WELCOME

I am delighted to share that the 30th Alzheimer Europe Conference, held online for the first time, was a big success! Almost 800 delegates from 42 countries connected, in an atmosphere of collaboration and solidarity, against the backdrop of the global pandemic. It was a huge pleasure to co-host the plenaries with Kim Coppes from Live Online Events and I am delighted with the great feedback we have received from many delegates and speakers alike, about their experiences of the event. Next year, we hope to see everyone face-to-face, in Bucharest, so mark the dates 29 November-1 December 2021!

During this year’s conference, the Neuronet and VirtualBrainCloud projects have a great presence at the conference, with the agenda featuring no less than four sessions hosted by each. Alzheimer Europe is proud to support European research projects like these. Another way in which we showcase this work is via our Dementia in Europe magazine. The latest edition was published this month and is available to view online, or to download, in the publications section of our website.

Our Annual General Meeting (AGM) also took place this month. The meeting saw the election of a new Board for Alzheimer Europe. I would like to extend a very warm welcome to new member Rene Friederici (Luxembourg) and say congratulations to our new Honorary Treasurer Marco Blom (Netherlands). I would also like to say a big thank you to outgoing Honorary Treasurer Maria do Rosário Zincke dos Reis and to bid a fond farewell to departing Board member Jesus Rodrigo, who decided not to stand for re-election this year. A warm welcome, also, to Chris Roberts who joins the Board as an ex-officio member, in his capacity as the Chairperson of the European Working Group of People with Dementia (EWGPWD) for the 2020-2022 term. The Board also thanked Helen Rochford-Brennan for her hard work over the last four years as Chairperson of the EWGPWD (2016-2020). I would like to add my personal thanks to Helen for all the work she has done in her four years on the Board and as Chairperson of the EWGPWD, and I am delighted to hear that she will remain as a member of the group. Thank you, also, to outgoing members of the group, Carol Hargreaves (Scotland) and Nina Baláčková (Czech Republic) for their important contributions.

MEP Sirpa Pietikäinen (Finland), Alzheimer Europe Board member and Chairperson of the European Alzheimer’s Alliance (EAA), submitted a written question to the European Commission this month. She asked about the place of dementia in the future priorities of the EU and we look forward to the Commission’s response on this important subject.

Last but not least, the European Medicines Agency (EMA) has approved the request to review the Marketing Authorisation Application (MAA) from Biogen, for its drug aducanumab for use in mild Alzheimer’s disease.

Jean Georges
Executive Director
COVID-19 SITUATION

1 October: Review of clinical trials database shows that vaccine and treatment trials for COVID-19 often exclude older adults

In 2019, and in response to several analyses showing inadequate inclusion of older adults in clinical trials, the US National Institutes of Health (NIH) expanded their “Inclusion of Children” policy to include older adults. This new policy, entitled “Inclusion Across the Lifespan”, means that all approved trials from 2019 onwards should include a plan describing how participants across the lifespan will be included, as well as the scientific or ethical rationale for excluding participants on the basis of age. There is clear evidence showing that COVID-19 hits older adults the hardest: people aged over 65 account for 30-40% of COVID-19 cases, and over 80% of deaths. To evaluate whether this age group is included in COVID-19 treatment and vaccine trials, Benjamin Helfand, Dr Sharon Inouye and colleagues reviewed all such trials entered into the www.clinicaltrials.gov database of worldwide clinical trials, publishing their results in the JAMA Neurology journal.

They identified 847 COVID-19 clinical trials, 195 of which included an age cut-off for exclusion. In addition, they identified 252 treatment clinical trials which did not have an age-based exclusion, but exclusions that were at high risk of affecting older adults, such as compliance concerns, specific comorbidities and requirements of technology. Looking at 18 vaccine clinical trials, 11 applied age cut-offs excluding older adults, and the remaining 7 had broader, nonspecific exclusions. Overall, the authors found that over 50% of older adults are likely to be excluded from COVID19 treatment trials, which may limit the ability of these trials to evaluate the efficacy, dosage and safety of treatments for older age groups. Concluding, they called for greater efforts to ensure COVID19 trials are fully inclusive.

https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2771091

1 October: Worst hit: UK Alzheimer’s Society publishes a new report on the impact of COVID-19 on people with dementia

The Alzheimer’s Society recently published a report entitled “Worst hit: dementia during coronavirus”. Based on published data from academic and non-academic sources, as well as data from four Alzheimer’s Society surveys of care home managers and people affected by dementia, the report reveals the devastating impact of COVID-19 on people with dementia, their families and caregivers.

According to data from the UK Office of National Statistics, over a quarter of people who died due to COVID-19 in England, Wales and Northern Ireland between March-June had dementia, linked in part to the fact that old age is the greatest risk factor for severe COVID-19 outcomes. The report emphasizes that care homes were not sufficiently protected during the first wave of the pandemic, stating that almost 40% of all deaths related to COVID-19 were in care home residents. Analysing the proportion of excess deaths, the report shows that between January and July there were 5,049 excess deaths of people with dementia compared to the 5-year average for the same period.

Beyond the mortality figures, the Alzheimer’s Society report draws attention to the increased loneliness and isolation experienced by people with dementia at the height of the pandemic, due to the cessation of care home visits and the shielding & social isolation advice provided by the UK government for people who were deemed to be clinically vulnerable. Their survey of 134 people with dementia revealed that 56% of those living alone in the community felt lonelier over lockdown; 46% reported a negative impact of lockdown on their mental health and 82% reported an increase in dementia symptoms. In care homes, 79% of managers reported that the lack of social contact was causing a deterioration in health and wellbeing, while a survey of over 1,000 carers revealed that 76% felt that their caring responsibilities had increased due to worsening symptoms. Alarmingly, over 90% of informal carers to people with dementia in the community stated that the person they care for had experienced interruptions to their regular health or social care.

To mitigate against the negative effects of COVID-19 as winter approaches, the Alzheimer’s Society report outlines 8 recommendations targeted at the UK governments, health and social care systems. These include regular, timely testing and adequate provision of PPE; clear and consistent guidelines; recognition of the key role played by informal caregivers; maintenance of appropriate contact between people with dementia in care homes and their loved ones; rehabilitation strategies including speech, language and physical therapies; and the implementation of a recovery plan to ensure that...
people can obtain a timely diagnosis of dementia without unnecessary waiting times. Crucially, the report highlights the need for urgent social care reform, calling for universal, person-centred care that is free at the point of delivery and is integrated with the NHS and other health systems.


28 October: Bosnian Alzheimer association pays tribute to heroes in white coats in the time of the COVID19 pandemic

In the sea of bad news which we can hear every day, about medical workers who are overtired and about overloaded health care systems due to COVID19, one piece of good news in Bosnia passed unnoticed:

A nurse voluntarily entered a retirement home where there was an outbreak of COVID19, to provide assistance to the residents.

COVID-19 was found to be present at the home, which is a public institution for the protection of older and frail people, in the small town of Goražde, in Bosnia and Herzegovina. The institution has no specialised medical care and there are only a few nurses to care for the 45 residents. Many of the residents are people with dementia; with cognitive decline; with mental illness; or with disabilities.

Two of the nurses and two of the caregivers became infected with the virus at the same time as a couple of residents were tested positive. The institution didn’t have the capacity (expert staff, equipment and knowledge) to tackle the situation. When a local daily newspaper published the story, a nurse called Mersih a Pecikoza who works in the town’s hospital, was starting her week-long summer break. Ms Pecikoza (pictured, left) has had recent health difficulties and surgery herself, both of which put her in the “high risk” group, but she went to the retirement home to offer her help, without a thought for her own safety.

She acquainted herself with the situation and with needs of the residents and seeing that they could not manage alone, she called on others to give their assistance, too, managing to gather a small team, where every member wanted to help in any way they could. The team was made up of:

- a colleague from the hospital, who gave required medical equipment
- a finance manager in a retirement home, who managed staff and resources
- the Director of the Institute for Public Health of the Bosansko Podrinjski Canton, who assisted with testing.

Over the next few days, they:

- stopped the virus from spreading further
- provided medical treatment for all infected residents
- gave training to support staff on how to deal with healthy residents and how to implement protection measures
- created a new plan for medical care until COVID-positive nurses could return from sick leave
- ensured normal functioning of all processes in the home.

This is a great example of sacrifice for others. It also demonstrating the importance of fostering expertise, knowledge and a good system, as well as nurturing empathy for others, especially those who are ill. We all have a duty to use our skills in crisis situations and a responsibility towards wider society.

ALZHEIMER EUROPE

28 September: Policy paper on intercultural care and support presented at EFID webinar

On 28 September, Dianne Gove (Director for Projects, Alzheimer Europe) presented the policy paper on intercultural care and support developed by Alzheimer Europe's working group on intercultural care and support (thanks to funding from the Robert Bosch Stiftung) at a webinar and online policy debate organised by the European Foundations’ Initiative on Dementia (EFID). The event was called “Addressing dementia...
Among people with a migration background – from diagnosis to EU policy actions”.

There was a good turnout and panellists included David Truswell (Chair of the Dementia Alliance for Culture and Ethnicity), John F. Ryan (Director for Public Health, country knowledge, crisis management, DG for Health and Safety, European Commission), and René Thyrian (German Centre for Neurodegenerative Diseases/DZNE). Owen Miller (Policy Officer, Alzheimer Europe) also participated in this webinar.

You can watch the video of this webinar, here:
https://www.youtube.com/watch?v=EneffU5WkUI&feature=emb_logo

5 October: AGM elects new Board, says farewell to Helen Rochford-Brennan and welcomes Hungary as a full member

Alzheimer Europe’s Annual General Meeting (AGM) was held online, on 5 October 2020. Chaired by Iva Holmerová the meeting was attended by representatives of 28 out of 35 full member associations and 2 provisional member associations.

Honorary Secretary Jim Pearson and Honorary Treasurer Maria do Rosário Zincke dos Reis provided an overview of the activities and finances of Alzheimer Europe in 2019. These were included in the published Annual Report which was launched at the meeting.

You can read the annual report online, here:

You can download the PDF of the annual report, here:

The members also proceeded to elect the new Board of the association which will be comprised of the following members for the 2020-2022 period:

**Office bearers:**
- Chairperson: Iva Holmerová (Czech Republic), re-elected
- Vice-Chairperson: Charles Scerri (Malta), re-elected
- Honorary Secretary: James Pearson (Scotland, United Kingdom), re-elected
- Honorary Treasurer: Marco Blom (Netherlands), newly elected to this position

**Members:**
- Stefanie Becker (Switzerland), re-elected
- René Friederici (Luxembourg), newly elected
- Sabine Jansen (Germany), re-elected
- Pat McLoughlin (Ireland), re-elected
- Sirpa Pietikäinen (Finland), re-elected
- Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD), ex-officio Board member with full voting rights
- Karin Westerlund (Sweden), re-elected
- Maria do Rosário Zincke dos Reis (Portugal), re-elected.

