ALZHEIMER EUROPE NEWSLETTER

WELCOME

Despite the strange and difficult year we have had, I hope that 2020 nonetheless contained some silver linings for everyone and that 2021 has started on a positive note.

The Alzheimer Europe team has every reason to be proud of its achievements over the past 12 months and I would like to thank everyone who supported us in our efforts to ensure dementia remains a European priority, even in the most challenging circumstances. The European Working Group of People with Dementia (EWGPWD), our members, partners and sponsors, the European Alzheimer’s Alliance, and the Alzheimer Europe Foundation and Board have all been instrumental in supporting our work. We also owe a big debt of gratitude to the EU and its health and research programmes, without which none of this would be possible.

During December, we held a series of online meetings, including a Board meeting, a meeting of the European Group of Governmental Experts on Dementia, a company roundtable with sponsors, the last session of the 6th edition of our annual Alzheimer’s Association Academy, and a meeting of the EWGPWD.

At the online European Parliament workshop, which was hosted by Sirpa Pietikäinen, MEP (Finland), we launched our new electronic report “Dementia as a European Priority – A Policy Overview”. It takes stock of dementia policy at an EU level and sets out recommendations for future priorities across Europe. We subsequently launched two more publications – a new guide targeted at health and social care workers and a policy briefing on intercultural care and support. All of our publications are available to download (PDF) or to view online, via our website.

At a national level, we were delighted to hear that both Norway and the Netherlands have launched new dementia strategies. Both documents build on the countries’ previous, successful national dementia strategies. I would like to congratulate our Dutch and Norwegian members on these positive developments and wish them every success in implementing these policies to their fullest effect, alongside their governments.

At a global level, a new report on Global Health Estimates by the World Health Organization (WHO) has revealed dementia as one of the three leading causes of death in Europe, and one of the top ten causes worldwide. With this in mind, Alzheimer Europe re-iterates its call to ensure dementia remains a political priority at a European level across health, research and social policy. We were therefore pleased to read that the European Parliament and the Council of the EU have agreed a deal in relation to the dedicated EUR 5.1 billion EU4Health programme, as part of the EU’s recently agreed long-term budget. They have also reached a political agreement on the future of the Horizon Europe research programme, running from 2021 to 2027.

We welcome this progress, and I wish you all a positive and healthy start to 2021!

Jean Georges
Executive Director
COVID-19 SITUATION

11 December: “Does father get a shot against coronavirus?” ethical considerations for vaccinations in the residential care setting

On 11 December, Jan Steyaert, Jurn Verschraegen and Leentje de Wachter of the Flanders Centre of Expertise on Dementia published an article on Sociaal.net (translated into English on the LTC COVID website), following on from the announcement that the COVID-19 vaccination programme will shortly be rolled out in Belgium. The Belgian authorities published a first version of their vaccination strategy earlier this month, which prioritises people living in care homes, and particularly those with conditions that increase the likelihood of severe COVID-19.

In their article, the authors discuss some of the ethical considerations for COVID-19 vaccination of people with dementia in the care home setting. These include the question of mandatory vs optional vaccination, as well as considerations around dementia and mental capacity to accept or refuse vaccination. They highlight the benefits of approaches such as advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected, whilst emphasizing that when it comes to advance directives, which help ensure individuals’ wishes are respected.

Importantly, the authors call for the voices of people with dementia to be listened to as much as possible; for example, by taking previous statements regarding flu or other types of vaccination into account. Where there are no previous statements or advance directives to rely on, legal representatives or family members with power of attorney could be consulted. Tools such as the “Framework for weighing previously expressed preferences vs Best Interests” may also be of use in this context.


18 December: Alzheimer Nederland examines impact of corona crisis on home carers of people with dementia

Every two years, Alzheimer Nederland conducts a study into the impact on, and support available for those providing home care for people with dementia. In particular, partners of people with dementia indicate that they have felt more under strain since the corona crisis, namely 72%. Among children who perform the role of carer for a parent or parent-in-law, 64% indicate that they feel more impacted. The increase in the perceived care burden is due to receiving less formal and informal support during the corona crisis. This is evident from the Caregiving Dementia Monitor, which is carried out every two years by Alzheimer Nederland, in collaboration with the Netherlands Institute for Health Services Research (Nivel). For this seventh survey, a total of 3,577 home carers of people with dementia completed a questionnaire about the perceived
burden of care, the impact of caregiving on their social life and about their experiences with support and care.

Among carers who receive support from volunteers, 42% indicate that they receive less support than before the crisis. Among carers who receive support from day centres, this figure is 45%. On a more positive note, however, 27% of the carers who receive support from neighbours have actually received more support from them since the crisis began.

The current survey by the Caregiving Dementia Monitor not only provides insight into the consequences of the corona crisis for home carers, but also provides a general insight into experiences with formal and informal care and support. A positive development is that more carers indicate receiving sufficient understanding of their situation from their immediate environment (80%) compared to 2018 (76%). More carers also indicate receiving unsolicited help from their immediate environment (35%) compared to 2018 (29%).

18 December: Spominčica – Alzheimer Slovenia performs several activities to support people with dementia in maintaining their cognitive and social abilities

The COVID-19 epidemic is an additional stress factor for both people with dementia and their relatives. During this time, people with dementia and their relatives are even more in need of advice, support, understanding, suggestions for home activities, or resolving other dilemmas they face. To help support them, Spominčica organises online workshops every Wednesday and Thursday morning.

In the workshops called “LET’S BRAINSTORM”, they cover areas such as memory training and other cognitive abilities, with various tasks, exercises, puzzles and other mental challenges. The workshop is suitable for anyone who wants to maintain their mental abilities and who wants to do something good to prevent dementia. Regularly performing various exercises helps to better maintain mental functions.

In the workshops called “LET’S SOCIALIZE”, they make sure that, even in the unpleasant period of COVID-19, people can maintain social contacts and talk about current topics that help and support people at home, in a pleasant atmosphere. During the workshops in December 2020, they discussed personal and general well-being and how it can be improved; how to remain calm and feel comfortable with a person with dementia, as much as possible. They also talked about the holidays and how they can spend them together with a person with dementia. Finally, they covered the topic of communicating in general and how to develop good communication and positive understanding with a person with dementia.

Spominčica also organised an online conference "LET’S TAKE CARE OF THE BRAIN! - The lives of people with dementia and their relatives during COVID-19" at which Štefanija Zlobec, president of Spominčica and experts Dr Vida Drame Orožim, neurologist and psychiatrist, Dr Polona Rus Prelog, psychiatrist and Professor Zvezdan Pirtošek, neurologist, presented the challenges that people with dementia and their carers, and healthcare professionals are facing. Moreover, special attention was given to how to structure the day to prevent the negative effects that social distancing and loneliness can have on cognitive abilities and on the mental health of the population. A debate followed, on the shortage of medicines, reduced access to healthcare professionals, electronic communication and telemedicine.

Sponsors of the month

Alzheimer Europe would like to express its gratitude to four new sponsors for its 2021 activities.

Read more about sponsorship opportunities here: http://bit.ly/sponsorAE

ALZHEIMER EUROPE

1 December: Third session of the Alzheimer’s Association Academy focuses on legal capacity and decision-making

On 1 December, Alzheimer Europe hosted an online workshop as part of its 2020 Alzheimer’s Association Academy (AAA). Chaired by Dianne Gove, Director for Projects at Alzheimer Europe (AE), the online workshop was entitled “Legal capacity and decision-making”. The workshop included four presentations and was attended by representatives from national Alzheimer’s associations, pharmaceutical companies and the European Working Group of People with Dementia.
Dianne Gove kicked off the workshop by describing the concept of legal capacity and the relationship between law and ethics, and outlined some of the recent work carried out by Alzheimer Europe’s Ethics Working Group, which is focusing this year on ethical issues related to legal capacity and decision making. Next, Matthé Scholten of Ruhr University Bochum (in Germany) delivered a presentation entitled “Legal capacity, dementia and the Convention on the Rights of Persons with Disabilities”. In his talk, Matthé addressed the concept of competence, discussing how competence can fluctuate as a function of time and depending on the task at hand. He described different decision-making models, such as the competence model, the radical CRPD model and the combined supported decision-making model, arguing in favour of the latter as an ethical approach to legal capacity and decision making for people with dementia. Catherine Quinn of the University of Bradford (United Kingdom) was the third speaker in the workshop, discussing how capacity is addressed in dementia research being carried out in England in accordance with guidance provided by the Mental Capacity Act. Drawing on her experience as a clinical trial manager and co-investigator, Catherine discussed the challenges of assessing capacity in dementia research, as well as practical issues around consent forms and patient information sheets. The final speaker of the workshop was Maria do Rosário Zincke dos Reis, Board member at Alzheimer Portugal and Alzheimer Europe. Drawing on her legal background, Rosário described recent developments in Portugal that have resulted in the creation of a new framework to regulate the legal capacity of adults who, due to disability, health or behavioural issues are not able to fully exercise their rights. She explored the extent to which these recent changes comply with the requirements of the CRPD.

The presentations were followed by an interactive discussion during which questions from the audience were addressed by the panel, including remote options for informed consent, the implications of the 5-year revision requirement in Portuguese law, how capacity legislation addresses incapacity due to behavioural problems and the nature of shared decision making.

7 December: Alzheimer Europe Board looks back on challenging year and plans for 2021

During an online meeting, the Alzheimer Europe Board reviewed the activities carried out by the organisation during a particularly challenging year and noted the great progress achieved on many fronts. In particular, the Board welcomed the proactive way in which the organisation has adapted to the COVID-19 pandemic and how it had supported member organisations by providing a resource centre, adopting important policy recommendations and organising online webinars to exchange good practices between members. Another highlight was the first Virtual Conference “Dementia in a changing world” which attracted over 700 participants from 46 countries. The Board reviewed the evaluation provided by conference participants in which plenary sessions, the conference platform and the interactivity were all very highly rated with 99% of respondents saying that they would recommend Alzheimer Europe Conferences to a colleague.

The Board also monitored the finances and noted that, despite a marked reduction in income of about 25%, the organisation had been able to budget very carefully and would therefore be in a position to end the year with a surplus.

