but also towards women (who make up the majority of the population with dementia in most countries), hence our adoption of feminism as part of our guiding theoretical framework. This does not exclude or discriminate against men. Their needs and interests must also be recognised and they may also be adversely affected by heteronormativity, as may people who do not have a long-term partner and women and men who do not have children.

The report is the outcome of work carried out by experts in the fields of dementia, gender studies, ethics, ageing, service provision, training of healthcare professionals and psychology. The expert working group was composed of men and women with and without dementia, and with different gender identities and sexual orientations. Some also had contact with people from gender and sexual minority groups who kindly provided testimonials on a few issues. Alzheimer Europe would like to thank the members of the ethics working group, namely Dianne Gove (Chair), Aileen Beatty, Andrea Capstick, Patrick Ettenes, Jean Georges, Fabrice Gzil, Phil Harper, Helga Rohra, Linn Sandberg, Anthony Scerri, Charles Scerri, Annemarie Schumacher Dimech and Karin Westerlund.

Jean Georges, Executive Director of Alzheimer Europe, commented:

"I am delighted that, following our work on intercultural care and support for people with dementia, we are now publishing recommendations on how policy makers, health and social care professionals and students of health and social care, among others, can ensure that people with dementia do not meet with prejudice and discrimination based on their sex, gender identity and sexuality, but rather that these factors are taken into account to provide appropriate care and support that is both adapted to their personal needs and mindful of their rights."

Helga Rohra, co-author of this discussion paper, said the report was "a new and highly-awaited insight into a neglected part of

a person with dementia: sexuality. See behind my disease – focus on heterogeneity! I am still me, with all my needs and longings!"

The report is currently available in English and can be freely downloaded from the Alzheimer Europe website:

<https://www.alzheimer-europe.org/reports-publication/sex-gender-and-sexuality-context-dementia-discussion-paper>

We will now turn our attention to the development of a compact guide for health and social care workers, a policy statement and a short summary that is accessible to a broader public, including people with dementia and carers/supporters. For further information about the report, please contact Dr Dianne Gove, Director for Projects: dianne.gove@alzheimer-europe.org

28 February: Dementia in Europe issue 38 published as an e-magazine

It is a great pleasure to introduce the 38th edition of our Dementia in Europe magazine. As ever, we have done our best to fill it with interesting and useful updates on European and national policy developments in the dementia field, campaigns and European research projects, among others.

The first section of the magazine looks at some of the key work our organisation has been involved in, in recent months. The opening article recounts the European Parliament Workshop held online in December 2021, which looked at the new Innovative Health Initiative (IHI) and how it will build on the success of the Innovative Medicines Initiative (IMI).

We then introduce a new European project, the European Platform for Neurodegenerative Diseases (EPND), and two new Alzheimer Europe publications for 2021, our Yearbook on dementia-inclusive initiatives and communities and our ethics report on sex, gender and sexuality in the context of dementia. These topics were also explored at two recent sessions of our ever-popular Alzheimer's Association Academy series. In the last article in this section, we share details of these two Academy sessions, both of which took place online.

In the Policy Watch section, we hear first from seven MEPs, all of whom are members of the European Alzheimer's Alliance, setting out their views on where dementia policy is heading at an EU level in the year ahead and how they will promote it in their role. We also share details of the European Group of Governmental experts on dementia, whose final meeting of 2021 featured presentations from the Global Coalition on Aging (GCOA) and the World Health Organization (WHO) were also present. The WHO's newly-launched Pan-European Mental Health Coalition is the topic of our next article, while the penultimate one takes on a more global flavour, focusing on the



World Dementia Council's series of "Global Dialogues" held throughout 2021.

This section closes with a contribution from our Finnish member, Muistiliitto – The Alzheimer Society of Finland, about their recently-published report highlighting the growing number of people with memory disorders and the corresponding increase in the financial impact on Finnish society.

The Dementia in Society section opens with two interview pieces, with people working in the field of dementia research and care in Europe. The first interview is with outgoing INTERDEM Chairperson Myrra Vernooij Dassen and her successor Marjolein de Vugt, while the next is with Sabine Jansen, who has stepped down from her position as Executive Director of the German Alzheimer association. We also hear from her successor, Saskia Weiss. In the next article, another of our members associations, Alzheimer Portugal, shares details about a recent study on "The cost and burden of Alzheimer's disease in Portugal" and explores some of the key findings.

Member of the European Working Group of People with Dementia (EWGPWD), Stefan Eriksson, spreads his message of hope and resilience to our readership, together with his daughter Janni. They recently took a hiking trip to climb Sweden's tallest mountain, recording the ups and downs of the trip and how dementia impacted on things, in a video diary.

The Davos Alzheimer's Collaborative, which has been in action for just over a year, aims at mounting a global response to Alzheimer's. Founding Secretary Drew Holzapfel speaks to us about this initiative, and what it has achieved so far, while the

next article in this section takes a rather different turn, exploring ageing and dementia-friendly urban design. Edition 7 of the Journal of Urban Design and Mental Health saw guest editors Daniel Gan and Zdravko Trivic focusing on this topic and they both provide comments, as does Helga Rohra, author of one of the papers included in the journal.

The last article in this section is a piece about the Forget Me Nots, a dementia-inclusive community choir in Ireland, that delegates had the pleasure of hearing at the closing ceremony of the 31st Alzheimer Europe Conference (31AEC).

The conference itself is the focus of the fourth and final section of the magazine, "Spotlight on 31AEC". The event, which was virtual for the second year in a row due to the pandemic, was co-moderated by Kim Coppes from Live Online Events and Jean Georges, Executive Director of Alzheimer Europe. It was a great success, with well over 600 participants, from 42 countries, as well as 260 speakers and 100 poster presentations. In this section, we revisit some of the key presentations, and special sessions. We also summarise the symposia held during the event, including the ever-popular EWGPWD session.

A big thank you to all the contributing authors, interviewees and to our sponsors, who make our magazine possible.

You can download the PDF via our website, here:

<https://www.alzheimer-europe.org/reports-publication/dementia-europe-magazine-issue-38>



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Alzheimer Europe networking (online)

On 1 February, Chris, Cindy and Ange participated in the Neuronet Communication Expert meeting.

On 1 February, the Alzheimer Europe Executive met.

On 1 February, Jean, Angela and Owen met with Gate Ventures to discuss a project proposal.

On 2 February, Ana, Dianne and Owen participated in a task force on dementia friendly design.

On 3 February, Owen attended an EU Commission webinar on its NCD initiative "Healthier Together"

On 3 February, Angela participated in an EPND communications meeting with ADDI.

On 3-4 February, Angela participated in the General Assembly meeting of the PRIME project.

On 4 February, Jean had a meeting with Lilly.

On 8 February, Jean had a meeting with the EFPIA AD team.

On 8 February, Jean met with Nutricia.

On 9 February, Jean met with the European Federation of Neurological Associations.

On 9 February, Cindy participated in an EPAD communications meeting with ADDI.

On 10 February, Owen attended the European Disability Forum's European Non-Governmental Organisations meeting.

On 10 February, Dianne, Ana and Jean met with Orion Pharma.

On 11 February, Angela met with ADDI for the EPND project.

On 15-16 February, Jean and Owen participated in a WHO-Europe regional technical consultation on the implementation of the European Framework for Action on Mental Health 2021-2025.

On 16 February, Gwladys visited the Convention Center Dublin, Ireland.

On 17 February, Chris attended the first periodic review meeting of the LETHE project.

On 17 February, Jean met with Biogen.

On 21 February, Cindy attended the PatientView webinar "Timely diagnosis of Alzheimer's disease: the common challenges in primary care".

On 21 February, Dianne took part in the STUDICODE meeting.

On 22 February, the Alzheimer Europe Board met.

On 22 February, the Board of the Alzheimer Europe Foundation met.

On 22 February, Ana, Dianne & Angela met with Eodyne for the TVB_Cloud project.

On 23 February, Angela attended a DataSavesLives core group meeting.

On 23 February, Ana participated in a consultation with the LETHE Advisory Board.

On 23 February, Jean met with Roche.

On 24 February, Jean met with EFPIA.

On 24 February, Dianne took part in the ImmiDem webinar and debriefing meeting.

On 25 February, Jean attended a Biogen Advisory Meeting.

On 25 February, Dianne and Ana participated in a consultation with the EWGPWD for the AI-MIND project.

On 25 February, Owen attended WHO Europe's NSA engagement sessions on the role of communities in the COVID-19 response.

On 28 February, Jean attended the PAVE (Project Alzheimer's Value Europe) meeting.

EU PROJECTS

1 February: Horizon 2020 project VirtualBrainCloud hosts a periodic review meeting

Last month, the EU-funded VirtualBrainCloud project (TVB_Cloud) participated in a review meeting with its EU project officer and project monitors. This is the second review meeting for the project, during which TVB_Cloud leaders presented

recent project advances and updates to expert reviewers appointed by Horizon 2020.