Congratulations to all of them and a warm welcome to new Board members Chris Roberts and René Friederici.

Outgoing Board member Jesús Rodrigo (Spain) did not stand for re-election. Alzheimer Europe and its Board would like to thank him for his service and contributions and wish him all the best.

https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-Board

The AGM voted to welcome Social Cluster Association (Hungary) as a full member of Alzheimer Europe, bringing the number of full members to 36, plus 3 provisional members.

https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-members

Following the election, there was an address by Helen Rochford-Brennan, who is stepping down as Chairperson of the EWGPWD, after four years in the position. She thanked Alzheimer Europe for supporting the EWGPWD and stressed the importance of representing people with dementia on the Board, stating that it had been her privilege to serve as an equal citizen with other Board members. She also spoke about the importance of being involved in research and of having national dementia working groups to empower people with dementia to share their experience and also to give hope to people when they are diagnosed.

The AGM also re-appointed “Auditeurs associés” as auditors for 2020-2022 and adopted the 2021 Work Plan and Budget. The next Annual General Meeting will take place in June 2021.

12 October: European Working Group of People with Dementia holds last meeting of term 2018-2020

On 12 October, the last meeting of the European Working Group of People with Dementia (EWGPWD) for the term 2018-
2020 was held. Members of the EWGPWD had the opportunity to discuss their various contributions to the AE annual virtual conference.

During the meeting there was also a demo of the conference platform. EWGPWD members bade a fond farewell to Carol Hargreaves (Scotland) and Nina Baláčková (Czech Republic). Alzheimer Europe and the EWGPWD wish to thank Carol and Nina for their important and positive contributions and their friends and family members, who supported them at meetings. We would also like to thank Helen Rochford-Brennan for her amazing leadership and work as Chair of the group since 2016.

16-20 October: Alzheimer Europe and its European Working Group of People with Dementia organise a series of pre-conference events for people with dementia and carers

Alzheimer Europe has published the 34th edition of its “Dementia in Europe” policy magazine in an electronic format. The decision to change to an electronic format was taken earlier in 2020, prior to the publication of issue 33, in light of some of the uncertainties around COVID-19 and its impact on service-providers.

The first section of the magazine highlights some of our efforts to ensure dementia remains a European priority. It includes: an article introducing our new Board of Directors; an interview with outgoing Chairperson of the European Working Group of People with Dementia (EWGPWD) Helen Rochford-Brennan; details of three EU projects in which we are involved (Paradigm, RADAR-AD and MOPEAD); and our recent position statement on the impact COVID-19 is having on dementia research.

In the Policy Watch section, we are delighted to feature: an interview with the European Commission’s Vice-President for Democracy and Demography, Dubravka Šuica; an interview with the German Minister for Family Affairs, Senior Citizens, Women and Youth, Franziska Giffey, who shared details of the new German National Dementia Strategy; details of the recent meeting of the European Group of Government Experts on Dementia; the latest EU policy developments in relation to the long-term budget of the EU, as well as health and research policies; progress on key areas of work of the World Health Organization (WHO), such as the new knowledge exchange platform as part of the Global Dementia Observatory (GDO) and a new toolkit for dementia inclusive initiatives; and an update on COVID-19 exit strategies across Europe and how countries are preparing to resume care and support services.

Our third section, Dementia in Society, covers: an interview with Kate Lee, the new CEO of the UK Alzheimer’s Society; a new working group of people with dementia launched in Vienna, Austria, in the early part of this year, seen through the eyes of Angela Pototschnigg, member of this new group and also of the EWGPWD; an article about the Bring Dementia Out
campaign in the UK, which seeks to challenge the stigma faced by LGBT+ persons with dementia, taking a rights-based approach; a commentary piece with Professor Gill Livingston, the lead author of “Dementia prevention, intervention, and care: 2020 report of the Lancet Commission” who outlines how best to prevent dementia and support those living with the condition, while four other experts in the field give us the European research project perspective (EU-FINGERS, PRIME, RECOGNISED and ADAIR); and finally, we introduce the newly-launched Brain Health Scotland initiative, which aims to help people of all ages to protect their brain health and reduce their risk of diseases including dementia.

The fourth and final section is a special overview of 30 years of Alzheimer Europe, to celebrate our 30th anniversary. Executive Director, Jean Georges reflects on his 24 years with the organisation and his views on the many achievements during this time; Chairperson, Iva Holmerová discusses the key areas of work for the organisation and the role of the Board over the years; outgoing Honorary Treasurer, Maria do Rosário Zincke Dos Reis then provides her insights on the financial position of the organisation and how this has changed over time; and a final article looks back at some of the key milestones in Alzheimer Europe’s 30 years leading the European Dementia Movement.

View online: http://bit.ly/DementiainEurope34Online
Download the PDF: https://bit.ly/DementiaInEurope34PDF
The entire back catalogue of Dementia in Europe magazines is also now available in this new electronic format, on our website: http://bit.ly/DementiainEurope

20-22 October: Alzheimer Europe holds its first ever virtual Annual Conference #30AEC

The 30th Alzheimer Europe Conference (#30AEC) “Dementia in a changing world” was held online from 20-22 October 2020. Almost 800 participants, from 42 countries, attended the conference, which boasted 260 speakers and 100 poster presentations, sharing their research, projects and experiences in an atmosphere of collaboration and solidarity, against the backdrop of the global COVID-19 pandemic.

Iva Holmerová, Chairperson of Alzheimer Europe opened the conference, extending a special welcome to the 35 people with dementia who were among the delegates, as well as their supporters. Following Iva Holmerová’s opening speech, delegates were also welcomed by Helen Rochford-Brennan, outgoing Chairperson of the European Working Group of People with Dementia (EWGPWD) and Myrra Vernooij-Dassen, Chairperson of INTERDEM.

Helen Rochford-Brennan addressed delegates from her perspective as a person living with dementia and as the outgoing Chairperson of the EWGPWD. She reflected on how much her life has changed during the pandemic, but also noted that many things remain the same: “People living with dementia continue to have their human rights denied and their voices unheard. We know this pandemic has affected people living with dementia in a disproportionate manner.” She asked those present to
consider what could concretely be done to avoid such a situation happening again in the future, and she implored everyone not to allow the pandemic to stop their important work, particularly in the areas of research and of evidence-based strategies, both for dementia and to put an end to the COVID pandemic. In closing, she thanked Alzheimer Europe, The Alzheimer Society of Ireland, her travel supporter Carmel Geoghegan, and her family, without whom the last six years in the EWGPWD (two as Vice-Chairperson and four as Chairperson) would not have been possible. She said that it had been a privilege and a pleasure, expressing particular gratitude to the Board of Alzheimer Europe for accepting a person living with dementia to serve on the Board, and for “sharing power in a meaningful way”, rather than the “all-too-often tokenistic” approach.

Myrra Vernooij-Dassen spoke on behalf of the INTERDEM network (Early detection and timely INTERvention in DEMentia). She emphasised that social distancing, which is the key measure used to protect against the coronavirus, has had deleterious effects on older individuals and people living with dementia. Measures to protect against the virus were denied to nursing homes and general practices. She emphasised that, during this public health crisis, we need to combat more than just the virus. INTERDEM calls for a more balanced approach, stressing the importance of taking the risk of social, mental, cognitive and physical breakdown into consideration, alongside the risk of infection.

As part of this year’s new conference format, Alzheimer Europe organised two plenary roundtable sessions, in lieu of keynote lectures. The first of these, “Dementia in a changing world”, saw a panel discussion including Adelina Comas Herrera, co-lead of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project; Mario Possenti, general secretary of Federazione Alzheimer Italia; Helen Rochford-Brennan and Lennert Steukers, Associate Director, Janssen Neuroscience Team. All plenary sessions at the conference were co-moderated by Jean Georges, Executive Director of Alzheimer Europe and Kim Coppes from Live Online Events.

Adelina Comas-Herrera referred to an updated report she co-authored, for which data was collected regarding the impact and mortality of COVID-19 in people living with dementia in nine countries. The percentage of people with dementia in care homes, whose deaths were linked to COVID-19, ranged from 29% to 75% across those countries. The ban on visits to care homes across the world has kept people with dementia detached from essential affective bonds and from the provision of family care, for many months. There is a pressing need, and also an opportunity for innovation.

Mario Possenti noted that the work of associations in Italy and beyond may have changed in terms of methods, but not in terms of commitment. Associations have found strength they did not know they had, and have come up with a multitude of innovative initiatives to meet the new needs of the COVID era. One challenge, however, has yet to be fully met: Creating a contactless community, supportive of the needs of people with dementia.

Helen Rochford-Brennan asked her fellow panellists and all delegates to reach out to people living with dementia in their countries and in their local communities; to support them in making sure their voices are heard and listened to; and to ensure they have the opportunity to participate in dementia research.

Lennert Steukers emphasised that a number of stages of research have been impacted: Discovery/preclinical work has suffered due to lab closures and technical unemployment of researchers; clinical trials have been suspended or severely delayed, which may impact data quality; and patient involvement has been difficult due to restrictions. The clinical trial landscape has dramatically changed and there has been a huge impact on the research community, with a whole generation of researchers being affected.

On 21 October, the second plenary session, on “Diagnosis and post-diagnostic support” opened with a presentation on “Improving the diagnosis of neurocognitive disorders: implementing the recommendations of the 2nd European Joint Action on Dementia”, given by Pierre Krolak-Salmon, President of the French Federation of Memory Centres. The next presentation saw clinical neurologist Edo Richard discussing ethical issues linked to the disclosure of diagnosis.

In the third presentation, Simon Lovestone, Vice-President, Disease Area Leader, Neurodegeneration, Janssen, looked at the pharmacological treatment of Alzheimer’s disease and at what we have learned in recent years; and the final presentation was delivered by Gunhild Waldemar, Professor of Neurology and Chair of the Danish Dementia Research Centre at Rigshospitalet, University of Copenhagen. She was one of the leading forces in the establishment of the new European Academy of Neurology (EAN) and her presentation, on medical management issues in dementia, shared the new recommendations from the EAN.
The third plenary of the conference, which took place later the same day, explored “Building dementia-inclusive societies”. Dianne Gove, Director for Projects at Alzheimer Europe, opened with a presentation on “Patient and public involvement approaches in dementia research: the experiences and contributions of the European Working Group of People with Dementia” (EWPWGD). Sabine Jansen, Executive Director, Deutsche Alzheimer Gesellschaft (DAzBG) shared some of the experiences of her organisation, with regards to promoting dementia-inclusive hospitals. The third presentation was given by Jacqueline Hoogendam, who is the coordinator for dementia policy and international affairs on Long-Term Care at the Ministry of Health, Welfare and Sport in the Netherlands. She listed some of the learnings from the Dutch dementia strategy - the “Deltaplan Dementie” – with regards to making Dutch society more dementia-friendly. The final presentation of plenary three was given by John Keady, who leads the inter-disciplinary Dementia and Ageing Research Team at the Division of Nursing, Midwifery and Social Work. He was the Chief Investigator on the multi-site ESRC/NIHR Neighbourhoods and Dementia Study and it was this study and the outcomes of the project which were the main focus of his talk.