Finally, the Board adopted the Work Plan and Budget for 2021.

9 December: Alzheimer Europe hosts an online European Parliament workshop on “Maintaining dementia as a public health and research priority during the COVID-19 pandemic”

On 9 December, Alzheimer Europe hosted an online European Parliament workshop, drawing its 2020 Alzheimer’s Association Academy series to a close. Chaired by Sirpa Pietikäinen, MEP (Finland), Chairperson of the European Alzheimer’s Alliance (EAA), the workshop included presentations from Alzheimer Europe staff, Members of the European Parliament (MEPs) and European Commission representatives. The event was attended by EU policymakers, representatives from national Alzheimer’s associations and national health ministries, pharmaceutical companies and members of the European Working Group of People with Dementia.

The theme for the Workshop was the impact of the COVID-19 pandemic on people with dementia, their communities,
healthcare systems and dementia research, as well as the need for dementia to remain a priority for the EU. MEPs Deirdre Clune and Mark Angel, Vice-Chair and member of the EAA respectively, kicked off the workshop by welcoming attendees to the meeting.

Dianne Gove, (Director for Projects at Alzheimer Europe) then described how the pandemic has negatively affected people with dementia and their communities, which have been hardest hit by COVID-19. In some EU countries, between 20-30% of COVID-19 deaths have been in people with dementia. In addition, many people with dementia have experienced an increase in feelings of loneliness and confusion, as well as a deterioration in symptoms. Dianne also emphasised the negative impact that loss of routine and contact with family and friends has had for people with dementia, placing them at greater risk for self-neglect and abuse.

Angela Bradshaw (Project Officer at Alzheimer Europe) looked at how healthcare systems have been stretched during the pandemic, leading countries to call up retired clinical staff and transforming standard wards into COVID-19 intensive care units. This has required additional investments from central governments, as described in the recent “Health at a Glance: Europe 2020” report from the Organisation for Economic Co-operation and Development (OECD) and European Commission. Alongside this, many national Alzheimer’s Associations have made heroic efforts to continue their support of people with dementia, providing online services and helplines as well as accessible resources and guidance. Angela described how dementia research has suffered during the pandemic, with the closure of research laboratories and the cessation or delay of numerous clinical studies. In the longer term, surveys indicate that many early-career researchers are considering leaving dementia research, with legitimate concerns that this area will be deprioritised in favour of infectious diseases research.

Owen Miller (Policy Officer at Alzheimer Europe) then introduced the new Alzheimer Europe policy report, “Dementia as a European Priority – a Policy Overview”. This report takes stock of dementia policy at EU level and lays out recommendations for future priorities. Describing how Alzheimer Europe has worked with its members and partners over the last three decades, Owen outlined some of the recommendations from the report, including the need for dementia research to be prioritised in EU research programmes such as Horizon Europe, and for dementia to be prioritised in policies on disability, chronic diseases, mental health and ageing.

Next, Isidro Laso Ballesteros, Cabinet Expert for Mariya Gabriel (EU Commissioner for Innovation, Research, Culture, Education and Youth) spoke about dementia as a priority of the current and future research programmes of the EU, highlighting the breadth of dementia research that has been funded by Horizon 2020, and lauding the efforts of the Innovative Medicines Initiative (IMI) in developing new diagnostics, tools and treatments for dementia.

The last speaker, Stefan Schreck, Adviser to the European Commission Health & Food Safety Directorate General, outlined how the proposed EU4Health programme will provide opportunities to strengthen health systems and promote best practice, providing a route for dementia to be addressed as a priority for the EU.

Drawing the workshop to a close, our host Sirpa Pietikäinen moderated a question and answer session, emphasising that the 95 members of the EAA will continue advocating for people with dementia and their carers at EU level.

9 December: Alzheimer Europe sets out future vision of EU dementia policy

On 9 December, at an online European Parliament workshop hosted by Sirpa Pietikäinen, MEP (Finland), Alzheimer Europe launched a new report “Dementia as a European Priority – A Policy Overview” which takes stock of dementia policy at an EU level and sets out recommendations for future priorities across Europe.

As the European Union is about to agree a new long-term budget and the details of the EU4Health and Horizon Europe programmes are being finalised, Alzheimer Europe reflects on the place of dementia as a political priority in Europe in recent years. This includes the different ways in which dementia policy and research have been supported by the three institutions of the EU, as well as some of the high-profile coordination and research projects which have been made possible as a result of EU funding.

In the report, Alzheimer Europe also highlights some of its key activities in campaigning for change, as well as the work it has coordinated and participated in, along with its national member associations, to raise the profile of the condition and build an evidence base to make the case for the prioritisation of dementia.

Despite the progress made and the knowledge generated, the report highlights that people living with dementia continue to face a number of challenges. These challenges, which concern wider society too, include the increase in the number of people living with dementia (estimated to double by 2050) and the societal and economic cost of dementia.

As a result, the report sets out a number of recommendations for the EU, outlining specific areas in which dementia should be prioritised across international, health, research and social policy. Recommendations include:

- Prioritising dementia research in EU Research Programmes (including Horizon Europe), providing a fair allocation of resources and funding for existing
programmes and better coordination between programmes

• Prioritising dementia within policies relating to chronic diseases, mental health and ageing, both at an EU and national level
• Supporting Member States to work towards the implementation of the World Health Organization’s Global Action Plan on Dementia 2017–2025
• Recognising dementia as a disability and including dementia in disability policies.

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

“Alzheimer Europe has worked with its members over the past three decades to ensure that dementia is a political priority at the European level. The policy landscape has changed dramatically during this time and we have seen considerable progress as both national governments and the EU have given dementia greater prominence within their health and research policies.”

“However, there is much still to do. The European Union and its Member States are on the cusp of historic deals on the EU budget, a greatly expanded Health Programme and the forthcoming Horizon Europe research programme. If we are to build on the knowledge, experience and progress gained in recent years, it is vital that dementia remain a political priority at a European level across health, research and social policy.”

The full report can be accessed on the website of Alzheimer Europe:

View online: https://bit.ly/DementiaEUPolicyOverview2020-online

11 December: Ethics working group meets to finalise report on legal capacity and decision making

Alzheimer Europe’s ethics working group, comprised of experts in dementia, ethics and law, met by Zoom on Friday 11 December for a final discussion in order to finalise the report on legal capacity and decision making. The work is advancing well and the report will be available at the beginning of next year. It will cover a wide range of issues and will contain recommendations. Areas covered include, for example, shared, supported and substitute decision making, involuntary placement, measures taken in connection with the current COVID-19 pandemic, consent to treatment, research and care, as well as voting, marriage and making a will.

14 December: EWGPWD takes part in consultation for work on the possible readaptation of a rehabilitation gaming system

Work is currently being carried out in the context of a project called “Virtual Brain Cloud” in which Eodyne (a company which is part of this project) has developed a “Rehabilitation Gaming System” (RGS). The RGS was developed for the treatment of deficits resulting from brain damage and has been used for people who have experienced a stroke. On 14 December, the European Working Group of People with Dementia (EWGPWD) took part in a consultation to reflect on the possible development of a similar approach for people with dementia. This was a Public Involvement activity in which the members of the EWGPWD discussed with Santiago Brandi from Eodyne different possible approaches and some of the issues that would be important to consider when developing a study to adapt these for people with dementia. There was considerable interest in this system and the EWGPWD is keen to pursue this issue further with Santiago. Ana Diaz and Dianne Gove co-moderated this session with Santiago Brandi.

17 December: Members of the EWGPWD enjoy a social gathering before Christmas

Although the European Working Group of People with Dementia (EWGPWD) is a working group, the members met on 17 December for a purely social gathering before Christmas. It was a nice atmosphere and the gathering was skilfully chaired by Chris Roberts, Chair of the EWGPWD. Members of the group exchanged their thoughts and feeling about the upcoming festive time, discussed a few serious issues facing people with dementia at Christmas, especially during the
pandemic, but also shared much laughter. Our thoughts were also with some members of the group who were unable to attend and all wished to be able to meet up in the new year.

17 December: Alzheimer Europe launches guide targeted at health and social care workers and a policy briefing on intercultural care and support

On 17 December 2020, Alzheimer Europe launched two new electronic publications: “Intercultural dementia care for health and social care providers: a guide” and “Policy briefing on intercultural care and support for people with dementia and their informal carers/supporters”.

The number of people with dementia from minority ethnic groups is increasing as migrant populations in Europe age and some ethnic groups have a higher risk of developing dementia. Although many symptoms of dementia can be managed with good care, the uptake of dementia care services by people from minority ethnic communities remains low.

Alzheimer Europe has responded to this challenge by developing, with a group of experts, a guide to support health and social care workers to provide intercultural dementia care and a policy briefing containing guidelines for policy makers. The association stresses the principle that every person with dementia should be aware of and have access to culturally appropriate dementia care. This work stems from Alzheimer Europe’s 2018 report on “The development of intercultural care and support for people with dementia from minority ethnic groups”.

In its newly-published guide, Alzheimer Europe encourages health and social care workers:

• to provide people from different ethnic communities with culturally appropriate and understandable information about dementia and existing services and support
• to make sure that people understand that dementia is a medical condition and that health and social care systems in Europe offer support and care to people with dementia and their families
• to explore the kind of support or services that would be helpful, adapt existing support if necessary and develop new innovative approaches that reflect the needs and wishes of people from different ethnic communities
• to develop cultural awareness, sensitivity and competence through an ongoing process of learning and exchange between and amongst health and social care workers and people from minority ethnic groups.

Alzheimer Europe further calls for health and social care workers to recognise that every person with dementia is unique. Although people with dementia may share some characteristics with other people from a particular ethnic group, it is important not to lose sight of the individual. Awareness and acceptance of cultural differences should not overshadow recognition of the many things that people from all ethnic groups have in common. It can and should provide a solid basis from which to explore the needs and wishes of each person.