The premise of TVB_Cloud is "exploiting the full potential of in silico medicine research for personalised diagnostics and therapies in cloud-based environments". TVB_Cloud aims to create a decision support system for clinicians, formed around a cloud platform for personalised brain simulations based on high-quality, multidisciplinary clinical data, encompassing brain scans, -genetic and blood-based biomarker data. This decision support system will enhance the early diagnosis, prognosis and



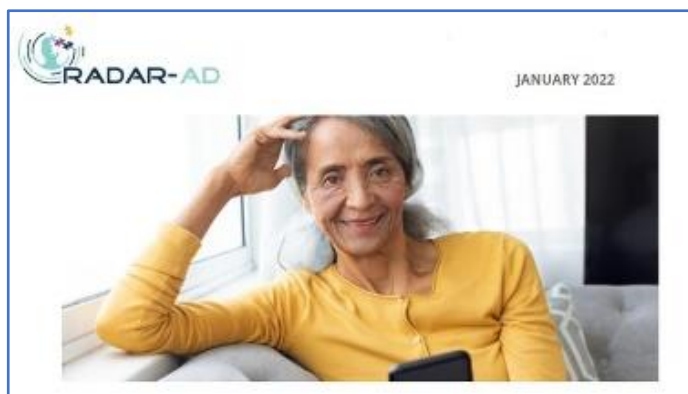
personalised treatment of neurodegenerative diseases, with an initial focus on Alzheimer's disease (AD) and dementia.

Involving 17 partners with expertise from many disciplines including brain imaging technologies, data protection, artificial intelligence and neuroscience, TVB_Cloud was launched in spring 2019 and receives almost EUR 17 million in funding through Horizon 2020. The review meeting brought together representatives from all these partner organisations, and was chaired by Prof. Petra Ritter of Charité University Hospital Berlin, the leader of TVB_Cloud. Over the course of the day-long review meeting, leaders of the nine TVB_Cloud work packages summarised activities and major achievements since the start of the project. The diverse range of dissemination and communication activities was highlighted, including a TVB_Cloud symposium at the Alzheimer Europe conference in 2021, and a European Parliament lunch debate with policymakers and stakeholders.

Much of the review meeting was dedicated to computational and AI developments, including presentation of the TVB_Cloud Virtual Research Environment and new tools including a digital brain atlas and a 3D viewer that maps biological mechanisms to different areas of the brain. To find out more about these and other developments from TVB_Cloud, visit the project website:

<https://virtualbraincloud-2020.eu/tvb-cloud-main.html>

1 February: RADAR-AD project publishes its fourth newsletter



The RADAR-AD (Remote Assessment of Disease and Relapse – Alzheimer's Disease). project has published the fourth edition of its newsletter. These e-newsletters provide colleagues and subscribers with the latest project updates from RADAR-AD.

The newsletters are sent twice per year, covering news over a six-month period. In the past six months, the RADAR-AD consortium has managed to make great progress with its research, despite the challenges surrounding the global COVID-19 pandemic. Read the full newsletter [here](#).

3-4 February: PRIME convenes its annual General Assembly meeting

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. On 3 & 4 February, PRIME hosted an online General Assembly meeting, bringing together consortium members from 17 partnering organisations that include academic institutions, SMEs, scientific associations and patient organisations.

The General Assembly (GA) meeting was kicked off by Janita Braalten of Radboud University Medical Center (RUMC), who co-coordinates PRIME with Barbara Franke, Geert Poelmans (Drug Target ID) and Christiana Krammer (Concentris). The first morning of the GA was dedicated to presentations from work packages that include studies of clinical data. Soren Dalsgaard (Aarhus University) presented an update on work in WP1, which is looking at the prevalence of insulin signalling multimorbidity across the lifespan. Next, Geert Poelmans spoke about WP4 "Mechanism validation and refinement at the genetic and genomic level" which has identified genetic overlaps between conditions such as obsessive-compulsive disorder, autism and type 2 diabetes - conditions that could potentially be termed "insulinopathies of the brain". Finally, WP5 leader Silke Matura of Frankfurt University Hospital presented work being carried out in WP5 on interventions and integrative modelling, looking at whether existing interventions could be repurposed to treat insulin-related multimorbidity.

The afternoon sessions on 3 February were focused on WP6 and WP7, which are dealing with communication, exploitation, ethics and training for PRIME researchers. Alexander Hage of the Mannheim Central Institute of Mental Health (CIMH) presented the work he has been doing to review existing clinical guidelines for brain and insulin disorders, including guidance from bodies such as NICE (UK) and EMA. Jeanette Mostert (RUMC), who is leading communication and dissemination activities, showcased some of the webinars and social media activities that have taken place over the last year, with Jan Buitelaar (RUMC) giving an overview of the status of research ethics management in the project.

The final day of the PRIME meeting was mainly focused on the preclinical research activities being carried out in WP2 and WP3. WP2 is led by Simone Macri (Istituto Superiore di Sanita, Rome), and is focused on mechanism validation and refinement in animal models of disease. Simone described the different

animal models that are being used to understand the insulin-based mechanisms that may contribute to brain disorders, and updated on new findings from these studies. Next, Simone Berkel of Heidelberg University Hospital provided an update on WP3, which is similarly looking at mechanism refinement and validation, but in cellular models of disease. Simone and her team are using induced pluripotent stem cells (iPSC) derived from people with type 2 diabetes to create "diseased" brain cells that can then be probed mechanistically using different experimental assays. This session was then followed by a round of brainstorming, where partners were able to ask questions and make suggestions about new avenues for research. Geert Poelmans then drew the meeting to a close, thanking attendees for their valuable input and contributions.

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

5 February: Pattern-Cog project is recruiting a postdoctoral researcher in machine learning for neurosciences, to be based in Kuopio



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 AI-based framework that can detect the earliest signs of impending cognitive decline. Alzheimer Europe is a partner in the Pattern-Cog project, which has recently launched and is coordinated by Prof. Jussi Tokha (University of Eastern Finland).

Prof. Tokha is currently recruiting a new postdoctoral researcher for Pattern-Cog, to be based at the A.I Virtanen Institute for Molecular Sciences at the Faculty of Health Sciences, University of Eastern Finland. The position will be located in Kuopio, and will involve the development of multi-view, multitask supervised learning algorithms capable of integrating longitudinal datasets from brain imaging, cognitive tests, lifestyle measures and genetic studies. For more information and to find out how to apply:

https://rekry.saima.fi/certiahome/open_job_view.html?did=5600&jc=16&id=000012619&lang=en

9 February: AMYPAD reports on recent progress



The Amyloid imaging to prevent Alzheimer's disease (AMYPAD) project has reported the important advances and major achievements that have been

made during the past year.

The Diagnostic and Patient Management Study (DPMS) has reached the end of the clinical phase, will all 844 participants across eight European sites having completed the protocol visits

and scans by the end of June 2021. The data quality check and cleaning process has been finalised.

2021 has been the most successful year to date in relation to the rate of recruitment and scanning for the Prognostic and Natural History Study (PNHS). Study sites have been able to recover from the impact of COVID-19 to a large extent and three additional Parent Cohorts have joined the PNHS study, now including 10 parent cohorts of which 8 Parent Cohorts are actively enrolling participants into the study. In total, 1181 participants have consented into the PNHS study and 1220 scans have been performed at the end of 2021.

The collaboration within the AMYPAD consortium has been productive and efficient during the fifth year of the project. AMYPAD performed amyloid PET scans on an unprecedented scale of participants suspected to be in the early stages of Alzheimer's disease. In parallel, technical, and operational aspects have been established and optimised. Data is being collected. 2022, the final year, will put the efforts on the data acquisition, management and analysis activities, resulting in the publication of additional results from the AMYPAD scientific work.

<https://amypad.eu/news/recent-news/highlights-2021/>

22 February: The AI-Mind study has kicked off

The AI-Mind consortium is pleased to announce that its study recently started. This clinical study is a key part of the AI-Mind project and will help to develop and validate artificial intelligence (AI)-based tools to predict who is likely to develop dementia.



The AI-Mind Connector will identify dysfunctional brain networks in an automated manner, and the AI-Mind Predictor will assess dementia risk using data from the Connector, enriched with information collected through advanced cognitive tests, and genetic biomarkers. The first participant was included in January 2022.

The AI-Mind study currently has 91 participants who have consented to participate (as of 22 February 2022) and aims to enrol 1,000 people with mild cognitive impairment (MCI), aged between 60 and 80 years, in five European clinical centres:

- Complutense University of Madrid (Madrid, Spain)
- Helsinki University Hospital (Helsinki, Finland)
- Oslo University Hospital (Oslo, Norway)
- Scientific Institute for Research, Hospitalization and Healthcare (Roma, Italy)
- San Raffaele Roma (Roma, Italy).

The AI-Mind study protocol includes electrophysiological recording (EEG) to measure brain activity, digitalised cognitive testing (CANTAB) about memory, thinking and language as well as blood sampling and an interview with clinical staff during the first appointment. People interested in the study can learn more about it in the dedicated sections of the AI-Mind website, also available in Norwegian, Italian, Spanish and Finnish as well as watch an explanatory video developed to inform potential participants about the AI-Mind study procedures.

With the goal to distinguish people at risk and not at risk of dementia in a group of MCI subjects, the AI-based platform with both tools, AI-Mind Connector and AI-Mind Predictor, will be tested and validated in the above European clinical centres.