The fourth plenary session took place on the morning of 22 October. Carol Brayne, Professor of Public Health Medicine and Co-Chair of the Cambridge Public Health Interdisciplinary Research Centre in the University of Cambridge, opened with a talk on the latest trends in the prevalence of dementia and discussed whether prevention messages are having an effect. Up next, Alexander Kurz, senior scientist at the Department of Psychiatry, Klinikum rechts der Isar, Technical University of Munich and Director of the university’s memory clinic, shared some of the findings of “INDEED, an interprofessional intervention in dementia education for South-Eastern European countries”. In the third presentation, Dympna Casey, Professor and Head of School in the School of Nursing & Midwifery NUI Galway looked at assistive technologies and explored what the role of social robotics could be in dementia; while Carlos Diaz, CEO of Synapse Research Management Partners and Coordinator of the IMI NEURONET project, was the final speaker in plenary four. He discussed the neurodegeneration portfolio of the Innovative Medicines Initiative (IMI), and looked at ways to ensure project results are converted to sustainable assets.

The fifth and final plenary session was held that afternoon, and took the form of a second roundtable. The discussion revolved around “Maintaining dementia as a European priority” and the panellists were Maria Carrillo, Chief Science Officer, Alzheimer’s Association (US) global research program; Dan Chisholm, Programme Manager for Mental Health at the WHO Regional Office for Europe, Nils Dahl, Senior Policy Advisor at Germany’s Federal Ministry of Health; Charles Scerri, Chairperson of the Malta Dementia Society, Vice-Chairperson of Alzheimer Europe and National Focal Point on Dementia in Malta; and Nicoline Tamsma, Policy Officer at the European Commission’s DG for Health and Food Safety, Unit Health Promotion, Disease Prevention, Financial Instruments.

Maria Carrillo said that “even now - especially now - Alzheimer’s and all other dementias must be maintained as a global priority. Even during the pandemic, at any given moment, discovery is happening and must not be delayed. As the world’s largest non-profit funder of Alzheimer’s and dementia research, the Association’s commitment to advancing the critical work of the scientific community is unwavering. We are committed to funding researchers directly, as we also relentlessly pursue additional resources on all fronts, including through our federal advocacy efforts.” That being said, she also stressed that her association’s first priority is the health and safety of study participants and study staff. The Association is also working hard to ensure that, even during the pandemic, people living with dementia have access to high quality, person-centred care.

Dan Chisholm drew attention to the fact that COVID-19 has served to expose the shortcomings of most countries’ preparedness and response capabilities, not only with respect to viral disease outbreaks but also to healthy ageing, dementia and long-term care. “The WHO continues to work through the crisis with its Member States and partners to develop and make available tools
and other measures to support implementation of its global action plan on the public health response to dementia, including a dementia-friendly and inclusion toolkit as well as risk-reduction guidelines for cognitive decline and dementia”, he said, and he pointed out that the WHO has also rapidly stepped up its work to provide guidance to countries on COVID-19, including clinical management, psychosocial support needs and maintenance of essential care and services.

Nils Dahl assured delegates that, during the past decade, Germany’s Federal Government has initiated numerous programmes and measures to support people with dementia and their relatives, culminating in the development of the country’s national dementia strategy and its adoption by the Federal Cabinet in July 2020. Amid the pandemic, the implementation of the dementia strategy remains a priority for the government, he stressed. He also emphasised that all actors involved in the process of the strategy’s implementation would take into account that persons with dementia might not only be at high risk of falling seriously ill if infected with COVID-19, but that they can be adversely affected by COVID-19-related restrictions as well.

Charles Scerri said that “times like these have taught us the importance of coming together, as European nations, in supporting individuals living with dementia” and that this could be achieved through innovative resources directed towards maintaining their wellbeing. We have also learned that individuals living with dementia, and those who care for them can become particularly vulnerable during such a crisis, he added, insisting that “Europe must do more by investing in more research, putting dementia as a top priority in its health and social programmes.”

Nicoline Tamsma drew attention to some of the Commission’s efforts to see dementia recognised as a priority, such as supporting initiatives via the EU Health Programme, including two Joint Actions. Since 2014, EU funds targeted to brain research have totalled EUR 3.17 billion, including EUR 683 million for research into neurodegenerative diseases, the majority dedicated to Alzheimer’s disease and dementia. The Commission also continues to support the work of Alzheimer Europe. With regards to how the pandemic has affected progress in the area of dementia research, the Commission is working with Member-States and international partners to tackle COVID and its consequences, she said. Finally, addressing the mental health impact, she pointed to a specific network space on the EU Health Policy Platform, set up by the Commission to support stakeholders and to facilitate practice and knowledge exchange, also with regard to vulnerable groups such as people with pre-existing conditions. Alzheimer Europe is among more than 65 participants.

The three-day conference, which also featured 24 parallel sessions and 6 special symposia on diverse topics for delegates to choose from, was formally closed by Alzheimer Europe Chairperson Iva Holmerová (pictured, left). She thanked speakers and poster presenters for sharing their research, projects and experiences. She also said a special thank you to the various sponsors of the conference: The European Union Health Programme (2014-2020), Roche, Biogen, the European Federation of Pharmaceutical Industries and Associations (EFPIA) and BBDiag.

All delegates were invited to mark the dates of the next Alzheimer Europe Conference (#31AEC) in their calendars. “Building bridges” will take place in Bucharest, Romania from 29 November to 1 December 2021. The 30th Alzheimer Europe Conference received funding under an operating grant from the European Union’s Health Programme (2014-2020).

20-22 October: Six special symposia held during #30AEC

On 20, 21 and 22 October 2020, during the 30th Alzheimer Europe Conference (#30AEC), six special symposia were held:

European Working Group of People with Dementia (EWGPWD): “My second new life: adapting after COVID-19”

One of the highlights of the second day of the virtual Alzheimer Europe Conference was a special symposium organised by the European Working Group of People with Dementia (EWGPWD). Members of the group shared individual videos, in which they talked about how the pandemic has affected them personally, and how they have managed to adapt to new circumstances and a “new life”.

The members of the group who shared videos were: Idalina Aguiar (Portugal), Nina Baláčková (Czech Republic), Stefan Eriksson (Sweden), Tomaz Gržinič (Slovenia), Carol Hargreaves (United Kingdom - Scotland), Bernd Heise (Germany), Angela Pototschnigg (Austria), Helen Rochford-Brennan (Ireland) and Geert Van Laer (Belgium).

The group hopes that these video clips will inspire people with and without dementia and give them hope that it is possible to find new ways to adapt during this pandemic, and beyond. The videos are available on demand (to registered delegates), via the Alzheimer Europe conference platform: https://30aec.alzheimereuropevirtual.org/

Lessons from COVID-19 for AD health system readiness

The response to the COVID-19 pandemic offers important lessons for health system readiness for Alzheimer’s disease (AD) in Europe. Across countries, the COVID-19 pandemic has
clearly shown that without the right measures in place, even highly-resourced healthcare systems can become rapidly overwhelmed by an unpredictable healthcare crisis that affects a large population. The pandemic illustrates the importance of analysing robust data correctly and responding quickly to changing scenarios by using healthcare resources effectively and efficiently. Specifically, the AD community itself has been directly affected by the prevailing COVID-19 situation, as individuals are often considered at higher risk of mortality and morbidity. This highlights the fragility of the current approaches to diagnosis, treatment and care for people living with AD. The number of people with AD is growing, and as illustrated by the COVID-19 pandemic, action needs to be taken to prepare health systems for the future rising demand from patients and their families as new diagnostic and treatment innovations emerge.

This special symposium, sponsored by Roche, brought together an expert panel to share their perspectives on and experiences of the lessons to be learned from COVID-19 for AD health system readiness, and to explore a range of topics, from healthcare access and service coverage, capacity constraints, the respective roles of primary and specialist care, and how to ensure medical innovation can support a patient-centred care model in AD.

**Dementia care and COVID-19**

This special symposium brought together four speakers to discuss the impact of the pandemic on people living with dementia and specifically on their access to care, from the perspectives of: a research institution (Fundació ACE); two national Alzheimer associations (Alzheimer Scotland and The Alzheimer Society of Ireland); and migrant family carers.

Mercè Boada detailed the sequence of events and actions undertaken within the Fundació ACE Memory Clinic to swiftly adapt to telemedicine consultations. She shared data on individuals under follow-up by the Memory Unit between 2017 and 2019, comparing this data with the number of weekly visits in 2020, before and after lockdown. Videoconference visits have become the norm, and neurologist and neuropsychologist evaluation protocols have rapidly been adapted to the new situation.

Carolien Smits (Pharos, Netherlands) shared that the COVID-19 era and ensuing government measures have resulted in anxiety and increased burden for migrant family carers. Professional care quality is under pressure and is becoming less culturally sensitive, in some cases.

Nicola Cooper presented the experience of Alzheimer Scotland which, in a few short weeks, transformed its care approaches through the use of technology, experiencing a paradigm shift in how it delivers services. Over 200 staff undertook digital skills training and now use the NHS approved Attend Anywhere video platform to deliver 1:1 support and a range of therapeutic group activities, including cafes and ceilidhs, for service users at home and in care settings.

Bernadette Rock (The Alzheimer Society of Ireland) in turn discussed Ireland’s experience of emergency psychosocial supports for people with dementia and their families. The outbreak of COVID-19 forced the closure of almost all community-based dementia-specific services and supports in Ireland, leaving thousands of people with dementia and family carers to fend for themselves. Specific needs of people with dementia, family carers and other stakeholders were identified via online and telephone surveys and, using this data, The Alzheimer Society of Ireland developed a new suite of emergency supports and services.

**It is time for European healthcare systems to prepare for Alzheimer’s breakthroughs?**

Currently, health systems in Europe are not ready to get the most out of potential breakthroughs in disease modifying therapies for Alzheimer’s disease and other dementias. To be able to fully benefit from these therapies, complex health systems will have to adapt and change and will have to ensure that they can detect and diagnose dementia early, deliver new medicines by infusion, and monitor treatment. While most of these improvements will need to be undertaken locally, by national and regional governments, there are also significant steps that can be taken at the European level.

The panel discussion in this symposium, which was organised by The European Federation of Pharmaceutical Industries and Associations (EFPIA), was an opportunity to raise awareness about the need for European healthcare systems to plan for Alzheimer’s breakthroughs and to identify solutions. “The time for action is now”, was the overriding message.