Intercultural dementia care necessitates support at all levels. In the Policy Briefing, which contains extensive recommendations, the association calls on governments to address structural and interpersonal discrimination against people from minority ethnic groups by raising cultural awareness, sensitivity and competences across the whole health and social care system, and to address inequity inherent in policies, practices and procedures. Making a commitment to and investing in intercultural care and support are key steps towards ensuring a just society, one in which people with dementia and their carers, regardless of their cultural backgrounds, can live well and flourish.

Alzheimer Europe would like to thank the members of the ethics working group, namely Dianne Gove (Chair), Jean Georges, Owen Miller, Sahdia Parveen, T. Rune Nielsen, Charlotte Plejert, Daphna Golanshemes, Debi Lahav, Michal Herz, Siri Jaakson, Mohammed Akhlaq Rauf, Ripaljeet Kaur, Carolien Smits, René Thyrian, and Jessica Monsees.

The guide is currently available in English, French and German, and will soon be available in Italian and Bulgarian. The policy briefing is available in English. These documents, as well as the initial report, can be freely downloaded from the Alzheimer Europe website:

Policy Briefing online view: https://bit.ly/AEInterculturalCarePolicyBriefingOnline
Alzheimer Europe networking (online)

On 1 December, Alzheimer Europe organised an Alzheimer’s Association Academy meeting on legal capacity.

On 1 December, Jean attended the Management Team meeting of the Dementia Panel of the European Academy of Neurology.

On 2 December, Dianne and Ana met with members of the RADAR AD Patient Advisory Board.

From 2 to 4 December, Jean attended the Lausanne VII meeting “Scaliming, linking and creating action to drive global innovation in Alzheimer’s disease”.

On 3 December, Gwladys attended a meeting from the new EU Convention Bureaux Network.

On 3 December, Owen attended a WHO meeting on the implementation of the iSupport resource.

On 7 December, the Alzheimer Europe Board met.

On 7 December, Chris held an online guest lecture about science communication at the University of Vechta (Germany).

On 7 December, Alzheimer Europe organised an Alzheimer’s Association Academy meeting on working with Working Groups of people with dementia during the Covid-19 pandemic.

On 8 December, Alzheimer Europe organised a meeting of the European Group of Governmental Experts on Dementia.

On 9 December, Alzheimer Europe organised a European Parliament Workshop on “Maintaining dementia as a public health and research priority during the COVID-19 pandemic”.

On 9 December, Alzheimer Europe organised a company round table meeting with its sponsors.

On 10 December, Jean met with the Alzheimer’s team of the European Federation of Pharmaceutical Industries and Associations (EFPIA).

On 10 December, Gwladys took part in the ICCA Workshop on the future of RFP (Request For Proposal).

On 10 December, Dianne and Ana met with the Executive of the EWGPWD.

On 11 December, Cindy, Ange and Chris organised a meeting of the Neuronet Communications Expert group.

On 11 December, Jean attended the Health Advisory Board of GSK.

On 14 December, Cindy, Ange and Chris attended the EU Big Data Stakeholder Forum organised by the EMA.

On 17 December, Cindy, Ange and Chris attended a meeting of the Neuronet working group “data sharing and re-use”.

On 18 December, Jean attended the final meeting of the ADDIA project.

EU PROJECTS

9-13 November: Early-stage researchers participate in a training week to kick- start the MIRIADE project

The recruitment of the 15 MIRIADE early-stage researchers (ESRs) is almost completed, with 14 ESRs already on board. Clearly, becoming an outstanding researcher is not a straight path, it includes working abroad as Marie Curie herself did. During this unprecedented pandemic situation, the doctoral researchers accepted the positions to achieve the MIRIADE common goal- an early diagnosis of dementia. Team MIRIADE held its first official network-wide training week, virtually, from the 9-13 November.

The training week kicked off with an introduction from the project coordinator, Prof. Dr Charlotte Teunissen, located at the Amsterdam University Medical Center, followed by a short introduction regarding the project logistics by the project manager, Kimberley Kolijn. A round of interactions by the diverse group of ESRs followed next. The first session also included several educational talks given by the different consortium partners and beneficiaries, broadly based on the topic of “Body fluid Biomarkers for Dementia”. The day ended with an engaging virtual social event organised for the ESRs.

Over the course of the remaining week, the ESRs attended a course regarding scientific integrity and several lecture-
discussion sessions on diverse technical as well as non-technical topics. These sessions were designed to equip the ESRs with the required skills, including innovation and project management, protein bioinformatics and entrepreneurship in biotechnology. An eye-opening session was the one engaging people with dementia that gave participants a deep insight into their perspective and created an inspiring discussion with the consortium. Dementia is a progressive, debilitating disorder that affects millions of individuals world-wide, and as scientists, it is of utmost relevance to remind ourselves that the ultimate end-goal of our research is the betterment of lives of real people who are living with these diseases.

The overall goal of this training week was to present to the ESRs the multifactorial nature of research and the different perspectives that dementia research constitutes. The training week, albeit virtual, was informative, educational, allowed the ESRs to form social bonds and most importantly, was a great way to kick-start the MIRIADE Project.

18 November: ROADMAP project publishes SLR on health-related quality of life in people with predementia AD, MCI or dementia measured with preference-based instruments

On 18 November, researchers from the international public-private ROADMAP project published a new research paper in the journal of Alzheimer’s Research & Therapy.

The paper focusses on getting reliable estimates of health-related quality of life (HR-QoL) for people in different stages of Alzheimer’s disease, respectively who have mild cognitive impairment (MCI) or dementia.

In order to do so, the scientists systematically searched for studies that reported on HR-QoL in these conditions. The team was able to include 61 studies after the application of their pre-defined ex- and inclusion criteria.

Reporting their results, the team notes that 48 of the studies used the EQ-5D for people with MCI or dementia and that 36 studies reported HR-QoL for mild and/or moderate disease severities. In addition to that, 12 studies reported utility values for MCI.

Concluding, the paper notes that there now exists substantial literature in this area, but reckons that further research is needed to better understand HR-QoL in the earlier stages such as in people with preclinical and prodromal AD and MCI.

https://doi.org/10.1186/s13195-020-00723-1

30 November: Professor Bengt Winblad summarises the aims and achievements of the MOPEAD project

The Models of Patient Engagement for Alzheimer’s Disease (MOPEAD) project recently came to an end. It was an EU-funded project, involving partners from five countries, including Karolinska Institutet in Sweden, where Professor Bengt Winblad is based.

In this video, Prof. Winblad, a well-known and celebrated researcher in the field of Alzheimer’s disease (AD), gives TouchNEUROLOGY an overview of the project, touching on its aims and design, as well as the major findings of the project.

http://bit.ly/3oXbIW

11 December: New article from RADAR-AD consortium published in “Frontiers in Neuroscience”

A new article from the RADAR-AD consortium was published in the Journal “Frontiers in Neuroscience”. The paper describes the role of Heart Rate Variability (HRV) (i.e. a measure of the variation in time between each heartbeat) in the future of remote digital biomarkers. It explains that Remote Measurement Technologies (RMTs), such as smartphones, wearables and home-based devices, as used in RADAR-AD, could complement current clinical practice and offer new insights into the activities of daily living, therapeutic interventions and behavioural tasks. The RMTs which measure HRV have the potential to identify digital biomarkers indicative of changes in health or disease. This could promote a more proactive and holistic approach to diagnosis and care in dementia. Read more here:

https://www.radar-ad.org/newsroom/new-publication-radar-ad-consortium

11 December: Two publications associated with RADAR-AD presented at 2020 IEEE International Conference on Human-Machine Systems

Two publications associated with the RADAR-AD project were presented at this year’s IEEE International Conference on Human-Machine Systems. The Institute of Electrical and Electronics Engineers (IEEE) is an organisation devoted to advancing innovation and technological excellence and is the
largest technical professional society in the world. It is created with the purpose to serve professionals involved in the electrical, electronic, and computing fields and related areas of science and technology.

Read more, here:
https://www.radar-ad.org/newsroom/two-publications-associated-
radar-ad-presented-2020-ieee-international-conference-human

14 December: AMYPAD announces end of recruitment in the Diagnostic and Patient Management Study

The members of the Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) project have recently announced the completion of the enrolment of research participants in its Diagnostic and Patient Management Study (DPMS).

In this randomised clinical study, participants suspected of possible Alzheimer’s disease were included to determine the usefulness of β-amyloid imaging as a diagnostic marker for dementia.

The first participant was recruited in Geneva, Switzerland in May 2018. The study recruited individuals with Subjective Cognitive Decline plus (SCD+), Mild Cognitive Impairment (MCI), and dementia from eight European study centres. Despite the negative impact of COVID-19, the project succeeded in recruiting 844 of the planned 900 participants when recruitment was formally ended on 30 October. A total of 245 people with SCD, 342 with MCI and 258 with dementia had been enrolled and will continue to be followed as scheduled.

According to Prof. Giovanni Frisoni, group leader of the laboratory of neuroimaging of aging at the University of Geneva: “This is a truly exceptional result. Despite being hit by 2 waves of the COVID-19 pandemic, participating memory clinics were able to recruit as many as 94% of the target group size. Even a once-in-a-century pandemic was unable to stop the AMYPAD Diagnostic and Patient Management Study.”

To date, 724 scans have been performed (including 53 repeat scans) and sites are now focusing on completing all remaining scans and collecting all data for the already enrolled patients. Results on the primary endpoint are expected in mid-2021.

The consortium would like to thank all study centres for their excellent support, hard work and high flexibility during these difficult times, as well as all research participants for their willingness to participate in the project and increase our understanding of the role and impact of amyloid imaging in the diagnosis and management of Alzheimer’s disease.

For further information, visit:
www.amypad.eu

14 December: The EU-FINGERS project convenes an online general assembly meeting

On 14 December, the JPND-funded project EU-FINGERS held its general assembly meeting online. Chaired by Professor Miia Kivipelto, the EU-FINGERS project leader, the online meeting welcomed over 30 project participants, including representatives from the 8 institutions and organisations that make up the EU-FINGERS consortium.

EU-FINGERS is looking at the topics of brain health as people age and the reduction of risk factors related to Alzheimer’s disease and dementia. The project builds on the work of existing, pioneering European intervention studies, and proposes a novel multimodal precision prevention toolbox to address the complex and heterogeneous nature of Alzheimer’s disease and dementia.