The AI-Mind project is funded by Horizon 2020, for a duration of 5 years. For more information about the AI-Mind study, please visit: <https://www.ai-mind.eu/study/>

or watch the explanatory video <https://youtu.be/-1Wn-KC5h-U>

22 February: After publication of "This is Me" mindful life-storytelling game evaluation in Journal of Aging Studies, MinD and Relish have launched the game under the name "All About Us"

On 15 December 2021, the evaluation of the MinD This is Me mindful life-storytelling game was published, open access in the Journal of Aging Studies:

<https://doi.org/10.1016/j.jaging.2021.100995>

It describes how the "This is Me" game was co-designed and evaluated by researchers from the MinD project team together with people with dementia, care partners and carers in four countries, including Germany, Netherlands, Spain and United Kingdom. Its aim is to provide support to people with early- to mid-stage dementia, especially following diagnosis. Based on concepts of life-storytelling and mindfulness, the game encourages players to talk about and reflect on their life experiences and aspirations, to help players focus on what they can and want to do with their lives.

The game consists of a gameboard, 66 question cards, a dice and four counters. The board shows a life-story path, divided into decades from childhood to 100+ years. During the game, players follow the life-story path to pick corresponding cards. They read out and answer the question on the cards. The other players can answer the same question, or move on to roll the dice anew and pick the next question card. The questions relate to memories, activities, relationships, experiences, achievements and dreams. The questions enable players to talk and share stories about the different stages of their lives. The life-story path leads the players from reminiscing about the past

towards what they can and may wish to do in the present and future.

During the evaluation, people with dementia who played the game in day groups with other people with dementia and caregivers felt that it was enjoyable, that it enabled them to share experiences, learn from and get to know others.

Participants enjoyed the social interaction and felt that it could help people get out of isolation and think together with others about the future.

The "This is Me" game has now been launched in collaboration between the MinD team and dementia wellbeing specialists Relish under the trademarked name "All About Us". It is now for sale on the Relish website and via online retailers:

<https://relish-life.com/dementia-games/group-games/all-about-us/>

Further information on the MinD project is available from the project website: <http://www.designingfordementia.eu>

For any questions or suggestions about the MinD project and its activities, please contact Professor Niedderer at k.niedderer@mmu.ac.uk



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/about-us/governance/finances/2022-sponsorship-opportunities>



EU project acknowledgements



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

AI-MIND – grant agreement 964220

AMYPAD – grant agreement 115952

PRIME – grant agreement 847879

RADAR-AD – grant agreement 806999

VIRTUAL BRAIN CLOUD – grant agreement 826421

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).

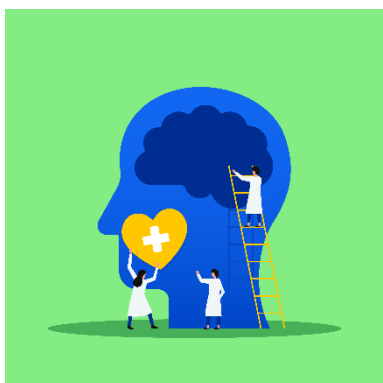
EU DEVELOPMENTS

28 January: OECD and EBRAINS host online discussion about future of European brain research and brain health agenda

On 28 January, the OECD's New Approaches to Economic Challenges (NAEC) group, in a joint initiative with EBRAINS, the Coordinator of the Human Brain Project (HBP) and Research Infrastructure for the study of the brain, hosted an online

discussion to articulate the vision and key elements of the future European brain research and brain health agenda. The meeting brought together representatives from the French EU Presidency, European Commission, World Health Organization, scientific societies, patient organisations, health professionals, as well as leading brain researchers.

In a world shaped by the pandemic, with all its economic implications, and in the face of new challenges posed by misinformation and mental health conditions, there is a need for new analytical approaches, tools, and insights.



Recently, the NAEC presented a [Neuroscience-inspired Policy Initiative](#) focusing on the concept of “Brain Capital”, which considers brain skills and brain health as indispensable parts of the knowledge economy. This principle-based approach to understanding the interplay between brain

function and health and the economy also highlights cost and burden. The impacts of adverse brain function have never been greater. However, there is a convergence of developments that might help place the brain at the centre of the EU policy agenda. Good brain health plays a significant role in an individual’s well-being and collectively has a profound impact on the economy and society. Poor brain health, or brain disease, carries devastating public health, social and economic consequences. Participants of the Round Table highlighted the scale of brain health issues, noting that, in 2021, more than 21 million people across the OECD member countries lived with dementia. Globally, dementia costs over USD 1 trillion per year and represents one of the leading causes of disability for older adults. This number is set to increase with population ageing over the coming years.

It was widely agreed that disruptions to brain health, such as mental health conditions and neurodegenerative diseases, are becoming increasingly prevalent and that psychological resilience is key to absorbing and adapting to social and economic shocks. Participants called for better prevention and education on the brain and mental health, noting that, while treatments are available, nearly two-thirds of people with a known mental health disorder never seek professional help.

It was also highlighted that although the role of the patient community has increased, it is often left out of research projects until the last minute. Meanwhile the EU has been traditionally lagging behind the US in funding clinical trials. Earlier involvement of patient organisations and patients in research projects, and large-scale clinical studies were therefore highlighted as important steps towards bridging the gap between research and clinical practice, and improving patient health.

Discussions also revolved around the creation of the European Health Data Space, which participants agreed will build a technological and process-based foundation for data sharing and exchange. It will enable convergence on data governance and allow efficient rules to ensure high standards for data quality and exchange. At the same time, it will facilitate the update and upgrade of essential data infrastructure and the exchange of information between European patients, health care systems, researchers, and planning and the design and implementation of clinical trials involving patients across multiple countries.

In closing, the meeting participants urged stepping up efforts at the European level, through more strategic funding streams and alignment of research agendas, and highlighted the pressing need to develop the European Health Data Space and set it on a roadmap to address the needs of the research and health community while ensuring that data safety, exchange, and governance are maintained at the highest level.

Alzheimer Europe’s Executive Director, Jean Georges, took part in this meeting. Read the full meeting report: <https://www.ebrains.eu/news/Towards-a-European-Brain-Initiative/>

1 February: Joint Action launches consultation on the use of health data

The EU-funded Joint Action, Towards the European Health Data Space (TEHDAS), is running a consultation for European citizens to find out what they think about how their health data could be used in the future.

Currently, health data is mainly used and shared among healthcare professionals to provide care treatment, however, it is indispensable for research to prevent and cure diseases and manage public health crises more effectively in the future.

TEHDAS is seeking views on how health data could be used in the future, including who could use it and for what purpose. The results of the consultation will support recommendations made by the TEHDAS project to the European Commission and to the member states on how the public should be involved in health data use and sharing. The consultation is available in English, French and Dutch. The consultation runs until 4 April 2022.



15 February: European Disability Forum submits UNCRPD report

The European Disability Forum (EDF) has contributed a report to the second review of the EU’s implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The EDF alternative report examines the European Union’s (EU) implementation of the UNCRPD, covering the period of time since the first review by UNCRPD Committee in 2015.

EDF’s report highlights that whilst some progress has been made by the EU in the intervening years (including through adoption of the European Accessibility Act, the European Strategy for the Rights of Persons with Disabilities etc.) the primary objective of the UNCRPD, to ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, has not been fully realised.



During EDF's drafting of the report, Alzheimer Europe contributed by highlighting issues relevant for people with dementia, their families and carers. The full report can be downloaded at:

<https://www.edf-feph.org/publications/edf-alternative-report-for-the-second-review-of-the-eu-by-the-crpdc-committee/>

17 February: EPF announces Anca Toma as new Executive Director



The European Patients' Forum (EPF) has announced Anca Toma as its new Executive Director, effective 7 March 2022.

In a press release sent to EPF members on 17 February, EPF President Marco Greco and current Executive Director Elisabeth Kasilingam welcomed Ms Toma, who is a public health

advocate working in tobacco control, with expertise in European public health policy and advocacy, and brings with her extensive knowledge and experience of EU policy and institutions, advocacy strategies, policy campaigns and project management. Ms Toma has led the Smoke Free Partnership (SFP) for the past four years, in addition to her 10 years working on pan-European campaigns in SFP. Her almost 20 years of working experience includes the private sector (public affairs consultancy) and the public sector. Elisabeth Kasilingam, CEO of the European Multiple Sclerosis Platform, who has been part-time Acting Executive Director of EPF since 2020 will be stepping down from this position at EPF and will resume her role within the EPF Board.

23 February: European Commission publishes additional EU4Health calls



DG SANTE has published an additional list of funding calls as part of the EU4Health Work Programme 2022. The funding is for action grants in eight areas, including:

- Call for proposals to monitor and strengthen the implementation of innovative approaches to prostate, lung and gastric cancer screening at Union level
- Call for proposals on prevention of NCDs – (other than cardiovascular diseases and diabetes)
- Call for proposals on promoting mental health
- Call for proposals to support the implementation of the Regulation on health technology assessment – training of patient and clinical experts contributing to joint health technology assessment activities
- Call for proposals to support increased capacity of notified bodies for medical devices

- Call for proposals to provide training for health workforce, including digital skills
- Call for proposals to support Member States and other relevant actors to implement relevant results of innovative public health research in relation to vaccination against COVID-19
- Call for proposals to develop early warning features and guidance in the area of pricing through the EURIPID database, based on competition cases.