**From brain health to Alzheimer’s disease – Addressing the challenges early in the patient journey**

Over the course of the last decade, research into the pathophysiology of Alzheimer’s disease has shown that early intervention will be important to maximise outcomes for the patient. Currently, detection, diagnosis and care planning all start once symptoms start to become more apparent, which is very often late in the disease course. To benefit from future advances in treatment and care, healthcare systems will need to appropriately recognise, diagnose and support people at the earliest stages of the disease – perhaps even before symptoms appear. Creating a policy response to drive the healthcare system to meet the emerging science will require support at both the regional and country levels to take urgent action.

In a time of social distancing and uncertainty in the world of healthcare, collaboration and communication among all stakeholders is more important than ever. This symposium sponsored by Biogen, offered perspectives from a variety of stakeholders, to better understand the current state of treatment and care, and where challenges exist in the patient journey. Participants examined ways in which healthcare systems are improving detection and diagnosis and reviewed policy actions to address barriers to challenges, such as late stage or misdiagnosis.
**Medical management of dementia**

People with dementia are at an increased risk of a number of comorbidities together with symptoms of dementia. Although no disease-modifying therapy exists for the neurodegenerative brain disorders causing dementia, adequate management of these issues may improve the quality of life, and slow down the progression of the disease. A number of challenges exist, however, such as lack of insight meaning that people may not seek medical assistance; and lack of access to medical staff, which may mean that people with dementia do not receive proper treatment and management.

The sixth and final symposium at the virtual Alzheimer Europe Conference explored the guideline of the European Academy of Neurology on “Medical management issues in dementia”. The Guideline aims to support physicians on a number of important medical management issues in the care of patients with dementia, including: systematic medical follow-up; treatment of vascular risk factors; management of pain; treatment of agitation and aggression with anti-psychotics; and management of epilepsy.

Four of the authors of the Guideline were present, to answer questions.

**23 October: European Working Group of People with Dementia holds first meeting of new group for 2020-2022 term**

The European Working Group of People with Dementia (EWGPWD) began its fifth two-year term of office with an online meeting on 23 October 2020. During this meeting, the group welcomed six new members.

The EWGPWD for 2020-2022 is composed of the following 15 members:

**Chairperson**: Chris Roberts (UK – England, Wales and N. Ireland)

**Vice-Chairpersons**: Bernd Heise (Germany), Kevin Quaid (Ireland) (new),

**Members**: Idalina Aguiar, Portugal; Stefan Eriksson, Sweden; Tomaž Grižinič, Slovenia; Nigel Hullah, UK – England, Wales and N. Ireland, (new); Petri Lampinen, Finland; Margaret McCallion UK–Scotland (new); Danny McDonald, UK-Scotland (new); Erla Jónsdóttir, Iceland (new); Angela Pototschnigg, Austria; Helen Rochford-Brennan, Ireland; Ditte Sigsgaard, Denmark (new), Geert Van Laer, Belgium.

The EWGPWD was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently and members elect their own Chairperson and Vice Chairs. The Chairperson is also an ex-officio member on the Board of Alzheimer Europe with full voting rights.

During the group’s first four terms of office (2012-2014, 2014-2016, 2016-2018, 2018-2020), members have actively participated in Alzheimer Europe’s annual conferences and contributed towards consultations for European projects in which Alzheimer Europe is involved, as well as to other areas of Alzheimer Europe’s work. They have also contributed to research conducted by external organisations on topics such as outcome measures that are meaningful to people with dementia and their carers, social health, people with dementia as peer-researchers, Public Involvement in dementia research and dementia-inclusive initiatives, and have attended a number of international dementia-related events, including one at the European Parliament, as representatives of the group.

**Alzheimer Europe networking (online)**

On 28 September, Dianne presented the AE policy paper at the EFID webinar on dementia and migration.

On 1 October, Cindy attended the EPAD General Assembly meeting.

On 1 October, Cindy, Chris and Ange attended the Neuronet Scientific Coordination Board meeting.

On 2 October, Angela participated in the second judging panel for the AAL Smart Ageing Prize.

On 2 October, Owen attended a webinar on the future of mental health and rights hosted by Mental Health Europe.

On 6 October, Dianne and Angela participated in a meeting of the Neuronet Working Group on Ethics and Patient Privacy.

On 6 October, Angela attended the General Assembly meeting of the VirtualBrainCloud project.

On 7 and 12 October, Dianne and Ana took part in a meeting of the EWGPWD.

On 5 October, Alzheimer Europe organised its virtual Annual General Meeting with its member organisations.
On 8-9 October, Cindy attended the AMYPAD General Assembly meeting.
On 13 October, Owen attended the Patients BioForum hosted by EuropeaBio.
On 15 October, Owen attended a workshop on dementia and hearing loss hosted by the Hearing Health Forum EU.
On 15 October, Ana participated in the PARADIGM PEOF session “Patient Engagement and Quality by Design”.
On 16, 19 and 20 October, Dianne and Ana participated in the demos and networking event for 30AEC delegates with dementia.
On 16 October, Dianne took part in the INTERDEM Taskforce zoom meeting on Intercultural Care.
From 20 to 22 October, Alzheimer Europe organised its 30th Annual Conference “Dementia in a changing world”.
On 23 October, Dianne and Ana participated in the first meeting of the EWGPWD 2020-2022.
On 23 October, Angela attended an EMA virtual training session.
On 26 October, Ana participated in the 1st PARADIGM informative session for the patient community.
On 26 October, Owen attended the Virtual Summit of the EU Health Coalition.
On 26 October, Jean had an exchange with representatives of the World Health Organization.
On 26 October, Angela attended the online EU Health Summit organised by the EU Health Coalition.
On 26 October, Jean met with France Alzheimer and the French Table Tennis Federation.
On 27 October, Jean attended the PRODEMOS work package leaders meeting.
On 29 October, Dianne attended the closing conference of the research project “Language and communication in multilingual speakers with dementia (funded by the Research Council of Norway).

EU PROJECTS

1 October: The EPAD project convenes an online GA meeting

On 30 September and 1 October, the European Prevention of Alzheimer’s Dementia (EPAD) project held its General Assembly meeting online. Chaired by Craig Ritchie and Serge Van der Geyten, the EPAD project coordinators, the online GA meeting welcomed over 100 delegates, including representatives from the 39 institutions and organisations that make up the EPAD consortium.

Leaders of each work package had the opportunity to reflect on the achievements and important lessons learned for future studies. Between some of the talks, a testimonial was given by several “Epadistas” (members of the project, study sites members and research participants making up the EPAD family). AE Project Officer Cindy Birck gave a talk on the EPAD communications. AE contributed as co-lead to the communication and dissemination activities for the EPAD project. Following the Work Package updates, Elisabetta Vaudano IMI Principal Scientific Officer, gave a presentation on IMI and shared some recommendations.

Craig Ritchie started the second day with an update on the EPAD asset portfolio. Next, a series of fireside chats took place. The aim of this session was to discuss a series of key topics that the clinical and clinical research field has been grappling with over the years with much work still to be done. 20 leaders in the field were invited to join the discussion with an emphasis on how we can learn in each topic from the past to help envisage the future direction. Before the wrap-up session, the IMI NEURONET project was presented along with the opportunities for EPAD. Craig Ritchie and Serge Van der Geyten then drew the meeting to a close, thanking all the participants for their active contribution to the meeting and all EPAD members for their enthusiasm and dedication during the last six years. The project started in January 2015 and received a no-cost extension from IMI, setting the end date in June 2020 for many members and October 2020 for all who were part of the longitudinal cohort study closure activities.

1 October: Neuronet convenes a virtual meeting of its Scientific Coordination Board

Neuronet, a coordination and support action (CSA) for the neurodegeneration projects of the Innovative Medicines Initiative (IMI) portfolio, aims to enhance collaboration and communication between projects, multiplying the portfolio’s impact and enhancing its visibility in Europe and beyond. The Neuronet Scientific Coordination Board (SCB) is composed of 18 leaders from IMI neurodegeneration projects and plays a central role in determining the overall scientific strategy of Neuronet. The SCB meets on a quarterly basis, bring wide-ranging scientific, clinical, R&D and computational expertise to the table and identifying key challenges and priorities for Neuronet to address.
The fifth Neuronet SCB meeting was held online on Thursday 1 October, attended by leaders of the AETIONOMY, EPAD, EQIPD, IDEA-FAST, IMPRIND, Mobilise-D, PHAGO, PD-MitoQUANT and ROADMAP projects along with members of the Neuronet consortium. Alzheimer Europe was represented by project officers Cindy Birck, Chris Bintener and Angela Bradshaw.

Carlos Diaz, Coordinator of Neuronet, kicked off the meeting by updating SCB members on recent Neuronet activities. These activities include new updates to Neuronet tools such as the Knowledge Base, as well as the recent, successful IMI interim review. Active discussions between SCB members ensued, on topics including assets beyond the neurodegenerative disease portfolio, challenges for digital data and biosample sharing, and how to best support the sustainability of large, public-private partnership projects.

In the second half of the meeting, Neuronet project leader Lennert Steukers summarised some of the research challenges being faced by IMI neurodegeneration projects as a result of COVID-19, and also updated on new collaborations that Neuronet is facilitating. Jacoline Bouvy and Diana O’Rourke of NICE then outlined recent findings from an impact analysis currently being carried out by Neuronet, which is aiming to assess the impact of the IMI neurodegeneration portfolio on collaboration, research and innovation. Finally, Carlos Diaz chaired a discussion on how to increase the visibility of the portfolio and identify new priorities for neurodegeneration research as we move beyond the IMI2 period and towards the new Horizon Europe framework programme.

6 October: The VirtualBrainCloud project convenes an online GA meeting

On 6 October, the H2020-funded VirtualBrainCloud project (TVB_Cloud) held its General Assembly meeting online. Chaired by Prof Petra Ritter, the TVB_Cloud project leader, the online GA meeting welcomed over 35 project participants, including representatives from the 17 institutions and organisations that make up the TVB_Cloud consortium.

The primary objective of TVB_Cloud is to create a decision support system for clinicians, based on a cloud platform for personalised brain simulations. These simulations are constructed using high-quality, multidisciplinary clinical data, including EEG and MRI scans, genetic analyses and blood-based biomarker data. The goal of the decision support system is to enhance the early diagnosis, prognosis and personalised treatment of Alzheimer’s disease (AD) and other neurodegenerative conditions.