During the consortium meeting, representatives from the different work packages in the project provided summaries of ongoing activities and briefly discussed their planned work.

Alzheimer Europe (AE) is involved in the Patient and Public Involvement (PPI) activities of the project and in this context, is setting up an Advisory Board to provide relevant input to the researchers from the perspective of people with Alzheimer’s disease across the disease continuum. AE is also co-leading the communication activities of the project. Jean, Dianne, Ana and Cindy took part in the meeting. Alzheimer Europe’s participation is supported by the Luxembourg national research Fund (FNR).

EU-FINGERS is also growing, as a new institution - the University of Luxembourg - has been welcomed in the consortium as an external collaborator. The University of Luxemburg runs a Programm Demenz Prävention (Dementia Prevention Program) led by Professor Rejko Krueger. The
program is aligned with the EU-FINGERS principles, adding to the expertise and data library of EU-FINGERS.

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

15 December: New MinD Network is announced

The MinD consortium is setting up a dedicated MinD Network to continue the exciting work that started with the European-funded MinD project (2016-2020) “Designing with people with Dementia: Designing for mindful self-empowerment and social engagement”, which finished in February 2020.

The mission of the MinD Network is to promote design as a beneficial tool to improve health and wellbeing in society, with relation to dementia. Drawing on the Recommendations and Design Guidelines from the MinD project, the MinD Network seeks to enable the innovation of methods, services, products and environments through a mindful co-design approach, which puts people with dementia, their families, friends, carers and care professionals at the heart and involves them in the co-creation process to develop design interventions that are both relevant and suitable to their wants, needs and wishes.

Core values of the MinD Network include a commitment to:

- person-focussed design
- promotion of wellbeing, empowerment and social engagement to enhance quality of life
- Mindfulness values to promote respect and dignity
- co-production, co-creation and co-design
- recognition of the power of design.

The aims of the MinD Network are to:

- facilitate joint research and professional development to develop policy and offer advice to policy makers, third sector organisations, professional practitioners, etc.
- promote and train diverse stakeholders in co-creation values and practices
- support the participation of people living with mild cognitive impairment or dementia to promote wellbeing and mindfulness
- promote mindful design as a way to encourage wellbeing, self-empowerment and self-esteem, and preserve dignity
- benefit from collective intelligence in collaborative innovation processes
- work towards the redesign of health and social care services and the creation of new roles to ensure continuity of care.

The MinD Network is still in the early stages. Further details and updates regarding activities and participation will be available on the Network’s pages, in 2021:

https://designingfordementia.eu/network

17 December: Challenges and best practice: Neuronet Working Group on data sharing holds an online meeting

The Neuronet Working Groups (WGs) are cross-project spaces for experts to discuss common issues, priorities and opportunities for synergy and collaboration, providing Neuronet with expert advice on four identified areas of interest: data sharing, HTA/regulatory interactions, patient privacy & ethics, and sustainability. As such, the WGs make an important contribution to Neuronet’s goal of compiling and leveraging the expert knowledge that is presently scattered across the different neurodegeneration projects in the Innovative Medicines Initiative (IMI) portfolio.

On 17 December, Neuronet hosted an online meeting of its WG on data sharing, moderated by Lennert Steukers, the Project Leader for Neuronet. Lennert kicked off the WG meeting with a brief overview of recent Neuronet activities, including the 2020 Public Event held as part of the 30th Alzheimer Europe conference. Next, Ghislaine van Thiel, Ethicist and researcher at the Julius Center of UMC Utrecht, delivered a presentation describing the work of the Big Data@Heart IMI project on ethical, legal and governance aspects of Big Data research. In particular, she highlighted the complexity and heterogeneity of data governance frameworks between institutions and clinical centres, and the difficulty of developing “one size fits all” solutions for data protection.

The main part of the WG meeting was focused on discussing different challenges frequently encountered in data sharing, in particular sociotechnical obstacles, legal complexities and organizational challenges. Representatives from several IMI projects, including Nigel Hughes (Janssen; EHDEN and EMIF), Rodrigo Barnes (Aridhia; EPAD), Antony Brookes (University of Leicester; EPAD) and Niamh Connolly (RCSI Dublin; PD-Mitoquant) discussed their experiences of these challenges,
also identifying potential tools and frameworks that could help overcome issues that impede effective health data sharing. Future WG meetings will focus on identifying concrete examples of best practice, working towards the development of a white paper on data sharing in neurodegenerative disease research.

https://www.imi-neuronet.org/working-groups/

### 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:

- **AMYPAD** – grant agreement 115952
- **EU-FINGERS** – INTER/JPND/19/BM/14012609
- **MOPEAD** – grant agreement 115985
- **Neuronet** – grant agreement 821513
- **RADAR-AD** – grant agreement 806999
- **ROADMAP** – grant agreement 116020

### Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 95, 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:** Monika Vana (Greens/EFA); Belgium: Petra de Sutter (Greens/EFA); 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). **Cyprus:** Costas Mavrides (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).

**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); Miaipetra 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); Chryssoula Zacharaopoulou (Renew). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Koulougliou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraki (EPP); Elissavet Vozemberg-Vronidii (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (ALDE); Matt Carthy (GUE/NGL); Deirdre Clune (NI); Ciárán Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ’Ming’ Flanagan (GUE/NGL); Billy Kelleher ( Renew Europe); Séan Kelly (EPP); Mairead McGuinness (EPP); Grace O’Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (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 Schrijver-Pierik (EPP). **Poland:** Elżbieta Łukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Boișoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brlguz (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 Farragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).

### EU DEVELOPMENTS

**8 December: European Group of Governmental Experts on Dementia meets online**

The European Group of Governmental Experts on Dementia has held its final meeting of 2020, connecting online to exchange updates and knowledge on the most recent and relevant developments in relation to dementia. The meeting was attended by representatives of 18 countries; Austria, Belgium (Flanders), Czech Republic, Estonia, Finland, France, Germany, Iceland, Ireland, Italy, Israel, Latvia, Netherlands, Norway, Poland, Slovenia, Switzerland and the United Kingdom (England). Representatives from the European Commission (DG SANTE) and the World Health Organisation (WHO) were also present in the meeting. In relation to dementia specifically, the group heard presentations on:

- The newly-published Dementia Plan 2025 in Norway
- A recent large-scale epidemiological study in Norway examining the prevalence of dementia in the country
- Confirmation of the publication of a new Dutch National Dementia Strategy which will run from 2021-2029
- Developments towards a follow-on from the French Neurodegenerative disease Strategy which concluded in 2019
- The WHO’s ongoing work to deliver on the Global Action Plan on Dementia, as well as recent developments at the 73rd World Health Assembly.

In relation to the ongoing COVID-19 pandemic and its effect on people with dementia and their carers, the group heard from:
- Adelina Comas-Herrera of the London School of Economics, whose research has focused on the impact of the pandemic in relation to long-term care services, as well as working on the Long-Term Care COVID website, a repository of resources and evidence focused on COVID-19 across care settings
- The Italian Institute of Health on emerging data about the effect of COVID-19 in Italy and the development of a resource aimed at supporting dementia care services to be able to operate safely
- The Dementia Expert Centre in Flanders, which shared some of the lessons learned, particularly in relation to the importance of reducing isolation and loneliness in people with dementia and carers, as well as outlining the non-clinical training resources they produced.

The next meeting of the group is expected to take place on 15-16 June 2021.

10 December: EU4Health Civil Society Alliance publishes open letter on governance arrangements

Ahead of the second EU trilogue on the proposed EU4Health programme, the EU4Health Civil Society Alliance has published an open letter to the German Health Minister Jens Spahn, highlighting the importance of an inclusive governance framework which involves civil society organisations.

Signed by Marco Greco, President of the European Patients Forum (EPF) and Alice Chapman-Hatchett, President of the European Public Health Alliance (EPHA), the letter emphasises that civil society organisations have a strong insight into the health inequalities across Europe. Additionally, it notes the proposal from the European Parliament for a EU4Health Steering Board which includes civil society, explaining that such an arrangement would allow for better coordination of EU funding instruments, as well as facilitating the uptake of pilot projects.

The letter concludes by asking the German Presidency of the Council to uphold the European Parliament proposal, with meaningful and structured participation of civil society in an inclusive, effective, transparent and sustainable way. You can read the full letter here: https://eu4health.eu/an-inclusive-eu4health-programme-to-better-meet-the-needs-of-people-in-europe/

11 December: European Parliament and Council of the EU agree Horizon Europe budget breakdown

The European Parliament and the Council of the European Union have reached a political agreement on the future of the Horizon Europe research programme which will run between 2021-2027.

The final agreed budget for Horizon Europe is EUR 95.5 billion, in current prices, which includes an additional EUR 4 billion recently recovered during negotiations on the Multiannual Financial Framework (MFF) and EU Recovery Instrument.

Of note within the agreement, there is:
- EUR 7.962 billion for health research
- EUR 6.401 billion for Marie Skłodowska-Curie actions
- EUR 2.405 billion for research infrastructures
- EUR 15.539 billion for digital, industry and space.

Following political endorsement by both the Council and the European Parliament, the agreement will be adopted as part of the regulation, which cannot be done formally until the adoption of the long-term EU budget 2021-2027.

It is expected that the programme will be ready to commence from 1 January 2021.

You can read more on the agreement here: http://bit.ly/3rT1FJQ

14 December: WHO Europe forms Non-Communicable Diseases Advisory Council

The World Health Organization Regional Office for Europe (WHO Europe) has established an Advisory Council on Non-Communicable Diseases (NCDs),
aimed at accelerating the response to NCDs and their risk factors across the WHO European Region.

The members of the NCD Advisory Council will include experts and clinical practitioners from governments, academia, think tanks, as well as professional and civil society organisations.

The key functions of the NCD Advisory Council are to:

- Provide advice for innovative approaches to reduce the prevalence of NCDs in the WHO European Region
- Recommend specific ways to strengthen collaboration with relevant sectors, partners and stakeholders
- Provide a forum for sharing policy and technical experience and knowledge
- Provide guidance and support to WHO/Europe in shaping the future architecture of the NCD political agenda at European, national and subnational levels.