The deadline for proposals is 24 May 2022. Further details on the calls can be found at:

https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/eu4h/wp-call/2022/call-fiche_eu4h-2022-pj_en.pdf



SCIENCE WATCH

3 February: NTG and Lumind IDSC Foundation publish report on dementia assessment in people with neuroatypical conditions

On 3 February, the National Task Group (NTG) and Lumind IDSC Foundation released their new report, which focuses on



the barriers to determining mild cognitive impairment (MCI) and dementia in adults with neuroatypical conditions. These conditions include autism, cerebral palsy, intellectual disability, Down syndrome, and significant sensory impairments.

Neuroatypical conditions (NAC) can affect intellectual development and function, cognition, movement and communication. To understand whether processes for assessing and diagnosing mild cognitive impairment and dementia are adapted to accommodate these conditions, NTG and Lumind IDSC Foundation convened a consultative panel of experts on NAC. The panel was tasked with identifying barriers, special needs and required adaptations for examining adults with NAC during assessments of MCI and dementia.

The Expert Panel concluded that current US guidelines for assessing for MCI or dementia do not provide sufficient information for assessing adults with NAC. They identified a number of challenges, highlighting the fact that many commonly-used assessments are not able to accommodate the cognitive, behavioural and motor differences that characterise many NAC. For example, people with NAC may experience difficulties with their vision, comprehension or communication, which would benefit from specialised instruments to assess MCI

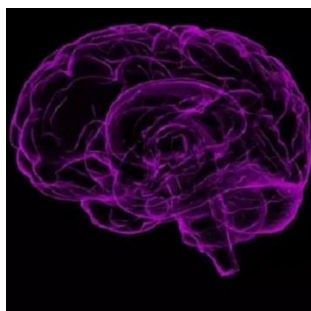
or dementia. In addition, clinicians may not have sufficient awareness of the nature of aging in people with NAC.

To address these challenges, the Expert Panel developed a series of recommendations. Firstly, they called for federal guidance to be broadened, to include adaptations of assessment practices for people with NAC. Second, they recommended enhancing the education of healthcare practitioners, to increase their understanding of how to differentially diagnose MCI or dementia in people with NAC, and how to plan post-diagnostic care. Finally, they called for more research to generate evidence-based information on assessing NACs as part of cognitive impairment screenings.

The report, 'Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments: Report of the Neuroatypical Conditions Expert Consultative Panel', can be accessed and downloaded on the NTG's website.

<https://www.the-ntg.org/screening-assessment>

4 February: Preclinical study shows a powerful immune response from the optimised amyloid-targeting vaccine ACI-24



On 4 February, AC Immune, a clinical-stage biopharmaceutical company focused on neurodegenerative diseases, announced new findings from its experimental vaccine ACI-24 in mouse models. Results were published in the journal *Brain Communications*.

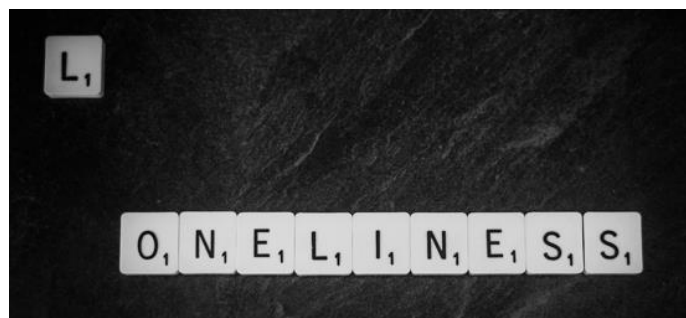
ACI-24 is an experimental anti-amyloid beta vaccine designed to prevent amyloid beta plaque accumulation and enhance plaque clearance. An earlier formulation of ACI-24 has been evaluated in small clinical trials with people with Alzheimer's disease (AD). These data showed that ACI-24 was able to induce an anti-amyloid beta immune response.

Scientists tested an optimised version of ACI-24 in mouse models and showed that the experimental vaccine could stimulate the production of antibodies against amyloid beta and was able to induce a strong immune response, substantially stronger in mice vaccinated with the optimised ACI-24 vaccine formulation compared to those vaccinated with the earlier formulation. In addition, ACI-24 was well-tolerated. Further data will be presented at the 16th International Conference on Alzheimer's and Parkinson's Diseases in March 2022.

The company plans to advance clinical development of the new ACI-24 formulation in AD and Down syndrome-related AD this year.

<https://ir.acimmune.com/news-releases/news-release-details/ac-immune-aci-24-data-brain-communications-show-amyloid-vaccine>

7 February: Loneliness can increase the risk of dementia in older adults, new research finds



A new study published in *Neurology* has shown that loneliness in older adults increases the risk of developing dementia in the longer term, highlighting the importance of social connections in maintaining brain health as we age.

In the study, led by Joel Salinas (NYU Grossman School of Medicine) and Sudha Seshadri (University of Texas), researchers analysed data and samples collected from the population-based Framingham Study cohorts. The Framingham Study was initiated by the United States Public Health Service in 1948, to investigate risk factors for cardiovascular disease, recruiting over 5000 people living in the town of Framingham, Massachusetts. Regular clinical examinations were carried out over the years, contributing to a valuable resource of data and samples which captures measures of vascular risk factors and cognitive impairment over a long period of time.

By analysing data and samples from the Framingham Study, which also included psychological measures of depression, anxiety and loneliness, the researchers were able to identify whether loneliness in older age was linked to developing dementia in later life. Focusing on 2308 participants with a mean age of 73 years, they observed that people who stated they felt lonely over 3 days a week were 53% more likely to develop dementia over the next 10-year period. Loneliness was associated with poorer executive function, lower total brain volume and greater measures of cerebral vascular disease. The risk of developing dementia was particularly marked in older adults whose baseline risk was relatively low due to age and absence of genetic risk factors. For these individuals, loneliness was associated with a tripling of dementia risk in later life, emphasising the importance of maintaining social connections for brain health.

<https://medicalxpress.com/news/2022-02-loneliness-dementia-older-adults.html>

8 February: Alzheon reports findings from its Phase biomarker II study evaluating ALZ-801 in early AD

On 8 February, Alzheon, Inc., a clinical-stage biopharmaceutical company focused on developing new medicines for neurodegenerative disorders such as Alzheimer's disease (AD), announced findings from its Phase II study evaluating biomarker effects of ALZ-801 (Valiltramiprosate) in early AD.

The ongoing Phase II study enrolled 84 people with early AD, who carried one or two copies of the $\epsilon 4$ allele of the apolipoprotein E (APOE4) gene. All participants received an oral tablet of ALZ-801 twice daily. The objectives of this study include determining the efficacy and safety/tolerability of ALZ-801.

The company reported interim analysis from a total of 80 participants (mean age 69 years) who completed the week 26 visit. Results showed a clinically relevant and statistically significant plasma biomarker reduction (29% reduction in plasma P-tau181 at 26 weeks and 18% reduction at 13 weeks) in participants who received ALZ-801. In addition to the biomarkers outcomes, the trial included a standard learning and memory test, Rey Auditory Verbal Learning Test (RAVLT), as a secondary outcome. Significant improvements on memory tests were observed for both immediate and delayed recall in participants who received AL-801. In addition, the safety profile was favourable and consistent with prior data. In the overall 84 participants, the most common adverse event was mild nausea. Alzheon is currently conducting a Phase III clinical trial evaluating the efficacy and safety of ALZ-801 in people with early AD carrying two copies of the APOE4 gene. Approximately 300 participants from US, Canada and Europe will receive either placebo or ALZ-801 twice daily for 78 weeks.

<https://alzheon.com/alzheon-reports-industry-leading-disease-modifying-effects-from-phase-2-biomarker-trial-of-oral-tablet-alz-801-valiltramiprosate-in-patients-with-early-alzheimers-disease/>

8 February: New article "What Matters to Patients with Alzheimer's Disease and Their Care Partners?" published in The Journal of Prevention of Alzheimer's Disease



While many studies explore the cognitive and functional aspects of Alzheimer's disease, relatively less focus has been put on gaining a deeper understanding of

patient and care partner priorities, particularly in the early stages where interventions may have the greatest impact in slowing or delaying progression.

A new article called "What Matters to Patients with Alzheimer's Disease and Their Care Partners? Implications for Understanding the Value of Future Interventions," has been published The Journal of Prevention of Alzheimer's Disease and provides a brief overview of the emerging body of literature on the Alzheimer's disease continuum, summarising what is understood about the impacts of the disease from the viewpoint of patients and their families, and outlining the emerging implications for future research and policy.

A key conclusion of the article is that there is a need to factor in the perspectives of patients and care partners to paint a fulsome picture of the impact of the disease on those most

affected, guide clinical research priorities, and assess the full value of interventions.

The article was authored by Professor Frank Jessen, University Hospital Cologne and German Center for Neurodegenerative Diseases; Jean Georges, Executive Director of Alzheimer Europe; Marc Wortmann, CEO, Marc Wortmann Consultancy; and Samantha Benham-Hermetz, Alzheimer's Research UK.

Access the full article here:

<https://link.springer.com/article/10.14283/jpad.2022.22>

10 February: New research points to an important role for our circadian clock in controlling the clearance of damaging proteins in animal models of Alzheimer's disease



A hallmark of Alzheimer's disease (AD) is the accumulation of damaging amyloid-beta proteins in plaques within the brain. Now, new research in animal models of AD has shown that our circadian clock may help regulate the clearance of amyloid beta proteins by immune cells, underlining the importance of a healthy sleep pattern.