During the TVB_Cloud General Assembly (GA) meeting, updates were provided on the two stakeholder meetings organized by leaders of the legal and ethical work package, including a GDPR workshop held online in September 2020 and the TVB_Cloud sessions to be held as part of our Annual Conference later this month. Alongside, project representatives from Fraunhofer SCAI, Forschungszentrum Jülich, Charité Medizinsuniversität Berlin and Indoc Research (among others) provided summaries of ongoing activities on data processing and FAIRification, ontologies and terminologies, development of the cloud-based infrastructure and construction of AD disease progression models. Prof. Ritter also provided an overview of the interim review for TVB_Cloud, which had a positive outcome. The next TVB_Cloud GA will be held early next year.


8 October: AMYPAD holds its first virtual General Assembly Meeting

On 8 and 9 October, the “Amyloid imaging to Prevent Alzheimer’s disease” (AMYPAD) consortium held its annual General Assembly as a virtual meeting. Frederik Barkhof and Gill Farrar, coordinators of the AMYPAD project, kicked off the General Assembly by welcoming over 100 attendees. Following on from the introductory session, the two first sessions were held on the clinical aspects of AMYPAD. The Diagnostic and Patient Management Study (DPMS) has currently reached 819 participants and over 600 amyloid PET scans were performed, since the study was initiated in April 2018. After that, a session was dedicated to the Prognostic and Natural History Study (PNHS). The study comprises collaboration among sites and parent cohorts in several countries across Europe. Currently there are six active cohorts recruiting participants into AMYPAD PNHS. 652 research participants have currently been recruited of which 466 have been scanned. Analysis of the data acquired in both studies has started and preliminary results were presented for both clinical studies. There was also a presentation on the publication strategy and the data access. Following on from this presentation, a roundtable discussion was held on the sustainability of the AMYPAD project. Different approaches on sustainability might be taken and collaborations with related initiatives are being explored. Then, the screen was given in turn to Elisabetta Vaudano (IMI) who gave a feedback on the AMYPAD progress and presented the IMI strategic research agenda. Finally, updates were provided on the management and financials.
On the second day, the AMYPAD consortium gathered for a scientific exchange and discussion. The WP2 “Tracer delivery, PET scanning and image analysis” is led by Juan Domingo Gispert (BarcelonaBeta Brain Research Center) and Chris Buckley (GE Healthcare). They both explained that WP2 has created a task force: Centiloid Working Group. Main findings and ongoing analyses were presented. Next, the floor was given to seven AMYPAD researchers to showcase their respective work in disease modelling. Gill Farrar and Frederik Barkhof then drew the meeting to a close, thanking all the participants for their active contribution to the meeting.

Cindy Birck represented Alzheimer Europe at the AMYPAD General Assembly meeting.

To keep up to date with AMYPAD’s progress follow @IMI_AMYPAD on Twitter and visit the website: http://amypad.eu/

**15 October: PARADIGM organises its October Patient Engagement Open Forum event**

On 15 October, two sessions were organised as part of the PARADIGM Patient Engagement Open Forum (PEOF). These were on the topics of “Patient Engagement and Quality by Design” and “Good Lay Summary Practice, communicating trial results to the general public”. Relevant materials and presentations are available online.

The two last sessions of the PEOF will be organised on 5 November (patient engagement from the regulatory perspective) and on 23 November (conclusion session). For registrations and further information about these and previous sessions, please visit: https://patientengagementopenforum.org

**15 October: EPAD project publishes a new paper on its research participant panel**

On 15 October, an international team of researchers from the European Prevention of Alzheimer’s Dementia (EPAD) project published an article in the journal Research Involvement and Engagement entitled “Involving research participants in a pan-European research initiative: the EPAD participant panel experience”.

One of the founding goals of the EPAD programme was to involve participants as research partners. EPAD set up a series of ‘participant panels’ in England, France, Scotland, Spain and The Netherlands. These panels were formed from groups of participants in the study who met at least twice a year with researchers.

This paper reports on the set up, running and experiences of the EPAD participant panel and describes how participants were invited to join. Panels successfully contribute to study documents, study videos and presenting at national and international meetings.

The authors of this paper include Director for Projects Dianne Gove. Congratulations to all, on this publication! https://doi.org/10.1186/s40900-020-00236-z

**17 October: Researchers from the ROADMAP project publish a paper on a new mapping algorithm to obtain EQ-5D indices**

On 17 October, researchers from the international ROADMAP consortium recommended a new mapping algorithm to estimate EQ-5D values from Quality of Life (QoL) data related to Alzheimer’s disease in the Quality of Life Research journal.

The team used a variety of statistical models to estimate utility directly, or responses to individual EQ-5D questions from QoL-AD. These were then trialled for patient-rated as well as proxy-rated questionnaires.

The algorithm allows researchers for the first time to conduct cost-utility analyses using datasets where the QoL-AD although no utility measures were collected. The article has been published open access and can be read here: https://doi.org/10.1007/s11136-020-02670-8

**20 October: First participant completes two-month participation in RADAR-AD study**

The first participant enrolled in the main RADAR-AD study has completed the two-month assessment period of the study. During this period the participant interacted with apps and wearable devices which measured their physical activity, sleep and heart rate, as well as thinking abilities and spatial navigation. Read more, here: https://www.radar-ad.org/newsroom/first-radar-ad-participant-completes-2-month-participation-radar-ad-study

**20 October: INTERDEM session at 30th Alzheimer Europe Conference explores lessons learned regarding technology, dementia and COVID-19**

An online symposium organised by the INTERDEM Taskforce Assistive Technology and looking at lessons learned regarding technology, dementia and COVID-19, took place during
Considering and sharing these lessons may stimulate further use of technology, hopefully also after Covid-19, and may promote physical, mental and social health of people with dementia and their loved ones.

22 October: INDUCT presents updated guide on Technology in Dementia at #30AEC

At the 30th Alzheimer Europe Conference, an updated version of the Best Practice Guidance on Human Interaction with Technology in Dementia was presented by Prof. Rose-Marie Dröes. This Best Practice Guidance includes an extensive set of recommendations on the development, usage and implementation of technology for people with dementia, resulting from the research which fifteen early stage researchers within the EU-Marie Skłodowska Curie funded INDUCT Innovative Training Network (2016-2019) from seven universities across Europe conducted in various areas of technology in dementia: Everyday life: meaningful activities: and health care.

The web-based version of this Best Practice Guidance was officially launched at the 29th Alzheimer Europe conference in the Hague (www.dementiainduct.eu/guidance/). The updated Guidance now contains 56 recommendations which are very useful for a variety of target groups, such as users, designers/developers, care professionals and providers, researchers, politicians and the media. Each target group can easily find specific recommendations relevant to them by means of the “theme” and the “target group”-oriented search engines.

In the coming years, recommendations resulting from the recently-started new Marie Skłodowska Curie DISTINCT-ITN (2019-2023), which focuses on technology to promote Social health in people living with dementia, will also be included in the Best Practice Guidance.

Take a look and find out which recommendations are relevant to you! Via this website, you can also download the full PDF of the updated Best Practice Guidance with all recommendations: www.dementiainduct.eu/guidance/

22 October: MinD project is represented at the 30th Alzheimer Europe Conference

The MinD project “Designing for people with dementia” was present at the 30th edition of the Alzheimer Europe Conference, with a virtual booth and an online seminar. Kristina Niedderer, Manchester Metropolitan University, UK, pointed out the potential of design to support
the psychosocial well-being of people living with dementia and presented two designs arising from the project.

For recall, the MinD project was a four-year project funded by the European Union’s Horizon 2020 Marie Skłodowska-Curie research and innovation programme. Interviews, focus groups and design sessions involving people living with dementia and their carers were conducted to better understand their needs and wishes regarding aspects such as social engagement and self-empowerment.

The seminar offered the possibility to discuss with attendees the two designs, which were developed in collaboration with people with dementia and carers, in order to help them to focus on the present moment and to face the future with more confidence: “This is Me”, a storytelling board-game, and the “Living the Life” booklet. This last one is already available in three languages (English, German, and Spanish) and can be downloaded and printed for free, from the MinD website: www.designingfordementia.eu.

This session was also an occasion to introduce the new two-year I-Do Service project “Facilitating Inclusion and Empowerment of People Living with Dementia through Access to Cultural and Creative Activities”, which began in October this year. Benefitting from previous experience with MinD, Isabelle Tournier will work to develop a user-friendly service for people living with mild dementia, to allow them to plan for and create or participate in tailored opportunities to realise themselves. Hosted by the Manchester Metropolitan University, this project is supervised by Kristina Niedderer and funded by the Marie Skłodowska-Curie Individual Fellowships programme.

For more information, visit www.designingfordementia.eu or contact Kristina Niedderer K.Niedderer@mmu.ac.uk or Isabelle Tournier I.Tournier@mmu.ac.uk

22 October: The VirtualBrainCloud project hosts sessions on AI, dementia and ethics at #30AEC

On 21 and 22 October, the Horizon 2020-funded VirtualBrainCloud (TVB_Cloud) project held two Alzheimer Europe conference sessions on the use of artificial intelligence (AI) in dementia research. The goal of TVB_Cloud is to develop a cloud-based decision support system for clinicians, to help them more accurately diagnose neurodegenerative diseases such as Alzheimer’s and Parkinson’s disease using multidisciplinary clinical data and personalized brain simulations.

In the first TVB_Cloud session, chaired by Katarina Stevanovic of TP21, project leader Petra Ritter (Charité Medical University Berlin) presented the TVB_Cloud approach to develop a cloud-based platform for personalized diagnosis and treatment of dementia. Martin Hofmann-Apitius of Fraunhofer SCAI outlined their knowledge graph approach to increase our mechanistic understanding of neurodegenerative disease, and to identify potentially druggable pathways. Viktor Jirsa (Aix-Marseille University) rounded off the session, illustrating how algorithms developed to analyse complex systems could help us understand brain networks in health and in disease.

The second TVB_Cloud session addressed the ethical, legal and social issues raised by the use of AI in dementia research. Bernd Stahl, Ethics Director of the Human Brain Project, outlined how some of the ethical issues raised by the use of AI in healthcare research could be mitigated at policy, organizational and project levels, to ensure that the benefits of AI do not outweigh the risks. Data protection is a major concern for big data research using AI, and Michael Cepic (University of Vienna) guided the audience through the General Data Protection Regulation, showing how it protects patient privacy whilst enabling health and care research. Rounding off the session, Richard Milne of the Wellcome Sanger Centre addressed the benefits and harms of risk disclosure when risk is detected using algorithm-based approaches, describing a potential route to mitigate harms whilst maximising benefit.


22 October: Working together to address common challenges for European neurodegeneration research: Neuronet hosts four sessions at #30AEC

Neuronet has been designed to boost synergy and collaboration across the projects of the Innovative Medicines Initiative (IMI) Neurodegenerative Disorders (ND) portfolio. With a total funding budget of EUR 386 million, and addressing the whole R&D spectrum from preclinical science to real-world data, the IMI ND portfolio brings together 18 public-private partnership projects and over 230 partnering organisations. Since its launch in 2019, Neuronet’s support activities have focused on key areas identified by projects as
challenging, including data sharing and accessibility, working with Regulators, and ensuring patient privacy. The Neuronet parallel sessions held as part of the Alzheimer Europe conference were designed to showcase the work of IMI ND projects in these key areas, stimulating discussion on major issues and how to address them.