Disappointingly, only four NCDs have been identified and considered for this Council: Cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. This is despite a recent WHO report showing dementia to be the third leading cause of death in Europe.

Alzheimer Europe will work with partners and stakeholders to consider the most appropriate response to this decision.

You can read more here on Advisory Council here: https://bit.ly/2XfLg47

14 December: European Parliament and Council agree EU4Health programme

The European Parliament and the Council of the EU have agreed a deal in relation to the dedicated EUR 5.1 billion EU4Health programme, as part of the EU’s recently agreed long-term budget.

The new programme will support actions across a range of health policy areas, including investing in health promotion and disease prevention measures, as well as preparing European healthcare systems to face future health threats.

Another objective of the programme will be to support Member States in developing healthcare standards at the national level. In addition, the programme will support communication activities to promote disease prevention and healthy lifestyles, as well as countering misinformation.

In response to the COVID-19 pandemic, the programme will support actions which foster the production, procurement and management of crisis-relevant products in the EU, in order to make them more available and affordable.

The Parliament and Council have also agreed that 20 % of the total budget should be reserved for health promotion and disease prevention, which address health risks. Furthermore, the digitisation of healthcare, including the creation of a European health data space, is also part of the agreement.

The agreement must still be ratified by a plenary vote of the European Parliament, as well as by the Council.

You can read more here on the agreement at: http://bit.ly/38fZmJ8

9 December: Her Majesty Queen Sofía, Honorary President of the Confederación Española de Alzheimer (CEAFA) takes part in videoconference to celebrate the organisation’s 30th anniversary

On 9 December, the Confederación Española de Alzheimer (CEAFA) organised a videoconference with Her Majesty Queen Sofía, to celebrate the organisation’s 30th anniversary

The members of the Board of Directors and representatives of all the autonomous entities that make up CEAFA, participated in the event and shared the situation with Alzheimer’s and other dementias in their communities. All agreed on the need to remain united and highlighted the importance of associations to combat the current pandemic and continue working to improve the quality-of-life of people with dementia and their family carers.

In her closing speech, Her Majesty thanked CEAFA for the commendable work it has carried out, with people affected by Alzheimer’s disease, over the last three decades, paying particular attention to the work being done in these difficult times in which, she said, “COVID has affected people with dementia so cruelly”.

14 December: Alzheimer Bulgaria holds online event to introduce its work to students of the American University in Bulgaria

An online event was held recently (26 October), at which Alzheimer Bulgaria introduced its work in front of the students of the American University in Bulgaria.

The main theme of the presentation was “How great it is being a volunteer”. Two volunteers from Alzheimer Bulgaria talked about the project “European Solidarity Corps”, which gave them the opportunity to become part of the association. They shared how they help, what motivates them and what the volunteer work brings to them.

They also talked about Alzheimer’s disease, the social and political problems that patients and the carers face, as well as about the projects on which Alzheimer Bulgaria is working.

The participants at the meeting showed great interest in the theme of the presentation and asked questions about the illness and the help which the volunteers give in order to improve the lives of those affected. They were invited to become part of the team of volunteers and to apply for the project “European Solidarity Corps”, next year. Some of them accepted the invitation and are now volunteers for Alzheimer Bulgaria.

14 December: Romanian Alzheimer society implements a new project - “Mental Health – Priority on the Public Agenda!”

The Romanian Alzheimer society, together with the Habilitas Association, is implementing the project “Mental Health – Priority on the Public Agenda!” The project I co-funded by the European Social Fund through the Operational Capacity (POCA) Program 2014-2020.

The project aims to:
1. increase the degree of monitoring and evaluation of public policies by developing a methodology and an evaluation report of public policies in the field of mental health
2. stimulate and strengthen social dialogue and collaboration between NGOs, social partners and public authorities in the field of mental health and socio-medical health through:
   I. monthly meetings within a newly created structure – the Social Dialogue Center
   II. organising a Social Dialogue Forum with the participation of 40 professionals
   III. launching a social dialogue platform that will allow interaction between NGOs, social partners, public authorities and other stakeholders, and reporting mental health issues and solutions
3. increasing the capacity of 51 NGOs and 2 stakeholders to get involved in the formulation and promotion of alternative proposals to government policies initiated by the Government in the field of mental health by organising public policy training, advocacy activities, equal opportunities for participation while encouraging, sustainable development and social responsibility
4. developing the capacity of 72 people, employees and volunteers from NGOs and trade unions to formulate alternative proposals to current public policies through specific training
5. optimise mental health legislation by developing and promoting an alternative public policy to the Mental Health Law and by organising a study visit to Scotland to transfer and adapt European best practices in public policy formulation.

The goal of the project is to formulate and promote alternative policies to the Mental Health Law (Law 487/2002 republished in 2012), with emphasis on dementia.

18 December: Alzheimer Nederland campaign “Wat Alz... Jij het bent” focuses on women’s risk of dementia

The number of people with dementia in the Netherlands is growing rapidly. 1 in 3 women get dementia and the chance of a woman dying of dementia is currently many times larger than the chance of her dying as a result, for instance, of breast cancer, a stroke or a heart attack.

Dementia is a disease with a huge impact. Not only for the person diagnosed, but also for the family and ultimately for society as a whole. This is why Alzheimer Nederland launched its campaign “Wat alz... jij het bent” (What if... it is you). This campaign drew attention to this brain disease through various videos and calls to action, because Alzheimer Nederland is trying to do everything it can to bring a future without dementia closer.

Watch one of the campaign videos (in Dutch), here: https://www.youtube.com/watch?v=_sbr0fFzwBo
**POLICY WATCH**

**1 December: Netherlands publishes new national dementia strategy 2021-2030**

The Dutch Government has published a new National Dementia Strategy 2021-2030, outlining its future priorities in relation to dementia policy in the country. The strategy is focused around three overarching themes:

- **A world without dementia** – focusing on dementia research.
- **Persons with dementia matter** – focusing on reducing stigma and prejudice.
- **Tailor-made support when living with dementia** – focusing on improving supports and services.

Each of the sections provides an analysis of the challenged faced, what the strategy aims to do and how it intends to meet the aim.

In addition to the overarching themes, the strategy also identifies four underlying areas which are key to ensuring the success of the strategy. These include:

- **Innovation** – focusing on the use of both technological and non-technological developments
- **Young person with dementia** – focusing on the specific needs of this population
- **International** – focusing on collaborations in relation to dementia research
- **Communication** – focusing on sharing the knowledge and experiences acquired from the work of the strategy.

You can read the full strategy here (in Dutch or English):


**2 December: Norway publishes new Dementia Plan 2025**

The Norwegian Government has published its new Dementia Plan 2025, outlining how the country’s approach to dementia policy up to 2025.

The development and publication of the new strategic document follows a positive evaluation of the previous Plan (which ran until 2020), building on previous areas of work. The Dementia Plan 2025 outlines three key goals:

- People with dementia and their relatives receive a timely diagnosis and receive high quality and personalised services
- People with dementia and their relatives are able to participate in a dementia-friendly society that allows them to live an active and meaningful life, with physical, social and cultural activity adapted to individual interests, desires and needs
- Increased research and knowledge about prevention and treatment of dementia.

To achieve these aims, the Norwegian Dementia Plan 2025 contains four main focus areas:

- Co-decision making and participation
- Prevention and public health
- High-quality and coordinated services
- Planning, skills and knowledge development.

Under each area, the long term strategic approach is outlined, followed by specific measures which seek to achieve the vision articulated. You can read the full Plan here (in Norwegian):

https://www.regjeringen.no/contentassets/b3ab825ce67f4d73bd240 10e1fc05260/demensplan-2025.pdf

**9 December: World Health Organisation’s Global Health Estimates reveal dementia as a top three cause of death in Europe**

Noncommunicable diseases (NCDs) now make up 7 of the world’s top 10 causes of death (up from 4 out of 10 in the year 2000) according to a new World Health Organization (WHO) report, published on 9 December 2020. The report, on “2019 Global Health Estimates” covers the period from 2000 to 2019. The estimates reveal trends over the last two decades in mortality and morbidity caused by diseases and injuries.

While heart disease remains the number one cause of death, globally, Alzheimer’s disease and other forms of dementia are now among the top 10 causes of death worldwide, ranking 3rd in both the Americas and Europe in 2019.

Against the backdrop of COVID-19 and its disproportionate impact on people with dementia, these statistics from the
WHO underline the importance of ensuring dementia remains a political priority across health, research and social policy. Alzheimer Europe’s new report “Dementia as a European Priority – A Policy Overview” sets forth a number of recommendations to ensure this happens. See the WHO’s Global Health Estimates, here: https://www.who.int/data/global-health-estimates

15 December: United Nations adopts resolution on Decade of Health Ageing 2021-2030

On 15 December, the United Nations General Assembly passed a Resolution declaring 2021-2030 the Decade of Healthy Ageing. The UN Resolution follows recent endorsement of the Decade by the World Health Assembly, whilst also expressing concern that despite the predictability of population ageing and its accelerating pace, the world is not sufficiently prepared to respond to the rights and needs of older people. The Resolution calls upon the World Health Organization (WHO) to lead the implementation of the Decade, in collaboration with the other UN bodies, as well as encouraging national governments, civil society, academia etc. to support the Decade’s goals.

- Initiatives undertaken as part of the Decade will seek to:
  - Change how society thinks, feels and acts regarding age and ageing
  - Facilitate the ability of older people to participate in and contribute to their communities and society
  - Deliver integrated care and primary health services that are responsive to the needs of the individual
  - Provide access to long-term care for older people who need it.

In addition, the Resolution acknowledges that ageing demographics impact upon health systems and many other aspects of society, including financial markets, demand for goods and services, including long-term care, social protection etc.

Furthermore, the WHO and UN are seeking inputs from all interested stakeholders to contribute to a collaborative platform where knowledge on ageing can be accessed, shared and produced in a single place.