Circadian rhythms are physical or biological changes that follow a 24-hour cycle, primarily regulated by light and dark - or sleeping and waking - in humans. These rhythms are collectively known as our body clock, running in the background to perform essential functions that keep our bodies working properly.

In a new paper published in the journal PLOS Genetics, a team of researchers led by Dr Jennifer Hurley of Rensselaer Polytechnic Institute used an animal model of AD to study the link between our circadian clock and amyloid beta proteins in the brain. Noting that AD is associated with sleep disturbances, the researchers looked more closely at immune cells that are responsible for the clearance of damaging proteins such as amyloid beta. This clearance process, known as phagocytosis, is thought to be regulated by circadian rhythms, which might provide the molecular link between our body clocks and sleep disturbance, and the accumulation of amyloid plaques in the brain in AD.

Using a series of experimental techniques, the researchers studied how and when immune cells clear amyloid beta proteins. They found that there was a daily oscillation in

amyloid clearance, which fluctuated according to the circadian clock. Closer inspection of the immune cells identified cell surface receptors, called chondroitin sulphate and heparan sulphate proteoglycans (CSPG and HSPG) that fluctuated in time with the circadian clock. Disabling these receptors with an enzyme stopped immune cells from clearing amyloid beta proteins, and increased the accumulation of amyloid plaques, identifying a mechanism that could link circadian clock dysregulation and sleep disturbance in AD.

<https://journals.plos.org/plosgenetics/article?id=10.1371/journal.pgen.1009994#sec002>

10 February: Arkuda Therapeutics raises USD 64 million in financing to test a new small molecule for frontotemporal dementia in 2023

On 10 February, Arkuda Therapeutics announced the completion of a USD 64 million (EUR 57.7 million) financing round that will support the further development of a new medicine for frontotemporal dementia.

Arkuda Therapeutics is a biotechnology company which is developing treatments that target the lysosome, a small organelle that is responsible for breaking down and disposing of damaging proteins and material inside cells. In certain types of frontotemporal dementia (FTD), lysosomes stop functioning properly, which contributes to the brain pathology that drives FTD.

Arkuda Therapeutics has already attracted the support of Pfizer, Eli Lilly and other companies. In its recent financing round, Arkuda was able to raise a further USD 64 million, which will help it advance its first-in class therapy to clinical studies. This therapy targets a protein called progranulin, which is known to play an important role in lysosomal function and inflammation in the brain. Arkuda plans to launch an early stage clinical trial in late 2023, which will recruit participants with a type of FTD that is caused by mutations in progranulin (GRN-FTD). GRN-FTD is an inherited form of dementia that is caused by a faulty copy of the progranulin gene, which leads to low progranulin levels.

In their press release, Arkuda explained that this is a first step in their broader strategy of exploring the clinical potential of its compounds, as there are multiple additional neurodegenerative diseases in which genetic links to progranulin biology have been established, including Alzheimer's disease and Parkinson's disease.

<https://www.arkudatx.com/news/arkuda-therapeutics-raises-64-million-series-b-financing-to-advance-pipeline-of-programs-targeting-lysosomal-biology-to-treat-neurodegenerative-diseases/>

13 February: IDEAL programme publishes study findings on methods and approaches for enhancing communication with people with dementia

Dementia can affect language processing and production, making communication more difficult. This creates challenges for including the person's perspective in research and service evaluation. A new study, published on 13 February 2022, aims

to identify methods, tools and approaches that could facilitate meaningful communication with people with moderate-to-severe dementia and support the inclusion of their perspectives.

This qualitative study was conducted as part of the IDEAL programme and involved in-depth, semi-structured interviews with 17 dementia research and/or care professionals with expertise in communication.

Transcripts were analysed using framework analysis. Useful skills and approaches were identified to help researchers engage and work with people with moderate-to-severe dementia and ensure their perspective is included. These covered getting to know the participant, using a variety of tangible tools and interactional techniques and considering the environment and context of the conversation. Find out more:

<https://journals.sagepub.com/doi/10.1177/14713012211069449>

15 February: AC Immune reports interim results from its Phase I/II study of tau AD vaccine

On 15 February, AC Immune, a clinical-stage biopharmaceutical company focused on neurodegenerative diseases, announced new interim data from its Phase Ib/IIa trial evaluating ACI-35.030 in early Alzheimer's disease (AD).



The Phase Ib/IIa study is a randomised, multicentre, double-blind and placebo-controlled clinical trial evaluating the safety, tolerability and immunogenicity of different dosages of ACI-35.030 and JACI-35.054 in people with early AD. ACI-35.030 is a vaccine designed to stimulate the generation of antibodies to pTau, which should bind to pathological Tau proteins in the brain and target them for clearance by the immune system.

The new findings, focused on the high-dose cohort of ACI-35.030, showed that at 10 weeks, the treatment led to a strong induction of antibodies selective for pTau and its aggregated form. These results were consistent with those previously announced for the trial's mid-dose. ACI-35.030 continues to be well tolerated with no clinically relevant safety concerns observed with all doses.

The study had already been expanded to include a total of 24 people with AD in the mid-dose cohort to generate additional data on immunogenicity and safety.

<https://ir.acimmune.com/news-releases/news-release-details/ac-immune-aci-35030-phase-1b2a-trial-interim-data-confirm>



16 February: Acadia Pharmaceuticals announces the resubmission of pimavanserin for AD psychosis to FDA



On 16 February, Acadia Pharmaceuticals Inc, announced that the company has resubmitted its supplemental New Drug Application for pimavanserin for the treatment of hallucinations and delusions associated with Alzheimer's disease (AD) psychosis to the US Food

and Drug Administration (FDA).

The resubmission came after a letter received in April 2021 from the FDA, stating that the application of pimavanserin for the treatment of dementia-related psychosis cannot be approved. This application was supported by findings from the HARMONY Phase III trial, which evaluated the safety and efficacy of pimavanserin for the treatment of hallucinations and delusions associated with Lewy Bodies, vascular dementia and frontotemporal dementia. The FDA did not mention any safety issues, it raised concerns regarding statistically significant data in some of the subgroups of dementia and insufficient numbers of participants with certain less common dementia subtypes.

Instead of a broad indication for dementia-related psychosis, Acadia has submitted a New Drug Application for pimavanserin specifically for hallucinations and delusions associated with AD psychosis. The resubmission provides additional analyses from two clinical studies, the Phase III HARMONY and the Phase II study-019 specifically done in people with AD psychosis. These additional analyses are intended to address the concerns raised by the FDA.

<https://ir.acadia-pharm.com/news-releases/news-release-details/acadia-pharmaceuticals-announces-resubmission-supplemental-new>

**Alzheimer's Society
Annual Conference
17 May 2022**

Registration open

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POLICY WATCH

17 February: World Disability Summit calls for health equity

As part of the World Disability Summit, held on 16 and 17 February 2022, a declaration was issued calling for governments, civil society, United Nations organisations, the private sector and other actors to commit to concrete action to address ongoing barriers in accessing health services for persons with disabilities.

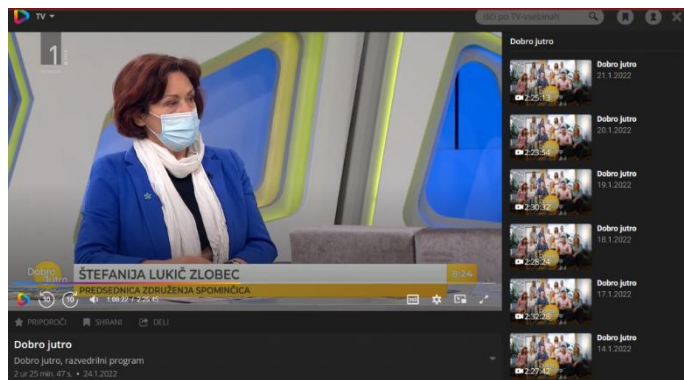
The declaration notes that the World Health Organization (WHO) is supporting countries to achieve disability-inclusive healthcare sectors, whilst also highlighting that a global report on the highest attainable standard of health for people with disabilities will be launched in December 2022, along with a Guide for Action. Further, the declaration cites the implementation of the UN Disability Inclusion Strategy through a three-year action plan as an example of good practice which should be further scaled-up. The full call was published in Nature and can be viewed at:

<https://www.nature.com/articles/d41586-022-00405-y>



MEMBERS NEWS

24 January: Alzheimer Slovenia takes part in "Good Morning" show on Slovenian national television, to raise awareness and inform people about risk reduction



On 24 January, Spominčica - Alzheimer Slovenija was raising awareness about dementia on the Slovenian television show "Dobro Jutro" (Good Morning), which is very popular across the Slovenian population, especially among older people. Štefanija L. Zlobec, President of Spominčica, discussed the importance of

dementia care for patients and carers, while Dr Milica G. Kramberger spoke on the neuroscientific subject of dementia, and Spominčica member and carer Nina Dovšak discussed her personal experience. The highlight of the show was the cognitive training, which allowed the two hosts to put themselves to the test. Listeners could also phone in to the show.

Štefanija L. Zlobec answered the question "Is dementia curable?". Because dementia is a disease for which no new, effective solution has been discovered in the last 18 years, the global medical community is increasingly highlighting the necessity and effectiveness of prevention and risk-reduction. Delaying, if not preventing, the onset of dementia is especially crucial for young people, she said, noting that risk-reduction includes anything that is healthy for the heart as this is also excellent for the brain. A healthy lifestyle, socialising, playing music, solving puzzles, and playing other mentally stimulating games are all examples of risk-reduction. Active living strengthens the brain, which is the most effective dementia treatment.