The first session, chaired by Carlos Diaz (SYNAPSE Research Management Partners), was entitled “Efficient data sharing: a must for science to respond to societal needs”. During this session, Nigel Hughes, Rodrigo Barnes and Colin Veal from the EHDEN and EPAD IMI projects discussed technical solutions that are being developed by IMI projects to overcome key obstacles to effective sharing of health data, including data harmonisation, federated networks, digital data discovery tools and research environments.

The second Neuronet session, entitled “Ensuring ethics and patient privacy whilst boosting research”, was chaired by Jean Georges of Alzheimer Europe and included presentations from Nathan Lea, Pilar Cañabate and Sébastien Libert of the EMIF, MOPEAD and RADAR-AD projects, showcasing how they have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research. The next topic to be addressed was Regulatory & HTA assessment, in a session chaired by Jean Georges of Alzheimer Europe and included presentations from Nathan Lea, Pilar Cañabate and Sébastien Libert of the EMIF, MOPEAD and RADAR-AD projects, showcasing how they have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research. The next topic to be addressed was Regulatory & HTA assessment, in a session chaired by Jean Georges of Alzheimer Europe and included presentations from Nathan Lea, Pilar Cañabate and Sébastien Libert of the EMIF, MOPEAD and RADAR-AD projects, showcasing how they have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research. The next topic to be addressed was Regulatory & HTA assessment, in a session chaired by Jean Georges of Alzheimer Europe and included presentations from Nathan Lea, Pilar Cañabate and Sébastien Libert of the EMIF, MOPEAD and RADAR-AD projects, showcasing how they have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research.

Neuronet project leader Lennert Steukers closed off the 2020 Neuronet Sessions, moderating a discussion on how COVID-19 has affected large public-private partnership projects which are addressing mobility disorders, digital biomarkers, stratified medicine and dementia prevention, among other topics. Participants included Martin Hofmann-Apitus, Lynn Rochester, Jochen Prehn, Andrew Owens, Walter Maetzler and Pieter Jelle Visser, leaders of the AETIONOMY, Mobilise-D, PD-MitoQUANT, RADAR-AD, IDEA-FAST and EMIF projects. In this roundtable session, participants discussed the research challenges caused by the ongoing pandemic, and how to ensure that neurodegenerative disease research remains a priority in the post-COVID period.

https://bit.ly/34U1uVn

27 October: PARADIGM organises informative sessions for patient communities

The four patient organisations members of the PARADIGM consortium (i.e. European Patients’ Forum, EURORDIS-Rare Diseases Europe, European AIDS Treatment Group and Alzheimer Europe) have jointly organised a series of “Questions and Answers” sessions for their members. The first of these four sessions was held on 27 October on the topic of “Raising awareness on managing competing interests in a multi-stakeholder environment: Guidance to patients and engaging stakeholders”. Maria Cavaller (EURORDIS) presented the different tools developed by PARADIGM on the topic of competing interests. This was followed by a very interactive discussion where attendees were able to ask questions and share their suggestions and comments. The following sessions are planned for November:

9 November
• Recommendations on required capabilities for patient engagement
• Patient engagement in medicines development: Recommendations on how to find the right match for the right patient engagement activity

16 November
• Patient Engagement Monitoring and Evaluation Framework

20 November
• Working with Community Advisory Boards: Guidance and tools for patient communities and pharmaceutical companies
• Guidance for reporting and dissemination of patient engagement activities.

For further information about the PARADIGM Patient Engagement Toolbox please visit:
https://imi-paradigm.eu/petoolbox/
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
- EPAD - grant agreement 115736
- Neuronet - grant agreement 821513
- PARADIGM - grant agreement 777450
- RADAR-AD - grant agreement 806999
- ROADMAP - grant agreement 116020
- VirtualBrainCloud - grant agreement 826421

**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).
**Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tolomić (ECR).
**Cyprus:** Costas Mavrides (S&D).
**Czech Republic:** Tomáš Zdechovský (EPP).
**Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D).
**Estonia:** Urmas Paet ( Renew Europe); Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Melpomeni Daskalaki (S&D); Sirpa Pietikäinen (EPP).
**Finland:** Jyrki Katainen (EPP); Antti Lindtman (Greens/EFA); Maija-Petteri Aho (S&D); Sirpi Pietikäinen (EPP).
**France:** François-Xavier Bellamy (EPP); Dominique Bilde (E&S); Nathalie Colin-Osterlé (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); Chryso Katsari (Greens/EFA).
**Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA).
**Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Smyraki (EPP); Elisavet Vozemberg-Vrioni (EPP).
**Hungary:** Tamás Deutsch (EPP); Ádám Kós (EPP).
**Ireland:** Barry Andrews (ALDE); Matt Carthy (GUE/NGL); Deirdre Clune (NI); Ciara Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ‘Ming’ Flanagan (GUE/NGL); Billy Kelleher ( Renew Europe); Seán Kelly (EPP); Mairead McGuinness (EPP); Grace O’Sullivan (Greens/EFA).
**Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D).
**Lithuania:** Vilija Blinkeviciute (S&D).
**Luxembourg:** Charles Goerens ( Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens/EFA); Nicolas Schmit (S&D); Isabel Wiesler-Lima (EPP).
**Malta:** Roberta Metsola (EPP); Alfred Sant (S&D).
**Netherlands:** Jeroen Lenaers (EPP); Annie Schijve (Pirik).
**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 Busoi, MEP (EPP); Marian-Jean Marinescu (EPP).
**Slovakia:** Ivan Stefanec (EPP).
**Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Groselj ( Renew Europe); Irena Vlahová (EPP); Romana Tomc (EPP); Milan Zver (EPP).
**Spain:** Izaskun Bilbao Barandica ( Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA).
**Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).

**EUROPEAN ALZHEIMER’S ALLIANCE**

1 October: Sirpa Pietikäinen MEP submits written question on dementia

European Alzheimer’s Alliance Chairperson, Sirpa Pietikäinen MEP (EPP, Finland), has submitted a written question to the European Commission asking about the place of dementia in the future priorities of the EU. The question submitted was as follows:

According to Alzheimer Europe’s Dementia in Europe Yearbook 2019, based on UN 2018 population estimates, there are 7,853,705 people living with dementia in the European Union. Primarily as a result of the ageing demographics in Europe, by 2050, this figure will almost double to 14,298,671.
The distinct and needs of people with dementia (of which Alzheimer’s disease is the most common form), mean it requires specific consideration as an issue in its own right, beyond being grouped under broader categories of mental health or non-communicable diseases.

- Where does the Commission envisage dementia being placed in future EU workstreams (including in the EU4Health Programme, the Health cluster of the Horizon Europe research programme, the Green paper on Ageing etc.)?
- Will the Commission undertake further coordinated action on dementia as it has done in the past, e.g. through the European Initiative on Alzheimer’s disease and other dementias, and if not, the rationale behind this?
- How is the Commission working with the WHO European Regional Office and Members States to implement international health policies, such as the Sustainable Development Goals (in particular number 3) and the Global Action Plan on the Public Health Response to Dementia 2017-2025?

You can find the question on the European Parliament’s website at:

1 October: Council of Europe publishes new guide on public debate on human rights and biomedicine

The Council of Europe (COE) has launched a new guide aimed at initiating and promoting dialogue on the challenges posed by biomedical developments, both for individuals and society. “The Guide to Public Debate on Human Rights and Biomedicine” developed by the Committee on Bioethics (DH-BIO) in line with Article 28 of the Oviedo Convention. It is also part of the Council of Europe’s action plan on Human Rights and Technologies in Biomedicine (2020-2025).

The guide is primarily aimed at government officials, public authorities, national ethics committees and other relevant institutions and organisations. It explores why public debate is important, as well as offering guidance about how to prepare for such housing. In addition, it refers to examples of public debate in a selected number of countries, providing good practice examples. You can read the guide here:

8 October: Expert panel on investing in Health publishes draft report

The Expert Panel on Effective Ways of Investing in Health (EXPH) has published a draft opinion on the organisation of resilient health and social care systems. The Panel received a mandate from the European Commission to look beyond the current pandemic crisis and consider how health systems can better prepare for future threats, specifically requesting a new framework for the organisation of health and social care systems. The paper:

- Identifies the building blocks of resilient health and social care organisation
- Explores the elements and conditions for capacity building to strengthen health system resilience
- Addresses healthcare provision for vulnerable patient groups and how to sustain such provision in a system under stress
- Defines an approach to develop and implement “resilience tests” of Member State health systems.

Within the report, dementia and Alzheimer’s are included under section 1.3.3, as a population which should be considered as vulnerable and for whom specific measures should be introduced. You can read the draft opinion here:
15 October: European Commission publishes European Disability Strategy roadmap

The European Commission has published its Roadmap for a new European Disability Strategy for 2021-2030. The Roadmap outlines the rationale and aims of the proposed Strategy, as well as inviting feedback and suggestions from all stakeholders. The strategy will build on the previous European Disability Strategy (which ran from 2010-2020), aiming to bridge the inclusion gap that persons with disabilities experience socially, economically and legally. In addition, the Roadmap commits to the Strategy being developed in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Furthermore, it will aim to support the mainstreaming of disability across all EU policy areas, programmes and instruments. Accompanying measures will include data collection, indicators, monitoring, reporting, awareness raising, ensuring the participation and consultation of persons with disabilities. The deadline for contributions is 12 November 2020. You can read more here: https://bit.ly/3ek139I

21 October: Council of the EU sets out negotiating position on EU4Health programme

The Council of the European Union has agreed its mandate to start negotiations with the European Parliament on the EU4Health programme (2021-2027). In line with the outcome of the European Council meeting across the summer, a reduced budget of EUR 1.7 billion (2018 prices) has been proposed. The Council points out that this budget is four times the size of the current Health programme for 2014-2020. The EU4Health programme aims to complement the national policies of the member states and to promote coordination between them in order to improve health in relation to:

- Serious cross-border threats to health
- Improving availability of health products and crisis products
- Strengthening the resilience and sustainability of health systems
- Increasing the use of digital tools and services related to health
- Strengthening the role of the European Union in global health.

The position also aims to address long-term traditional public health issues, such as the prevention and treatment of communicable and non-communicable diseases, to improve mental health and long-term care and to reduce health inequalities. You can read more here: https://bit.ly/326CPer

3 October: Alzheimer Bulgaria takes part in a regular running event in order to spread awareness

On 3 October, in one of the parks in the city of Sofia, Alzheimer Bulgaria took part in a regular Saturday 5km running event, held by “5kmrun”, to help spread the idea of preventive healthcare through sport. The slogan of the event was “Let’s outrun dementia together”. This is the second time that Alzheimer Bulgaria has participated in the 5km run, this time by way of celebrating
21 October: “Let’s Talk about Dementia” is bringing the conversation into the heart of communities across Ireland

Dementia: Understand Together is partnering with the IRS group of radio stations to help get Ireland talking about dementia.