More information on the Decade of Health Ageing can be found at: https://www.who.int/initiatives/decade-of-healthy-ageing

18 December: World Dementia Council launches second in series of papers on the impact of dementia-friendly initiatives

On 18 December 2020, 3 months exactly after it launched the first paper in a series reflecting on evidence underpinning the impact of dementia friendly initiatives (DFIs), the World Dementia Council (WDC) has published the second paper in this series. Globally, more and more countries have seen the launch of DFIs to raise awareness and to help people living with dementia to continue to live as well as possible. The project came out of a 2018 WDC summit in London, which brought together dementia experts from across the globe to look at some of the challenges faced in reaching the 2025 goals on dementia, set by the G8 in 2013. The WDC conducted literature reviews, held workshops around the world and issued a call for evidence. Evidence was submitted from across all six continents by governments, civil society, business, and people living with dementia and their caregivers.

The first paper was published in September and considered what different countries, organisations and individuals meant by “dementia friendly” and what the projects were trying to achieve. This second paper considers how initiatives sought to deliver impact in three broad areas of ambition: raising awareness, enabling participation and providing support. A subsequent, concluding paper will be published in coming months. The WDC welcomes feedback on the papers and will review all comments before producing a final report in 2021.

You can find the first and second papers, here: https://worlddementiacouncil.org/DFIs

SCIENCE WATCH

4 November: Cortexyme’s Phase II/III GAIN trial of COR388 in Alzheimer’s disease passes futility analysis

On 4 November, Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders, announced that the independent Data Monitoring Committee (DMC) conducted a pre-planned interim analysis on the Phase II/III GAIN trial of COR388. The GAIN Phase II/III study is a randomised, double-blind and placebo-controlled study assessing the efficacy, safety and
The tolerability of two dose levels (40 and 80mg) of COR388 oral capsules in people with mild to moderate AD.

The interim analysis included approximately 300 research participants who have reached six months of treatment. As part of the interim analysis, the DMC looked for futility and efficacy and recommended Cortexyme to continue the GAIN Trial as planned to the one-year endpoint. The company recruited 643 research participants in the US and Europe and top line results for the fully enrolled population are expected in December 2021.

On 9 November, Amylyx Pharmaceuticals, a clinical-stage pharmaceutical company developing a novel therapeutic for Amyotrophic Lateral Sclerosis, Alzheimer’s disease (AD) and other neurodegenerative diseases, announced that the last research participant has completed the planned 24 weeks in its Phase II PEGASUS trial.

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On 9 November, Amylyx Pharmaceuticals, a clinical-stage pharmaceutical company developing a novel therapeutic for Amyotrophic Lateral Sclerosis, Alzheimer’s disease (AD) and other neurodegenerative diseases, announced that the last research participant has completed the planned 24 weeks in its Phase II PEGASUS trial.

The PEGASUS Phase II trial is a 24-week randomised, double-blind, multi-site and placebo-controlled study evaluating the safety and tolerability of AMX0035 in people with late mild cognitive impairment or early dementia due to AD. AMX0035 is a combination of existing compounds designed to prevent neuroinflammation and nerve cell death.

The company completed the enrolment of this PEGASUS trial in June 2020. Top-line results from the trial are expected for the first half of 2021.

On 12 November, AlzeCure Pharma AB, a Swedish pharmaceutical company that develops a broad portfolio of drug candidates for diseases affecting the central nervous system, announced that it has received approval to initiate a Phase I clinical trial with ACD856, one of its therapy candidates for Alzheimer’s disease (AD). Approval has been received from the regulatory authorities in Sweden. The primary study objective of this trial is to evaluate the drug candidate’s tolerability and safety.

"It is gratifying that just a few months after we completed our first clinical study with positive results, we now have all regulatory approvals in place to be able to start a second study with our primary candidate ACD856. Cognitive disorders, and especially Alzheimer’s disease, is a disease area in great need of new and more effective treatments, and I am very much looking forward to the continued development of this important drug candidate”, said Martin Jönsson, CEO of AlzeCure Pharma AB.

On 18 November, AZTherapies, a clinical-stage biopharmaceutical company developing novel therapies to change neurodegenerative diseases progression, announced the completion of its COGNITE Phase III clinical trial evaluating the safety, tolerability and efficacy of ALZT-OP1 for the treatment of early Alzheimer’s disease (AD). The last participant has completed all predefined assessments.

The COGNITE study is a 72-week global, randomised, double-blinded and placebo-controlled Phase III study designed to determine if ALZT-OP1 will slow down, arrest, or reverse cognitive and functional decline in people with early AD. The combination drug therapy ALZT-OP1 consists of the administration of two previously approved drugs for other indications that act on important mechanisms relevant to AD,
with a new formulation to enable rapid pulmonary uptake and crossing of the blood-brain barrier.

More than 600 research participants from Australia, Europe and US were enrolled in the COGNITE trial. The company plans to begin data analysis soon and the top-line results are expected in the first quarter of 2021.

https://aztherapies.com/2020/11/18/aztherapies-completes-cognite-phase-3-trial/

1 December: Clinical study links air pollution to positive amyloid-PET scans in people with cognitive impairment

Earlier this month, JAMA Neurology published a clinical research article by Dr Leonardo Iaccarino and Prof. Gil Rabinovici, identifying an association between increased particulate air pollution and amyloid plaques in the brains of people with cognitive impairment, as observed using amyloid-PET scans.

Using data from over 18,000 participants in the Imaging Dementia-Evidence for Amyloid Scanning (IDEAS) Study, the researchers collated United States Census information on their air pollution exposure at two timepoints: 1-2 years before their amyloid-PET scans, and 13-15 years prior to that. Looking at two measures of air pollution, ground ozone levels and PM2.5(particulate matter) levels, and matching them to the postcodes of IDEAS participants, Dr Iaccarino and colleagues cross-referenced the results of their amyloid-PET scans to the levels of pollution experienced in the years prior to scanning. No associations between ground ozone levels and brain amyloid levels, however people who lived in areas with high PM2.5 levels were on average 15% more likely to have positive amyloid-PET scans. In line with the recent Lancet Commission on dementia prevention, intervention and care, these findings support the need to consider air pollution in calculations of lifetime risk for Alzheimer’s disease and dementia.

https://jamanetwork.com/journals/jamaneurology/article-abstract/2773645

2 December: What patients want to know and what we actually tell them – analysis of ABIDE observational study recordings published in Alzheimer’s & Dementia: Translational Research and Clinical Interventions

On 2 December, Dr Agnetha Fruijtier, Prof. Ellen Smets and colleagues published an article in Alzheimer’s & Dementia: Translational Research and Clinical Interventions, in which they show that diagnostic consultations in memory clinics do not always address all the key informational topics for patients. The ABIDE Delphi study conducted with patients, care partners and clinicians identified 25 informational topics of particular importance and relevance for these groups during the initial diagnostic consultation. These topics include information on diagnostic testing, the test results themselves, diagnosis and prognosis, and also practical implications of the diagnosis. In their study, Dr Frujtier and colleagues sought to evaluate how these topics are addressed in the real-world setting, who initiates discussion of specific topics, and at which point this occurs during diagnostic consultations. They analysed the audio recordings of diagnostic consultations performed with 71 patients seen by 32 clinicians, showing that on average, 12 of the 25 important informational topics were addressed per patient. Some topics were addressed very rarely (e.g. PET scan results; 2/71 consultations) while others were addressed very frequently (e.g. Next appointment date and time: 70/71 consultations). Topics in the category “Information and Diagnosis and Prognosis”, which were deemed most relevant by patients and care partners but not by clinicians, were addressed least frequently, and not at all in 50% of the consultations. In addition, patients and/or care partners initiated topic discussion much less frequently than clinicians (10%). When they did, they often enquired about one of the more rarely-addressed topics. To improve the range of topics addressed in diagnostic consultations and increase patient/care partner-directed discussion, the authors recommend providing the topic list to patients and care partners beforehand, to allow them to prepare for the consultation in advance.


10 December: Molecular profiling of tau proteins shows how modifications accumulate during the development of Alzheimer’s disease

On 10 December, Dr Hendrik Wesseling, Prof. Judith Steen and colleagues published an article in Cell, showing that tau accumulates successive mutations that promote protein aggregation in Alzheimer’s disease.
The accumulation of tangled aggregates of tau protein in the brain is one of the pathological hallmarks of Alzheimer’s disease (AD), with recent studies indicating that disease-associated tau can spread through the brain via neuronal connections. Thanks to technological advances in microscopy and proteomics, researchers have found that aggregated tau has many post-translational modifications (PTMs), which may account for its tendency to tangle. PTMs are subtle chemical changes that determine how complex proteins are folded, by altering their electrical charge, structure and interactions with each other.

In their Cell article, Dr Wesseling and colleagues set out to determine the importance of different tau PTMs in AD, to understand how these accumulating modifications might cause tau aggregation and how this varies between individuals with AD. Extracting tau proteins from postmortem brain samples donated by 49 people with AD and 42 unaffected peers, they performed proteomics analyses to generate a high-resolution map of the different tau PTMs detected in these samples. People with AD had over 100 times the amount of insoluble, pathological tau compared to their unaffected peers, enriched with a particular isoform of tau protein. Looking more closely at the insoluble tau fraction, the researchers observed larger amounts of certain tau PTMs from the brains of people with advanced, symptomatic AD, with some heterogeneity between disease groups. They also observed successive accumulation of different tau PTMs at different stages of AD, suggesting that tau collects different, tangle-causing modifications as the disease progresses.

https://www.sciencedirect.com/science/article/pii/S0092867420313933

11 December: Dietary supplementation with Souvenaid is a cost-effective intervention for patients with prodromal Alzheimer’s disease

On 11 December, Dr Javier Mar, Prof. Myriam Soto-Gordoa and colleagues published an article in Alzheimer’s Research & Therapy, in which they investigated the cost-utility of the Souvenaid dietary supplement in patients with prodromal Alzheimer’s disease (AD), as classified by the International Working Group-1 criteria.