Dr Gregorič Kramberger added her thoughts on prevention: "According to studies, 40% of all risk variables can be modified before the first signs of dementia arise, hence delaying dementia. Mental activity, such as learning other languages and listening to music, as well as a healthy Mediterranean diet and socialising, are among them. Because we fall into a habit as we get older, it's necessary to break it at least twice a week by challenging ourselves and doing something different."

Ms Dovšak, for her part, shared her experiences of spending 11 difficult years caring for her husband, who had Alzheimer's dementia from the age of 57.

Spominčica appears in the Slovenian media on a regular basis, raising awareness about dementia, specifically about the importance of recognising the first signs, getting an accurate diagnosis, and destigmatising the condition. Spominčica noted that "Slovenia is gradually progressing toward the dementia-friendly environment that we all strive for".

26 January: Alzheimer Slovenia co-creates TV documentary on dementia featuring member of the European Working Group of People with Dementia Tomaž Gržinič

Spominčica - Alzheimer Slovenija was invited to co-create the 30-minute long documentary "Facing Dementia", which aired during prime time on Slovenian national television on 26 January 2022 and which received a lot of positive feedback. Among the participants were Štefanija Lukič Zlobec, President of Spominčica, Milica Gregorič Kramberger, a member of professional committee of Spominčica, and Tomaž Gržinič (pictured), member of the European Working Group of People with Dementia (EWGPWD).

The presenter highlighted that there are more than 32,000 people in Slovenia who have dementia, and that this number is expected to nearly double by 2050. Dementia is one of the most



expensive diseases in terms of social and health costs, as well as caregiver burden. That is why Spominčica organises caregiver self-help groups and dementia trainings, as well as raising awareness in local communities by establishing "Dementia Friendly Points", which include hospitals, care homes, ministries, pharmacies, and other locations where people can get information about dementia, and assistance, if needed. Spominčica also runs an SOS telephone line because caregivers and people with dementia sometimes require immediate assistance.

During the documentary, Dr Milica G. Kramberger, a neuroscience specialist, noted that dementia is a symptom of neurodegenerative diseases such as Alzheimer's. At first, we can see that a person with dementia begins to forget things and loses orientation, she said. The disease can be seen in the brain as it progresses. In the Neuroscientific Clinic in Ljubljana, disease is investigated using transplant tests, laboratory blood tests, head imaging, and cerebrospinal fluid examination. Irregularities can appear between 10 and 20 years before the onset of dementia.

Štefanija Lukič Zlobec started working as a volunteer at Spominčica when her husband Jaša Zlobec Lukič got diagnosed with dementia at a fairly young age. From the start, she has cared deeply for people with dementia and has tried to connect as many dementia specialists as possible, at an international level. She thus quickly became a very important part of the Spominčica team. In 2014, she became the President of the organisation. She stated in the documentary that, as a carer, you hope for a different diagnosis. Dementia is incurable and can last for a long time. It is difficult for people with dementia because they are losing knowledge as well as memories. She emphasised that, regardless of the disease, people with dementia understand things until the end, even if we believe they don't. It is so difficult to accept that your loved one is changing, she noted.

The documentary also showed how Tomaž Gržinič, a member of the EWGPWD, manages to live alone and how he copes with his condition and manages to live relatively normally. He enjoys riding his bike, cooking, hiking in the Slovenian mountains, tending to his garden, driving a car to his country house and playing tennis every Monday with his friends. The most

humorous part of the show was him joking with his tennis teammates about organising a trip. They said that when he organises a trip, they never know where they're going, but that's not a problem because it's a never-ending journey into the unknown, which they enjoy. Tomaž was familiar with dementia because his father had it as well. He stressed the importance of seeing a doctor if you notice signs of dementia. It is possible to slow dementia if you see a doctor as soon as you notice symptoms. He is relieved that his friends have accepted his disease and are not embarrassed by it. He didn't want to stay inside and hide due to his dementia because he believes it would be harmful to him, which is why he is so active in everyday life and regularly visits Spominčica for a chat and laugh.

The documentary also went on to examine the life of a married couple (the husband had dementia and the documentary looked at how he and his wife were still able to spend quality time together), and spoke to Slovenian dementia specialist Jože Škerlj.

Because of the stigma, there are too few employees working in the field of dementia, and there are insufficient funds allocated in Slovenia. Because there is no cure for dementia, they must use nonpharmacological approaches and raise awareness about the early warning signs of dementia and how to communicate with people who have dementia. They require calm, routine, predictability, and a sense of belonging. Spominčica's founder, Dr Kogoj, stated: "The focus should be on the person, not the disease." The documentary is available to watch (in Slovenian), here:

https://365.rtvlo.si/arhiv/izzivi-srebrne-generacije/174842465?fbclid=IwAR20Y0NwgS11wfcEGekjzU81DmhZgw9KCbUfHKWAHaf3-FcQ_VJ7g_nkuo

28 January: Social Cluster Association's INDA programme receives "Lifelong Health" special prize



At the end of January 2022, the "Lifelong Health" Special Prize was awarded to the Social Cluster Association's INDA programme, "Living with dementia – complex support for caregiving families". The "It Speaks to

Me!" Health Literacy Award, launched by the Association of Innovative Pharmaceutical Manufacturers (AIPM), was given by a jury of experts in several categories.

As a member of the European Federation of Pharmaceutical Industries and Associations (EFPIA), one of the most important objectives of the AIPM is to ensure access to medical solutions based on modern discoveries for as many Hungarians as possible

Improving the level of health literacy will continue to be a priority for Innovative Pharmaceutical Manufacturers.

Dr Péter Holhacker, Director of the AIPM emphasised that authentic and comprehensible communication about health and health risks had recently become even more important due to an increase in often "life-threatening fake news" on social media. For this reason, it was one of the important aspects in this year's evaluation of applications. During the evaluation, in addition to professional content, the jury also awarded the reliable and easy-to-understand communication of scientific facts and arguments to as many people as possible through popular and up-to-date communication platforms.

The Social Cluster Association implemented its INterprofessional Dementia Approach (INDA) programme in Hungary – which is still running and improving. A quarter of a million people in Hungary country are living with dementia, with the vast majority of them living in their own homes. The focus of INDA is not only people with dementia, but also family carers. The Demencia Információs Órák (DIÓ - Dementia Information Classes) is a thematically structured, 12-session interactive programme to expand the knowledge of family members. It has already been realised in six cities across the country. The aim of DIÓ is to support family carers. This support is unique, due to the participation of personal mentors who are available to help participants personally, to deal with individual life situations, during the whole programme.

Information booklets have been created, to address each family member. These show the symptoms of dementia in different ways according to the age of the target audience. Aimed at pre-schoolers, the family booklet promotes acceptance through the story of Uncle Walnut.

Winning the award is another opportunity for the Social Cluster Association to highlight dementia publicly and in the media.

www.demencia.hu; www.nekemszol.hu

12 February: Alzheimer Larissa celebrates "World Hugging Day" in Greece

Inspired by the celebration of the annual World Hugging Day on 12 February 2022, the association Alzheimer Larissa in Greece proceeded with three relevant actions, aiming to inform about the therapeutic effect of hugging, as a non-pharmacological intervention for patients.



On 18 January, Maria-Arístea Naka informed caregivers of people with dementia about the therapeutic results of embracing the human body, focusing on people with dementia. She presented different types of hugging and measured the benefits of its application as a non-pharmacological intervention and interaction: it was found to influence behavioural disorders, reduced stress, improved mood and generally the quality of life of people with dementia. Carers who

intended to apply the empathic embrace had the opportunity to participate in a relevant discussion at the end of the event.

On 20 January, Athanasia Tambouri and Maria-Aristea Naka applied an intervention aiming to improve the mood of patients through the presentation of images of people, animals and birds hugging.

On World Hugging Day, 12 February, Alexandra Mano and Konstantina Bethava conducted a computer-assisted mental exercise workshop on a group of patients. The participants had to select on the screen the occasion during which they gave more than one hug. The participants were enthusiastic to use the screen, circling the event of their choice and then telling their related stories.

15 February: Confederación Española de Alzheimer (CEAFA) has a new President



The Confederación Española de Alzheimer y otras Demencias (CEAFA) has a new Governing Board in place since the beginning of January 2022 and as of 15 February, has announced Mariló Almagro as the new president of CEAFA. Ms Almagro replaces Cheles Cantabrana in this position, which she will hold for the

next three years.

Her objective is to continue working for the detection and diagnosis of dementia that, in Spain, affects a total of 1,200,000 people, in addition to defending the interests, needs and rights of all people living with Alzheimer's and other types of dementia in Spain.

In her own words, this new stage is "a personal and professional challenge. I hope I am able to meet expectations and to keep up the good work done so far by the entire Confederation and, above all, to continue reinforcing the work that the entity has been doing for the people who live with this disease."

During her mandate, the new Governing Board aims to continue working to put dementia on the political agenda, seeking the necessary social commitment to carry out actions that help change the stigma associated with the disease.

CEAFA brings together more than 300 family associations and represents the interests and needs of the more than 4.8 million people affected by dementia (including family carers) in Spain with Alzheimer's disease and other Dementia (also including family caregivers).