This year has been a particularly difficult one for people living with dementia and their carers, families and friends, as many may have been “cocooning” to stay safe from COVID-19, missing social connections or support services. The winter months, with shorter days, darker evenings and colder
weather will present new challenges for people to engage with their communities, go for walks or see a much-missed friend. To help ensure that people with dementia and their families know that they are not forgotten, and to continue raising awareness in communities about ways to reach out, support and engage, The Alzheimer Society of Ireland (ASI) looked at how this can be done safely, during the pandemic. The ASI wanted to get people talking about dementia where it matters most—in their communities—so they took the conversation into ten communities through their much-listened-to, trusted local radio stations.

Over a three-week period, they highlighted dementia through:
- 20 interviews with people with dementia, family carers, community champions and service providers
- “on demand” audio pieces which are available on each of the stations’ websites and Facebook pages, as well as the Dementia: Understand Together website: https://www.understandtogether.ie/

The many stories, shared by a variety of interviewees, are inspirational, emotional and encouraging. They provide practical advice and information on alternative supports and activities, as well as bringing hope to listeners.

A key message from Dr Helen Rochford Brennan (pictured), Member and former Chair of the European Working Group of People with Dementia, former Board Member of Alzheimer Europe and member of the Irish Dementia Working Group was:

“Be kind to yourself and let other people be kind to you”. We are very grateful to the many interviewees for their support and fantastic conversations.

27 October: Greece marked World Alzheimer’s Month with several events across the country

Many events celebrating World Alzheimer’s Day and World Alzheimer’s Month (September) were organised by Alzheimer’s associations across Greece, all of which are members of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders. The events were mainly organised through web platforms due to the COVID-19 pandemic.

The Panhellenic Federation created a TV spot with famous Greek actors, that aired on 12 TV channels throughout the entire month, raising awareness among the general public. Also, the September issue of the Panhellenic Association’s Alzheimer’s newsletter, besides being available for on-line reading, was also distributed with the Sunday newspapers, in 32,000 copies! Both the TV spot and the newsletter were done under the banner “Express yourself”, in an attempt to fight stigma, through personal stories of well-known people. The President of the Panhellenic Federation, Magda Tsolaki, gave an online speech at the beginning of the month and on 21 September, an online press conference was given by five professors of neurology, covering all the new developments on Alzheimer’s/dementia. The press conference, as well as a press release on Alzheimer’s Disease International (ADI)’s World Alzheimer Report got good press coverage.

Some of the events that took place throughout Greece were:

**Athens:** The Athens Alzheimer Association organised a successful online seminar for caregivers and a face-to-face training for health professionals, as well as tests in an elderly care unit, “Nestor”, while “Karelleio Alzheimer Unit of Apostoli” carried out informative online seminars on Alzheimer’s disease.

**Thessaloniki:** Alzheimer Hellas organised a successful online seminar for caregivers and presented the “20-40” photo album in which 20 male and 20 female participants are photographed at the age of 40 each holding a photo of themselves at the age of 20. The theme of the event was “A transition through the 20 years of our lives. Preserving our memory, our identity and our image”. Proceeds will be used for Alzheimer’s research.

**Crete:** The Alzheimer’s Disease and Related Disorders Association of Heraklion Prefecture “ALLILENGII” made appearances on the island’s TV and radio stations, and launched a telephone chat-line for people affected by the disease.

**Patra:** The Frontizo association developed useful videos with advice on differed aspects of the disease that are available to the public.

**Larissa:** The Alzheimer’s Disease and Related Disorders Association of Larissa organised its 2nd Memory Walk.

**Chalkida:** The Alzheimer’s Disease and Related Disorders Association of Chalkida ran a weekly stand providing information to the public, where people could also schedule appointments for a memory test. An online seminar on stress management was also organised.

**Rhodes:** The Alzheimer’s Association Panakeia held an online webinar entitled “Let’s talk about dementia”, and carried out blood-pressure tests and memory tests in the city centre, to promote the importance of healthy living.
27 October: The Alzheimer Society of Ireland welcomes EUR 13 million dementia investment in Ireland as a positive step

The Alzheimer Society of Ireland (ASI) has welcomed the Government’s decision to invest EUR 13 million in dementia community supports in Budget 2021 as a welcome step in dealing with the sharp deterioration in health of both people with dementia and their family carers, caused by the COVID-19 pandemic.

In last year’s Budget, the door opened for The ASI and this year they have stepped through it. It is a great achievement for everyone at The ASI and for those they represent. This is a source of much-needed hope and is long overdue given the neglect of dementia as an issue by successive Governments.

The EUR 13 million investment includes four of The ASI’s Budget asks, which they particularly welcome:

- EUR 5 million investment for community dementia supports, including EUR 2.5 million for The ASI to further expand its day care in the home service and other community supports
- EUR 7 million to provide 250,000 hours of dementia appropriate home care
- funding of nearly EUR 1 million to recruit an additional 11 Dementia Advisors in 2021 (bringing the total to 30 in place by end of 2021)
- EUR 127,000 for the Dementia: Understand Together Community Activation programme with funding support for a National Coordinator and a Programme Support Officer.

Other highlights in Budget 2021 included:

- expansion of the Memory Technology Resource Room Network
- four new memory assessment and support services in Sligo, Mayo, Waterford and Wexford
- education for staff in the acute hospitals about dementia and delirium care
- implementation of the National Clinical Guideline on Appropriate Prescribing of Psychotropic Medication for non-cognitive symptoms in people with dementia
- Carers Support Grant increased by EUR 150 up to EUR 1,850
- Increase in the dependent relative tax credit from EUR 70 - EUR 245 for family carers.

On 28 September, Dr Sara Linse, Prof Oskar Hansson and colleagues published an article in Nature Structural & Molecular Biology, analysing the mechanism of action of four anti-amyloid antibodies that have been evaluated in clinical trials: aducanumab, gantenerumab, bapineuzumab and solanezumab. Based on the results of their laboratory analyses, each of these antibodies interferes with different aspects of the amyloid process. Amyloid plaque formation is a neuropathological feature of Alzheimer’s disease (AD), caused by the accumulation and aggregation of amyloid beta proteins in the brain. As part of this process, amyloid-beta proteins build up in

SCIENCE WATCH

28 September: Not all anti-amyloid antibodies are equal, according to a new study published in Nature Structural & Molecular Biology
a highly toxic oligomeric form, damaging brain cells and instigating other forms of neuropathology. The last two decades have seen the development of several anti-amyloid antibodies for clinical trials, designed to target amyloid aggregates for removal by the immune system. Of the four antibodies listed above, aducanumab has advanced the furthest in development, and is currently under evaluation at the US Food and Drug Administration – while clinical trials for bapineuzumab have been discontinued. To understand the differing clinical findings for these four antibodies, and to fully decipher their mechanisms of action, Dr Linse and colleagues performed kinetic analyses and quantitative binding measurements, assessing how each antibody interferes with the different stages of the amyloid accumulation process. Their results confirm that each antibody binds a different part of the amyloid protein, and has a differential affinity for monomeric and fibrillar (plaque) forms of amyloid-beta. Due to these differing affinities, the antibodies each interfere with different stages of the amyloid aggregation process, with varying efficacy. Among the four antibodies, aducanumab was identified as a highly effective inhibitor of the key molecular process that leads to amyloid oligomer formation.

https://www.nature.com/articles/s41594-020-0505-6

1 October: Bavarian Government launches open innovation contest

During September, in the context of World Alzheimer’s Day, the Bavarian Government launched an international Open Innovation Contest, aiming to encourage worldwide IT developers to create new digital tools for people living with dementia and their family carers. The closing date for applications is 15 November 2020. For more information and to apply: www.digidem-bayern.de/oiw

2 October: Bavarian Government launch innovation contest

Innovation Contest, aiming to encourage worldwide IT developers to create new digital tools for people living with dementia and their family carers. The closing date for applications is 15 November 2020. For more information and to apply: www.digidem-bayern.de/oiw

1 October: Athira Pharma initiates new Phase II/III study of ATH-1017 in mild to moderate AD

On 1 October, Athira Pharma, a clinical-stage biopharmaceutical company aiming to restore neuronal health in neurodegenerative diseases announced the initiation of the LIFT-AD Phase II/III study evaluating ATH-1017, a once-daily investigational drug for the treatment of mild-to-moderate Alzheimer’s disease (AD). The LIFT-AD study is a randomised, double-blind and placebo-controlled Phase II/III study evaluating the safety and efficacy of ATH-1017 in people with mild-to-moderate AD. The company expects to recruit approximately 300 research participants in the US and Australia.


2 October: US FDA to discuss aducanumab at November 6 meeting of the Peripheral and Central Nervous System Drugs Advisory Committee

In October 2019, Biogen and Eisai announced plans to pursue regulatory approval for aducanumab, a monoclonal antibody drug that targets aggregated amyloid-beta proteins in Alzheimer’s disease. On 7 August, the US Food and Drug Administration (FDA) accepted the biologics licence application for aducanumab for priority review. If approved, aducanumab would become the first disease-modifying therapy for Alzheimer’s disease (AD).

On 2 October this year, the FDA announced that aducanumab would be discussed at an upcoming meeting of the Peripheral and Central Nervous System Drugs Advisory Committee, to be held on 6 November. The meeting will be broadcast live online, via the FDA website. By 4 November, the FDA will share all background material and prerecorded presentations online. Interested parties can also submit questions, information or data, which will be considered by the FDA and, if submitted prior to October 23, forwarded to the committee.


6 October: EIP Pharma announces positive results from Phase II AscenD-LB trial of neflамapimod in mild to moderate dementia with Lewy Bodies

On 6 October, EIP Pharma Inc., a clinical stage therapeutics company focused on treatments for neurodegenerative diseases, announced that the AscenD-LB Phase II trial met its primary objective of improving cognition in people with mild-to-moderate dementia with Lewy Bodies. The AscenD-LB study is a randomised, double-blind and placebo-controlled trial evaluating the effect of neflамapimod in mild-to-moderate dementia with Lewy Bodies. 91 research participants were enrolled in the US and the Netherlands, they received neflамapimod or placebo with food for 16 weeks. Findings showed that neflамapimod was well tolerated. The AscenD-LB trial met its primary endpoint by demonstrating a
significant improvement on cognition as assessed by the Neuropsychological Test Battery (NTB). In addition, improvements were observed on multiple secondary clinical endpoints.