The LipiDiDiet clinical trial evaluated the efficacy of Souvenaid, a dietary supplement drink, in prodromal AD. Although no improvement in the Neuropsychological Test Battery was observed, participants who received Souvenaid performed better on the Clinical Dementia Rating Sum of Boxes (CDR-SB) cognitive test, indicating some cognitive benefit from taking the dietary supplement for 2 years. In their Alzheimer’s Research & Therapy, Dr Mar and colleagues aimed to assess the cost-utility of Souvenaid compared to placebo in patients with prodromal AD, under the conditions applied in the LipiDiDiet trial. Creating a model to simulate the natural history of AD across the lifespan, the researchers calculated the economic cost (in EUR) and utility (in quality-adjusted life years/QALYs) of Souvenaid, including direct and indirect costs such as social care costs and balancing these against the yearly cost of the diagnostic procedure (EUR 2,900/yr) and Souvenaid (EUR 1,200/yr).

Analysis of the trial data showed a dementia progression rate of 41% in participants receiving placebo, compared to 34% in participants receiving Souvenaid. The economic evaluation revealed that the treatment had a favourable cost-utility ratio, amounting to EUR22,743/QALY – lower than the willingness-to-pay threshold accepted by the Spanish government (EUR25,000). Together, the results indicate that treating patients with prodromal AD with Souvenaid is cost-effective compared to placebo, under the conditions analysed in the LipiDiDiet trial.

https://alzres.biomedcentral.com/articles/10.1186/s13195-020-00737-9#Abs1

14 December: AlzeCure Pharma starts preclinical development phase with ACD857 for AD

On 14 December, AlzeCure Pharma AB, a Swedish pharmaceutical company that develops a broad portfolio of drug candidates for diseases affecting the central nervous system, announced that is has begun a preclinical development phase with its drug candidate ACD857 for Alzheimer’s disease (AD). This preclinical development program includes preclinical safety and tolerability studies, formulation work and stability testing. ACD857 is derived from the NeuroRestore platform, with the aim of developing symptom-relieving drugs for cognitive disorders.
The company has recently announced that it has received approval to initiate a Phase I clinical trial with ACD856, another therapy candidate for AD, in Sweden.

14 December: Eli Lilly announces the start of recruitment for the New IDEAS study

On 14 December, Eli Lilly and Company, a global health care leader developing medicines that make life better for people, announced the start of recruitment for the New IDEAS: Imaging Dementia—Evidence for Amyloid Scanning study.

The New IDEAS study, directed by the Alzheimer’s Association, will serve as a follow-up to the IDEAS study, which included more than 18,000 participants. The New IDEAS study is an observational, open-label and longitudinal cohort study assessing the impact of amyloid PET brain scans on patient management and associated health outcomes in a more diverse population presenting cognitive impairment. A major limitation of the IDEAS study was a lack of racial and ethnic diversity. The new study will enrol 7,000 US Medicare beneficiaries with mild cognitive impairment or dementia over 30 months, including at least 50% of African American and Hispanic/Latino participants.


15 December: vTv Therapeutics’s experimental AD drug fails to meet its primary endpoint in Phase II study

On 15 December, vTv Therapeutics, a clinical-stage pharmaceutical company focused on the development of human therapeutics to fill unmet medical needs, announced top-line results from its Phase II trial of azeliragon in people with mild Alzheimer’s disease (AD) and type 2 diabetes. Azeliragon is an oral small molecule inhibitor of RAGE (receptor for advanced glycation end products), which is thought to promote inflammation and amyloid beta deposition in the brain. The Elevage Phase II study is a randomised, double-blind, placebo-controlled, and multicentre trial evaluating the safety and efficacy of azeliragon in people with mild AD and impaired glucose tolerance in US and Canada.

The company reported that the trial did not meet its primary objective of demonstrating an improvement in cognition as assessed by the 14-item Alzheimer’s Disease Assessment Scale – Cognitive Subscale (ADAS-cog14) relative to placebo. Results from the 6-month trial showed that the azeliragon treated group had a decline from baseline in ADAS-cog14 compared to the placebo group, however these differences were not statistically significant. These findings include data from 43 participants with mild probable AD and type 2 diabetes who received either azeliragon (5mg) or placebo orally once daily.

“We will continue to analyse the data to determine if there are potential benefits or future applications for azeliragon in Alzheimer’s, dementia or related indications that we or other interested parties may seek to pursue, said Steve Holcombe, chief executive officer”, vTv Therapeutics. http://bit.ly/3nqU2XS

15 December: TouchNEUROLOGY discusses emerging therapeutic targets for Alzheimer’s disease with Bengt Winblad

TouchNEUROLOGY recently spoke to world-renowned Alzheimer’s disease (AD) researcher Bengt Winblad of Karolinska University Hospital and Karolinska Institutet, Stockholm, Sweden. Professor Winblad, a member of the TouchNEUROLOGY Editorial Board, spoke about emerging therapeutic targets for AD and the role of the FKBP51-Hsp90 complex in underlying pathophysiological processes. You can watch the interview, filmed at the 6th Congress of the European Academy of Neurology (EAN) and 1st EAN Virtual Congress: https://bit.ly/37hpW4a

15 December: Clinical study emphasises the importance of good heart health in midlife for dementia prevention in later years

On 15 December, a group of researchers led by Prof. Miia Kivipelto and Prof. Chengxuan Qiu published an article in PLOS Medicine, identifying an association between healthy cardiovascular lifestyles in midlife and reduced risk of dementia in later years.

The recent Lancet Commission on dementia prevention, intervention and care identified 11 lifestyle habits or treatable diseases that are associated with increased risk of developing dementia. In their recent PLOS Medicine study, Profs. Kivipelto and Qiu took a closer look at cardiovascular health factors
including smoking, physical activity, diet, body weight, blood glucose, cholesterol and blood pressure, aiming to understand how these metrics in midlife and later life might be associated with the development of dementia as people age.

Analysing data from 1,449 participants in the Finnish Cardiovascular risk factors, Aging and Dementia (CAIDE) study, the researchers categorized participants based on their cardiovascular health (CVH) factors, identifying those with ‘poor’, ‘intermediate’ or ‘ideal’ CVH factors in midlife or later life. CAIDE participants were followed for an average of 21 years, allowing the researchers to see which participants developed dementia over time. Compared to those with ‘poor’ CVH factors in midlife (e.g. smokers with high blood pressure and low physical activity levels), participants with ‘intermediate’ or ‘ideal’ levels of cardiovascular health in midlife were at lower risk of developing dementia. Although the numbers of people who developed dementia during the study period were fairly small, the study results underline the importance of maintaining life-long cardiovascular health to reduce dementia risk in older age.

https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003474

16 December: Evaluating the Alzheimer’s disease data landscape: issues with heterogeneity, bias and interoperability

On 16 December, Colin Birkenbihl, Prof. Martin Hofmann-Apitius and colleagues published an article in Alzheimer’s & Dementia: translational research and clinical interventions, in which they evaluate the data landscape across several major Alzheimer’s disease (AD) cohort studies.

Longitudinal cohort studies are defined as clinical research studies that follow a group of individuals over a defined period of time, obtaining clinical samples and data from the research participants at regular intervals. Studies such as these allow researchers to understand how disease develops and what factors might affect disease progression, among other facets. Longitudinal cohort studies are of particular value for research on progressive, neurodegenerative diseases like AD. However, it can be hard to compare or pool data across different cohort studies - something that is essential to really understand whether research results are reproducible. One of the reasons why these comparisons are challenging is the fact that studies are often designed differently, with varying inclusion/exclusion criteria, clinical protocols and data access conditions. In particular, there is substantial variability between studies in accessibility of patient-level data.

To assess the data landscape in AD, Colin Birkenbihl and colleagues analysed datasets from 9 cohort studies (A4, ADNI, ANMerge, AIBL, EMIF-1000, EPADv1500, JADNI, NACC and ROSMAP), summarising the data parameters and describing how they overlap between studies. The largest of these, NACC, includes over 40,000 research participants, although on average each cohort recruited between 1200-3600 participants. In general, they observed fairly large biases towards high levels of education and, in particular, a strong bias towards white/Caucasian ethnicity. Scoring different data parameters based on accessibility, they observed that while some straightforward modalities were accessible across all studies (e.g. sex, age, education), other modalities were much more heterogeneous, such as imaging data, lifestyle parameters and fluid biomarker samples – indicating a lack of interoperability across datasets and cohorts. In addition, the extent of longitudinal follow-up and sampling varied extensively between studies and data modalities, with a particular paucity in MRI and CSF biomarker categories. All the analyses reported in the article have been made available through ADataViewer, an interactive web application developed by Fraunhofer SCAI that displays the findings in data availability maps.

Overall, these results highlight the challenges facing investigators wishing to validate their analyses across cohorts, or researchers aiming to model disease mechanisms using AI approaches. Many AD datasets are not interoperable, using different data models and providing variable access to raw data. Of particular concern, the lack of ethnoracial diversity in most cohorts also means that AI-based models developed or trained using these data could suffer from bias.


ADataViewer can be accessed here:
https://adata.scai.fraunhofer.de/

16 December: AB Science announces positive results from Phase II/III of Masitinib in Alzheimer’s disease

On 16 December, the pharmaceutical company AB Science announced that its Phase II/III clinical trial evaluating Masitinib in Alzheimer’s disease (AD) met its primary endpoint. Masitinib is an oral drug classed as a tyrosine kinase inhibitor that targets important cells for immunity.
The 24-week trial was a multicentre, double-blind, randomised and placebo-controlled study evaluating the efficacy and safety of masitinib as an add-on therapy to cholinesterase inhibitors and/or memantine. 718 European participants with mild and moderate AD who have been treated for a minimum of 6 months with a stable dose of cholinesterase inhibitor (donepezil, rivastigmine or galantamine) and/or memantine received placebo or one of two doses of masitinib. The co-primary outcome measures were the Alzheimer’s Disease Cooperative Study Activities of Daily Living score (ADCS-ADL) and Alzheimer’s Disease Assessment Scale-Cognitive Subscale score (ADAS-Cog) after 24 weeks of treatment. The study reported that masitinib (4.5 mg/kg/day) had a significant treatment effect compared to the control on both cognition and daily activity measured by the two primary endpoints. The company added that the safety of masitinib was acceptable and consistent with the known tolerability profile for masitinib. The company plans to present study results at an upcoming conference.