<https://www.ceafa.es/es/que-comunicamos/noticias/marilo-almagro-nueva-presidenta-de-la-confederacion-espanola-de-alzheimer-ceafa>

17 February: Alzheimer Bulgaria is working on the project "Dementia Dog Friends"



Alzheimer Bulgaria is currently working on the project "Dementia Dog Friends", funded by Solidarity Projects, which is part of the European Solidarity Corps programme. The project started at the end of summer 2021 and has a duration of one year. The funding for it is EUR 6,740.

The objectives of the programme include engaging young people with social problems and improving their project management skills. The project is therefore carried out by five young volunteers who are supported and guided by a mentor from Alzheimer Bulgaria.

The project aims at raising awareness of the problems around communication with people with dementia and the need to improve this. It also focuses on the need to improve society's attitude towards stray animals. To sum up, the results of the Dementia Dog Friends project aim at providing a new social service that involves stray animals in sanctuaries so as to improve the emotional state of people with dementia.

Project activities include meetings between people with dementia from the Alexandrovsk nursing home for older people, and dogs from the "Every Dog Matters EU" sanctuary. The five volunteers and psychologists will take part in the meetings in order to research the benefits of such communication, and will prepare a report that will be published on the Alzheimer Bulgaria website. Two training sessions for volunteers have also been held, so far, as part of the project activities. Topics covered include: "What is dementia?", "How to communicate with people with dementia in nursing homes?", and "How to manage projects and create reports".

Alzheimer Bulgaria is working together with the "Every Dog Matters EU" sanctuary, which supports the idea of inclusion of animals in social and health services in order to improve the emotional state of patients, as well as to include animals in society.

A training session will be held in April 2022, at the sanctuary, about how to train dogs to include them in patient care and in particular in the care for people with dementia.

<https://alzheimer-bg.org/en/alzheimer-bulgaria-association-is-working-on-the-project-dementia-dog-friends/>

21 February: Alzheimer Hellas is working on a project teaching English with the use of songs for people with mild cognitive impairment



The Erasmus+ funded "E.L.So.M.C.I." programme is a two-year pan-European initiative, which began in September 2020 and aims to develop an educational programme on teaching English to people with mild cognitive impairment (MCI) and using English songs as a main tool for the teaching

process. Learning a foreign language has been shown to be a good way to stimulate cognitive functions, slowing down cognitive decline. To do this, people with MCI are involved in workshops that, by using innovative approaches and methodologies, will help them learn English.

The project coordinator is Alzheimer Hellas (Greece) and the partners are Alzheimer Valencia (Spain), Anziani e Non Solo (Italy), Spominčica - Alzheimer Slovenia (Slovenia) and University Psychiatric Hospital Vrapče (Croatia). In the past month, the consortium has finalised the training materials for the workshops that have been included in a methodological guide. This guide contains all information and educational materials to implement the workshops. At the moment the workshops have already started in Greece, Spain, Croatia and Slovenia, while they will start in Italy next months.

The next steps of E.L.So.M.C.I project will focus on the creation of an e-learning platform and an online training course about MCI, how to teach English using songs and how to implement the workshops. To find out more, visit: <https://www.songsforcare.eu>

23 February: France Alzheimer launches election campaign



**FRANCE
ALZHEIMER
& MALADIES APPARENTÉES**

In the run up to the first round of the Presidential Election in France on 10 April, France Alzheimer has launched a campaign highlighting the lack of focus on dementia as a policy issue, calling for candidates to prioritise it.

To build the profile of dementia as a policy matter and to encourage members of the public to raise the issue with candidates, France Alzheimer has

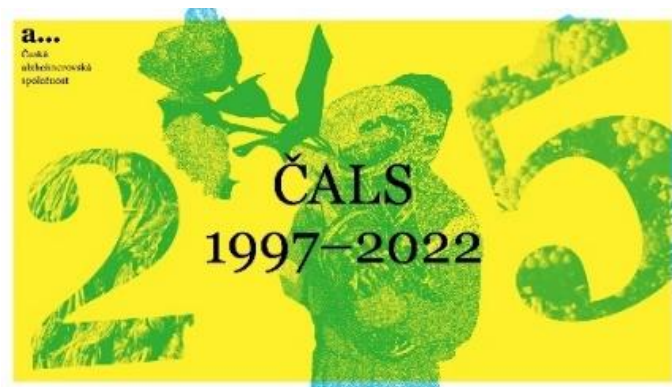
developed a campaign to engage the public and encourage them to highlight the issues related to dementia which matter the most to them.

The campaign includes 29 proposals which are the result of daily field work carried out by France Alzheimer's 101 local associations. These are included on the campaign website, where people are invited to identify which are the most important to them. The proposals are divided into six themes:

- Strengthening the recognition and rights of people with Alzheimer's disease
- Targeting prevention and better diagnosis
- Adapting the care pathway and accompanying the life course
- Reducing out-of-pocket expenses
- Reinvesting in research
- Recognising and supporting caregivers.

Furthermore, France Alzheimer will organise meetings with candidates this spring to make its demands known and to ensure that neurodegenerative diseases are included in the programmes of those whose mandate it is to protect populations, particularly the most vulnerable in society. Further information on the campaign can be found on the dedicated campaign website: <https://www.alzheimeradisparu.fr/>

25 February: The Czech Alzheimer's Society has been helping people with dementia and their families for 25 years!



The Czech Alzheimer's Society (ČALS) celebrates a significant anniversary this year, it has been supporting people with dementia and their families for 25 years! At the beginning, enthusiastic volunteers from the ranks of doctors, social workers and family caregivers, led by Iva Holmerová and Hana Janečková, prepared the foundations for the association's further work - as early as 1997, the first leaflets were produced, and they began to provide the first consultations to families whose lives were derailed by dementia.

To name some significant events, a major milestone was in 2002, when ČALS succeeded in contributing to the fact that cognitives began to be covered by public insurance. In 2008, they launched a successful project focused on early diagnosis of Alzheimer's disease, and since then ČALS has screened the

memory of more than 12,000 people free of charge in a non-medical setting and recommended 36% of them to see a specialist.

Collaboration has always been important in the life of ČALS, which is why 2015 was also an important year for them, when they found collaborators in all Czech regional cities. They are grateful that since its inception they have been able to benefit

from the experience shared not only by Alzheimer Europe and Alzheimer's Disease International, but also by other national Alzheimer associations. The main anniversary celebrations will take place in September around World Alzheimer's Day.



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LIVING WITH DEMENTIA

29 January: Helen Rochford-Brennan interviewed by Tommy Tiernan on national Irish television



Helen Rochford-Brennan appeared on The Tommy Tiernan Show on national Irish television station RTE, on 29 January 2022. Helen, an international dementia ambassador and a member of the European Working Group of People with Dementia (EWGPWD), spoke in-depth about living with Alzheimer's dementia and about her work campaigning for people with the condition.

Helen was 57 when she first got what she said was an "earth-shattering" diagnosis of early-onset Alzheimer's.

"It's called early-onset and to get a diagnosis is very difficult, I understand. It was hard to identify in the beginning because I was working and a busy woman," she said, "but when I got the diagnosis, of course, it was earth-shattering. I was in Galway and I was driving back to Tubbercurry and I was trying to think what I was going to say to Sean [husband] and Martin [son]. All that kept coming up in my head was that maybe in an undisclosed amount of time I may not remember them, or remember all the memories we shared along the way."

She continued: "It is difficult to live with it but it is liveable with. You have to have strategies and I think that is what has sustained me, to be honest with you: Working really hard every day and getting out in the fresh air and meeting people. You have to be pretty resilient and in particular, in the last year and a half I have had to be quite resilient because I was isolated at home."

Helen went on to say that more support is needed for people with dementia in Ireland, especially those living at home who receive very little support, "which has been a big issue in this country when it comes to funding, because we're not supported to stay at home, because the policy for home care in Ireland, as it stands, is take a shower and take your medicine. So as long as I am clean and lipstick is on and I take my medicine, that's grand. That's not good enough. We need support to live at home as long as we can and to have that choice."

Home Care, she stressed, is not just about personal care, it's about social activity also. It is vital that we take a more holistic view, she said. The Alzheimer Society of Ireland commented that it had received an overwhelming and hugely positive response to Helen's appearance on the show, via social media.

Helen Rochford Brennan commented, after the television interview: "I have received the most heartfelt letters from people I have never met. One lady wrote to say that her mother was beginning to go out again, after watching my interview. That is my job done, in telling my story, just to help others." The interview is available to view on the RTE Player, here:

<https://www.rte.ie/player/series/the-tommy-tiernan-show/SI0000001918?epguid=IP000067669>

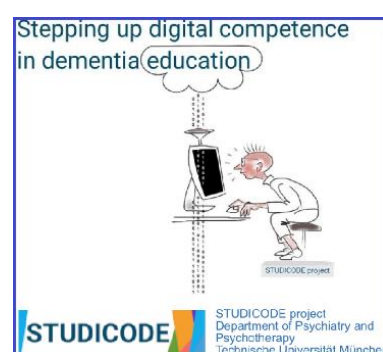
EDUCATION

21 February: STUDICODE project group presents its online course about dementia for medical students

The aim of the STUDICODE project (Stepping Up Digital Competence in Dementia Education) is to strengthen the digital teaching competence of lecturers by developing a multimedia online course about dementia. At a meeting on 21 February 2022, the outline of the course was presented to representatives from academia and patient organisations from

Southeast Europe. Furthermore, the media formats used in the course were discussed with meeting participants.