**16 December: Novo Nordisk plans to initiate Phase III trial of semaglutide in early AD**

On 16 December, Novo Nordisk A/S, a Danish multinational pharmaceutical company developing innovative biological medicines, announced that it plans to initiate a Phase III clinical trial in Alzheimer’s disease (AD) with its drug semaglutide in the first half of 2021. The company intends to enrol approximately 3,700 research participants with early AD to investigate the efficacy and safety of once-daily oral semaglutide (14mg), compared to placebo. Oral semaglutide (7 mg and 14 mg) is approved as an adjunct to diet and exercise to improve glycaemic control in adults with type 2 diabetes in the US, EU and Japan.

**21 December: Invitation to European Researchers to join forthcoming European Crucible which will gather European future research leaders with their counterparts from Scottish institutions**

Calling early/mid-career research leaders from life, physical, engineering, computational, mathematical, environmental and social sciences, arts and humanities working in Europe. On behalf of Scottish Crucible, the University of Luxembourg, Scottish Research Pools and partner institutions, you are cordially invited to apply for a place on the forthcoming “European Crucible” which will gather European future research leaders with their counterparts from Scottish institutions. Recognising the importance of international research collaboration, and following the success of Scottish Crucible over the past decade, the European Crucible workshops (taking place in February and March 2021) will stimulate new international research collaborations between Scottish and European researchers. These virtual meetings, or “Labs”, will aim to create a new network for research leaders between Scotland and Europe, and to enable international collaboration on interdisciplinary research and innovation topics with additional engagement with policy-makers and industry. This first European Crucible programme will have an emphasis on innovative collaborations at the interfaces between Life Sciences and other disciplines. The deadline for European applications is 13 January 2021, at 10.00am (GMT). The organisers aim to confirm places by 29 January 2021. You can find out more, and apply, here:


**23 December: European Academy of Neurology/European Alzheimer’s Disease Consortium publishes position paper on diagnostic disclosure, biomarker counselling, and management of patients with mild cognitive impairment**

Alzheimer Europe is delighted to have contributed to a new position paper position paper on diagnostic disclosure, biomarker counselling, and management of patients with mild cognitive impairment. The paper, published by the European Academy of Neurology/European Alzheimer’s Disease Consortium, in
open access in the European Journal of Neurology, looks at the importance of counselling through the diagnostic process and adequate post-diagnostic support for people receiving a diagnosis of mild cognitive impairment (MCI).

A panel of dementia specialists was appointed to write this paper, including Jean Georges, Executive Director of Alzheimer Europe.

Some of the recommendations made in the paper are:

- Prior to diagnostic evaluation, the wishes of the patient should be sought.
- Diagnostic disclosure should be carried out by a dementia specialist taking the ethical principles of “the right to know” versus “the wish not to know” into account.
- Disclosure should be accompanied by written information and a follow-up plan.
- It should be made clear that MCI is not dementia.
- Pre-biomarker counselling should always be carried out if biomarker sampling is considered and post-biomarker counselling if sampling is carried out.
- A dementia specialist knowledgeable about biomarkers should inform about pros and cons, including alternatives, to enable an autonomous and informed decision.
- Post-biomarker counselling will depend in part on the results of biomarkers.
- Follow-up should be considered for all people diagnosed with MCI and include advice on brain health and possibly treatment for specific underlying causes.
- Advice on advance directives may be relevant.

The paper concludes that further studies are needed to enable more evidence-based and standardised recommendations in the future.


DEMENTIA IN SOCIETY

1 December: New Global Brain Health Leader Awards aim to develop dementia-related projects

To address the growing public health crisis of dementia, the Alzheimer’s Association (US), Global Brain Health Institute, and the Alzheimer’s Society (UK) have announced funding for 23 small-scale pilot projects as part of this year’s Pilot Awards for Global Brain Health Leaders. Their aim is to address global challenges in dementia, including access to care, stigma, brain health risk factors, and other key issues through a competitive funding programme for emerging leaders in brain health and dementia. The COVID-19 pandemic, which is straining health systems, increasing social isolation, and disproportionately affecting people living with dementia and their caregivers, is demanding a reimagining of service delivery and the Pilot Awards for Global Brain Health Leaders programme hopes to provide fertile ground for such innovation.

The 2020 awards will drive pilot projects that address disparities in dementia diagnosis, treatment, and care for vulnerable populations and their families. They span 15 countries across five continents, including, Belgium, Denmark, France, Ireland, Israel, Spain, Turkey and the United Kingdom (UK). The 23 awardees will join an overall portfolio of 88 pilots in 28 countries.

The total funding of approximately EUR 486,000 includes about EUR 21,100 for each individual award to enable the recipients to pilot test a project and then, if successful, seek further resources to scale up their work. Find out more, here:


4 December: Viggo Mortensen’s directorial debut “Falling” explores a difficult father-son relationship, worsening as dementia progresses

On 4 December, the film “Falling” – a drama written and directed by Viggo Mortensen - was released in the United Kingdom. Its first screening took place at the 2020 Sundance film festival. The film stars Mr Mortensen as John Peterson, a
middle-aged gay man whose conservative and homophobic father Willis (Lance Henriksen), starts to exhibit symptoms of dementia, forcing him to sell the family farm and move to Los Angeles to live with John and his husband Eric (Terry Chen). As the father’s illness progresses, his lifelong anger builds to a new, unmanageable level and the test for John (Viggo Mortensen), is how to extend compassion to a man who has rarely shown any to him or the rest of his family (his husband and young daughter, as well as his sister). Although Mr Mortensen’s late father had dementia, the film is not a portrait of him. “He was a much better communicator than Willis is and we had a better relationship. But there are enough traces of him in what Lance plays – fragments of conversations we had, some difficult moments – that it was constantly moving for me to see.” Viggo Mortensen was determined to be honest about the illness and the way it is experienced, both by the person diagnosed and by their family. “Movies which deal with this subject generally show someone who’s confused. My experience is that this isn’t the case – it’s the ones observing the person who get confused. Memory is subjective anyway. Why is his present any less valid than yours? If your father is saying he had breakfast with someone you know has been dead for 30 years, don’t say: ‘He died years ago,’ say: ‘What did you guys eat?’ On some ethical level, you think: ‘I’m lying’...but you’re giving something that makes them feel good. It’s not about you.”

JOBS OPPORTUNITIES

11 December: Fundació ACE seeks Head of Clinics to manage, supervise and coordinate its Memory Unit

Fundació ACE is looking to recruit a Head of Clinics to manage, supervise and coordinate its Memory Unit in Barcelona. The contract is full time and permanent.

Role
Managing, supervising and coordinating the Memory Unit, under the policies and regulations established by the Centre Management and in accordance with the procedures and standards set by current Health Regulations. The candidate should guarantee excellent quality care for users, optimising the existing materials and human resources.

Profile
• Degree in Medicine and Surgery, specialisation in Neurology, Geriatrics or Psychiatry (MIR examination)
• Sound clinical training and experience, from 5 to 10 years, in the area of neurodegenerative diseases
• Specific knowledge and experience in the health sector, as in quality and management of hospitals or specific units
• High motivation and leadership, being a model to the team
• Excellent English oral and written communication skills
• Management of internal and external relations with the aim of promoting the team
• Results-oriented management: assistance, quality and sustainability
• Expansion expectations of the Organisation in terms of digitalisation, model outsourcing and development of new units and programmes
• Good communicator focused on the promotion of the diagnostic unit in social networks.

Applications will be evaluated by the Fundació ACE Board of Directors supported by an outside expert committee. For any questions, or to submit your application, please email: rrhh@fundacioace.org

EDUCATION

16 December: EFNA launch e-learning platform for neurology advocates

The European Federation of Neurological Associations (EFNA) has developed a pilot series of e-learning modules linked to its advocacy activities, available free of charge to the public. The platform includes three modules that aim to upskill participants on how they can effectively advocate in a virtual world by identifying and engaging key stakeholders and developing partnerships, hosting successful online events and developing and disseminating key advocacy messages.

The courses are video-based and divided into sections that can be watched independently at times that suit the viewer. Each module includes supporting notes and worksheets, as well as the option to take a quiz on the content and receive a personalised certificate of completion.

Find out more and register for any of the courses, visit: www.efna.net/elearning/
NEW PUBLICATIONS & RESOURCES

19 December: New Slovene-English e-booklet about dementia is published, aimed at adolescents

The Association of Western Styrian Region for Help at Dementia Forget-me-not Šentjur (Slovenia) has published a new e-booklet in Slovene and English, aimed at informing adolescents about dementia. The booklet is called “Every person with dementia needs a hug”.

Insights about the disease are presented in this illustrated booklet, with the aim of making dementia less “scary”.

The idea for the publication came from the association’s many years of experience interacting with people living with various forms of dementia, as well as listening to their relatives. In addition, a recent survey on knowledge of dementia revealed that young people have a largely negative attitude towards symptoms developed by their relatives with dementia. This could also be a consequence of the lack of knowledge of the disease.

http://www.spomincica-sentjur.si/index.php/e-knjige

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

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

Alzheimer Europe Staff:
Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Conference and Event Coordinator: Gwladys Guillory; Director for Projects: Dianne Gove; Project Communications Officer: Christophe Bintener; Project Officers: Cindy Birck, Angela Bradshaw, Ana Diaz; Policy Officer: Owen Miller; Finance Officer: Stefanie Peulen; Administrative Assistant: Grazia Tomasini.
### AE CALENDAR 2021

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<td>Meeting with Lundbeck</td>
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<td>6-7 January</td>
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<td>14 January</td>
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<td>27 January</td>
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### CONFERENCES

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<tr>
<td>18-21 Feb 2021</td>
<td>12th Panhellenic Conference of Alzheimer’s Disease (PICAD) and the 4th Mediterranean Conference on Neurodegenerative Diseases (MeCoND), <a href="http://www.alzheimer-conference.gr">www.alzheimer-conference.gr</a></td>
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<tr>
<td>29 Nov-1 Dec 2021</td>
<td>31st Alzheimer Europe Conference</td>
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31st Alzheimer Europe Conference
Building bridges
Bucharest, Romania
29 November to 1 December 2021

www.alzheimer-europe.org/conferences #31AEC