The course is tailored to the learning needs of medical students at undergraduate level and may also be a useful complement to the teaching environment in the fields of



psychology, speech therapy or occupational therapy. The course is being created by four project partners from the Memory Center in Bratislava, Slovakia, the University of Ljubljana, Slovenia, the Carol Davila University of Medicine and Pharmacy, Romania, and the Technical University of Munich in Germany. The online course is planned to launch at the end of 2022. You can find more information about the project here:

<https://www.studicode.med.tum.de/en>



DEMENTIA IN SOCIETY

20 February: Film "En mis zapatos" explores themes around dementia, family and caregiving



In the film "En mis zapatos", Paco Mora, a well-known Spanish flamenco dancer, dedicates his life to the care of his mother Carmen, who has dementia due to Alzheimer's disease.

At the same time, Paco is organising a theatre and dance show so that his mother can also be a dancer, which is her dream.

Find out more about the film, here:

<https://www.wip.be/films/en-mis-zapatos/>

24 February: Petri Lampinen receives merit award for patient and customer safety



The Finnish Patient and Customer Safety Association recently awarded Petri Lampinen, member of the European Working Group of People with Dementia (EWGPWD), a badge of merit and a diploma in patient and customer safety. He developed an informative whiteboard with magnetic buttons and colour coding that brings him and those close to him security. The board helps him remember household safety matters such as turning off the cooker, to pay bills and to take his medication, among other things. It has been of such help that it has afforded

a break in homecare visits and has attracted interest across Finland, allowing others to develop similar systems for themselves or their family members with dementia.

Congratulations to Petri on this great achievement!

28 February: Take part in a multi-country study exploring experiences of caring for people living with Alzheimer's during COVID-19

Researchers at the University of Westminster (London), in partnership with Alzheimer's Disease International (ADI) and Roche are conducting a multi-country study exploring experiences of caring for people living with Alzheimer's during COVID-19.

The study will explore how people with dementia and carers have felt during the pandemic and will explore their experiences of accessing support, including how this has been impacted by the pandemic. It will take place in four countries: Brazil, South Africa, United Kingdom and United States. Roche has provided funding and, alongside ADI, has contributed to the development and design of the study. Find out more and take part, here:

<https://www.westminster.ac.uk/research/groups-and-centres/portraits-of-care>



JOB OPPORTUNITIES

14 February: Alzheimer Europe is looking to recruit two project officers and an administrative assistant



Alzheimer Europe is looking to fill three full-time Luxembourg-based positions:

Project Officer for Public Involvement (full time), on a permanent basis

As the Project Officer for Public Involvement, you will:

- Become an active member of the organisation's public involvement team and support all public involvement activities of Alzheimer Europe
- Collaborate with and support the European Working Group of People with Dementia and its contributions to AE's work and involvement in research projects
- Support the development of the organisation's new European Carers' Working Group
- Identify new consultation methods to include the views of people at risk of developing dementia
- Help with the writing of dementia-inclusive publications
- Contribute to scientific publications on Public Involvement in European dementia research
- Help in the dissemination of EU-funded research projects
- Support the communication of medical and research developments to the wider dementia community and the general public via the organisation's newsletter and website

You should have the following experience and qualities:

- Completed university education in a scientific field (such as dementia studies, psychology, sociology or similar)
- Experience in a similar position (background in patient and public involvement would be considered an advantage)
- A good understanding of dementia research and the contributions to research of people with dementia and their carers
- A perfect knowledge of English (knowledge of other European languages would be a plus)
- Excellent writing and communication skills, including communicating scientific concepts in easy-to-understand language
- Experience of social media
- Proficiency in Microsoft Office applications
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad and present at project meetings, scientific conferences and other networking opportunities.

Project Officer for risk prediction, artificial intelligence and data governance (full time), on a permanent basis

As the Project Officer, you will:

- Collaborate with projects funded by Horizon Europe and the Luxembourg Fonds National pour la Recherche (FNR)
 - **ADIS** (Early diagnosis of Alzheimer's disease by immune profiling of cytotoxic lymphocytes and recording of sleep disturbances)
 - **Pattern-Cog** (Personalised ageing pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals)
 - **eBRAINS-Health** - Actionable Multilevel Health Data

- Contribute to discussions on risk prediction & detection, data sharing and data governance, as well as on artificial intelligence
- Contribute to the development of policy positions on risk prediction, detection and disclosure
- Collaborate with the public involvement team to identify the views of people with dementia and mild cognitive impairment on these topics
- Contribute to the communication and dissemination activities of EU-funded research projects
- Support the communication of medical and research developments to the wider dementia community and the general public via the organisation's newsletter and website

You should have the following experience and qualities:

- Completed university education in a scientific field (such as epidemiology, bioinformatics, artificial intelligence or another field relevant to the position)
- Experience in a similar position (background in data governance or data sharing policies would be considered an advantage)
- A detailed understanding of dementia research and/or data governance and sharing
- A perfect knowledge of English (knowledge of other European languages would be a plus)
- Excellent writing and communication skills, including communicating scientific concepts in easy-to-understand language
- Experience of social media
- Proficiency in Microsoft Office applications
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad and present at project meetings, scientific conferences and other networking opportunities.

Administrative Assistant (full time), on a permanent basis

As the Administrative Assistant, you will:

- Support the Alzheimer Europe Board and Executive Director by preparing meeting documents and minuting meetings
- Assure efficient processing and managing of document flows
- Handle telephone calls, contacts with internal and external partners, messages and requests
- Provide active assistance in day-to-day activities and perform various organisational, administrative and secretarial duties efficiently
- Keep mailing lists and databases up-to-date
- Respond to general mail requests and deal with filing
- Update the Alzheimer Europe website pages

- Support the team with the organisation of events (preparation of documents and presentations) and the Annual Conference (queries and invoices).

You should have the following experience and qualities:

- Completed secondary education and experience in a similar position (education or background in communication or secretariat would be considered an advantage)
- A perfect knowledge of English (knowledge of French and other European languages would be a plus)
- Good writing and communication skills
- Experience of social media and website content management
- Proficiency in Microsoft Office applications
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad for Board meetings on a quarterly basis.

To apply for any of these three positions:

Please send your CV, together with a cover letter (both documents in English), by 13 March 2022, to: Alzheimer Europe, 14, rue Dicks, L-1417 Luxembourg or via E-mail to info@alzheimer-europe.org

28 February: Senior Research Fellow opportunity with the Association for Dementia Studies at the University of Worcester

The University of Worcester is seeking an experienced and inspiring Senior Research Fellow in Dementia Studies to be a key

player in the Association of Dementia Studies and contribute to research across the wider School of Allied Health and Community. The post is offered full-time but part-time applicants will be considered. The team is particularly interested in hearing from candidates who have a track record in research in later stages of dementia, complex diagnoses, family care, distress behaviours, frailty, care homes and hospital care. The closing date for applications is 14 March 2022. For further details and to apply, visit:

<https://jobs.worcester.ac.uk/Vacancy.aspx?ref=SAHC2201>





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Contact Alzheimer Europe:

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Alzheimer Europe Board:

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Alzheimer Europe Staff:

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AE CALENDAR

Date	Meeting	AE representative
1 March	Neuronet data sharing working group meeting	Angela
1 March	EU FINGERS Advisory Board meeting	Ana and Cindy
2 March	Meeting with European Federation of Neurological Associations and GAMIAN	Owen and Jean
2-3 March	EMA PCWP & HCPWP meeting	Angela
9 March	EFPIA Patient Think Tank	Owen
10 March	DataSavesLives webinar	Angela
10-11 March	RADAR-AD annual meeting	Dianne and Ana
11 March	Biogen PAG Steering Committee Meeting	Jean
14 March	Meeting with EFPIA AD Platform	Jean
14 March	NeuroCohort Taskforce meeting	Angela
14-15 March	BIAF (Brussels International Association Forum), Brussels, Belgium	Gwladys
16-18 March	AD/PD Conference in Barcelona, Spain	Jean
17 March	Meeting with Novo Nordisk	Jean
18 March	EMA raw data advisory group meeting	Angela
23 March	Meeting with Roche	Jean
28 March	World Dementia Council in London, UK	Jean
28 March	European Commission Information meeting on disability framework programmes and operating grants	Jean
29 March	Biogen briefing session	Owen
30 March	Astellas Workshop on multimorbidities	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
28 April	Diagnostik und Früherkennung von Demenzerkrankungen, https://demenz-konferenz.ch/	Bern (Switzerland) and online
17 May	Alzheimer's Society Annual Conference 2022, https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/annual-conference	London, UK
1-3 June	XII Biennial Conference – Barcelona Pittsburgh, https://www.fundacioace.com/bcnpit/	Barcelona & online
7-9 June	7 th World Conference on Adult Capacity, https://wcac2022.org/	Edinburgh, Scotland
8-10 June	30 th European Social Services Conference, https://essc-eu.org/	Hamburg, Germany
9-11 June	35 th Global Conference of Alzheimer's Disease International, https://adiconference.org/	London & online
25-28 June	8 th 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 nd 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



32nd Alzheimer Europe Conference

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17 to 19 October 2022

www.alzheimer-europe.org/conferences

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