The company is planning to advance development of neflamapimod into Phase III and to present detailed results at the 13th Clinical Trials in Alzheimer’s Disease (CTAD) meeting in November 2020.

**9 October: Researchers investigate disease progression probabilities in dementia with Lewy bodies**

On 9 October, scientists from the USA published an article on the estimated transition probabilities in dementia with Lewy bodies (DLB) in the journal of Alzheimer Disease & Associated Disorders.

The team used data from longitudinal, cognitive evaluations to single out health states for DLB, they then estimated the probabilities of transition throughout DLB disease stages.

In their paper, the researchers reported that the estimated transition probabilities indicate that people with mild DLB over the age of 60 had a 54% probability of remaining mild, 30% probability of progressing to severe DLB, 4% probability of being institutionalised, and 12% probability of dying after 1 year.

**19 October: Large genome-wide association study identifies new Alzheimer’s disease risk genes in African-American individuals**

On 19 October, Dr Brian Kunkle and a team of coinvestigators from the Alzheimer’s Disease Genetics Consortium (ADGC) published an article in JAMA Neurology identifying several risk genes and pathways that occur more frequently in African-American individuals.

Well-established Alzheimer’s disease risk variants such as ApoE4 were identified through large-scale genomic studies that scan the genomes of hundreds or thousands of people to find genetic signatures associated with a particular trait or condition. However, many of these studies were conducted in predominantly non-Hispanic white populations, which means that the genetic variation specific to non-white, BAME groups may not have been adequately captured.

To address this issue, Dr Kunkle and colleagues performed a genome-wide association study (GWAS) of datasets from 8006 African-American individuals from the ADGC, including 2784 with Alzheimer’s disease (AD). Analysis of the genomes of these individuals confirmed the results of previous studies identifying APOE and ABCA7 as risk loci for AD, as well as variants in or near to the loci for TREM2 and AKAP9 – showing that there is some overlap in genetic risk between populations with different ethnic backgrounds. The researchers also identified several novel risk loci and pathways for AD specific to African-American individuals, although pathways such as immunity and lipid processing were shared across ethnic groups.

**20 October: Modelling study reveals that dementia risk reduction programmes could reduce dementia rates by 8.5%**

The recent Lancet Commission on dementia prevention, intervention and care identified modifiable risk factors that could account for almost 40% of dementia cases worldwide. Following on from this publication, a team of investigators led by Prof. Gill Livingston of University College London have shown that dementia risk reduction programmes that target lifestyle factors and treatable diseases could save over GBP 1.8 billion a year in England and reduce dementia rates by 8.5%.

Published in the Lancet Healthy Longevity journal on 20 October, the study reviewed scientific articles on interventions that target the modifiable risk factors from the Lancet Commission. Using a modelling approach, the researchers identified key dementia risk factors that could be feasibly be targeted by preventative interventions, and assessed the cost saving that could be obtained in England alone. By implementing public health programmes to treat hypertension, reduce smoking and improve hearing in mid-life, they estimated an annual cost saving of GBP 1.86bn, taking...
into account the cost of each intervention and factoring in the costs of social and health care.


21 October: Biogen submits Marketing Authorization Application to EMA for aducanumab

On 21 October, the biotechnology company Biogen reported its third quarter 2020 financial results. In the third quarter, Biogen continued to execute on its strategy and had a total revenue of USD 3,376 million. In this press release, it was also disclosed that Biogen submitted the Marketing Authorization Application (MAA) to the European Medicines Agency (EMA) for the review of aducanumab as a treatment for Alzheimer’s disease (AD). The application is subject to validation of whether the EMA accepts the application for review.

https://investors.biogen.com/static-files/9d0b52a8-22b5-4742-af9d-8138469ac89f

27 October: Alzheon announces the recruitment of the first participant with early AD in Phase II trial of ALZ-801

On 27 October, Alzheon Inc., a biopharmaceutical company focused on developing new medicines for people with Alzheimer’s disease (AD) and other neurological disorders announced the initiation of a Phase II study evaluating biomarker effects of ALZ-801 in early AD. Research participants with early AD who carry one or two copies of the ε4 allele of the apolipoprotein E (APOE4) gene will receive an oral tablet of ALZ-801, administered twice daily for two years. The Phase II study is aiming to access the effects of ALZ-801 on fluid and imaging biomarkers shown to be sensitive early markers of AD progression. The study will include a battery of biomarkers that reflect amyloid and tau pathology and neuronal injury. Recently, the company received a USD 47 million grant from the US National Institute on Aging (NIA) to advance a Phase III study of ALZ-801 in APOE4/4 homozygous people with early AD. The trial is expected to start in Q1 2021.

DEMENTIA IN SOCIETY

17 October: Delays in dementia diagnosis lead to effects of isolation being magnified

Carmel Geoghegan, who supports Helen Rochford-Brennan, former Chairperson and current member of the European Working Group of People with Dementia when she is travelling, spoke to Ireland’s largest farming news portal, Agriland, about how delays in dementia diagnosis may be magnifying the impact of isolation for many people. On 17 October, Agriland published an article on this subject.

You can read the full article, here:


30 October: Marketing authorisation application for Aducanumab accepted by European Medicines Agency

In its 21 October press release, Biogen disclosed that it had submitted a European Medicines Agency Marketing Authorisation Application (MAA) for Aducanumab, a monoclonal β-amyloid antibody that has been evaluated in several Phase 2 and 3 clinical trials on mild Alzheimer’s disease and mild cognitive impairment. On 30 October, Biogen and Eisai announced that the European Medicines Agency (EMA) had accepted the MAA for review following a standard timetable.

Aducanumab will now be evaluated by the EMA’s Committee for Medicinal Products for Human Use (CHMP), a process that can take up to 210 days. If the CHMP issues a favourable scientific opinion, the European Commission will then decide whether to grant a marketing authorization for the drug, which would be valid in all EU and EEA-EFTA states. Aducanumab is currently under priority review at the US Food and Drug Administration (FDA), with an FDA advisory committee meeting due to take place on 6 November.

https://bit.ly/3kZ0OUk

LIVING WITH DEMENTIA

26 October: Idalina Aguiar shares news about Portuguese patient associations united in a “Movimento Cuidar dos Cuidadores Informais”

Recently recognised by a legal statute that still doesn't acknowledge the struggle, challenges or difficulties they have to deal with, informal carers remain an invisible part of the caring process in Portugal. That’s why, with the support of Merck Portugal, the “Movimento Cuidar dos Cuidadores Informais” was recently launched.

An idea that we consider to be a success already, since in record time it has been able to bring together 24 different patient associations, all with the same goal: to care for those who take care of others. The main objective is to understand what remains to be done for informal carers in Portugal, improving their quality of life and, consequently, that of the patients.

The objectives of this new Movement include the implementation of a survey of the Portuguese population, to assess their perceptions of informal carers and also a survey of informal carers to identify their struggles and needs that have continuously been neglected. The implementation of a national communication and awareness plan and the launching of a communication campaign intend to give voice to these people. At the same time, the Movement wants to develop a public project that involves all stakeholders, including public services, and concentrate efforts in information campaigns, reviewing of the current legislation and development of a psychological support solution for the carers alongside training sessions and other types of online support.

This work is only just beginning, but the teamwork which has been developed until now reveals the level of commitment to the thousands of people who, every day, give up a little bit of themselves to take care of the ones they love.

It was a pleasure to see that all people with dementia and their carers, will be included in this Movement.

Idalina Aguiar is a Member of the European Working Group of People with Dementia and is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words to English.

https://movimentocuidadoresinformais.pt/

JOB OPPORTUNITIES

30 October: The University of Liverpool has two openings for PhDs in dementia care

The University of Liverpool is offering two new fully-funded PhD studentships in dementia care. Both students will join a growing team of dementia care researchers, clinicians, and service providers, all linked up together.


The other is focussing on “Primary care as a link between diagnosis and care in dementia and ethnic minority groups”: https://bit.ly/3jSSDr8

The closing date for applications is 9 November 2020 and studentships are open to UK and EU applicants alike.

30 October: The University of Worcester has an opening for a PhD in Dementia Studies

The University of Worcester has an opening for a fully-funded full-time PhD studentship on “The impact of a strategic regional approach to scaling up Meeting Centres for people affected by dementia”, starting in February 2021.

The area for investigation focusses on the factors affecting the regional take-up of Meeting Centres for people affected by dementia across a geographic region such as a local authority or city council. The programme will explore how best may these be tackled, and what lessons they have for the regional development of Meeting Centres in the United Kingdom.

The closing date for applications is 9 November 2020 and interviews will take place on 30 November 2020.

https://www.worcester.ac.uk/documents/Brooker-full-advert.pdf
30 October: VUmc is recruiting a senior researcher / data manager for the AMYPAD PNHS

VUmc is seeking a Senior Researcher / Data Manager to join its team in Amsterdam. The successful candidate will work in the AMYPAD Prognostic and Natural History Study (PNHS). As part of the European project, the VUmc acts as Sponsor or a multi-national multi-centre clinical trial, which has multiple Parent Cohorts as sources of recruitment and non-imaging data.

The position of data manager/steward/scientist involves a varied list of tasks, ranging from coordination of multiple teams involved in the process of obtaining, cleaning and integrating data, to actively exploring the data and planning/executing the main analyses in the study. You should have the following experience and qualities:

- A demonstrably driven organiser with academic background (PhD) preferably in the (bio)medical or neurosciences field;
- Previous experience in data management and stewardship;
- Strong analytical skills and statistical knowledge;
- Good eye for detail & ability to keep a good overview of the entire process;
- Comfortable with a multi-disciplinary and international team;
- Strong communication skills;
- Previous experience with amyloid PET and/or Alzheimer’s disease;
- Previous experience in data harmonization is a plus.

Contract duration is one year with possibility of extension for one additional year.

Candidates should send their application by 10 November 2020 for an intended start date of 1 December 2020.

Read more about the role and how to apply, here: https://www.werkenbijvumc.nl/vacatures/senior-researcher-data-manager/

1 October: European Academy of Neurology publishes infographic to support its guideline on medical management of dementia

Earlier this year, a European Academy of Neurology (EAN) guideline on medical management issues in dementia was published in the European Journal of Neurology. The guideline, co-authored by Jean Georges, Executive Director of Alzheimer Europe addressed important medical management issues in dementia including systematic medical follow-up, vascular risk factors, pain, use of antipsychotics, and epilepsy.

The EAN has now published an infographic to support the guideline. View the infographic: https://bit.ly/2GNiWS4

Read more about the guideline: https://bit.ly/3lyHPQf

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: Maria do Rósario Zincke dos Reis (Portugal). Members: Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (Ireland), Stefanie Becker (Switzerland), Marco Blom (Netherlands), Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Peltikäinen (Finland), Jesus Rodrigo (Spain), Karin Westerlund (Sweden).

Alzheimer Europe Staff:
Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Conference and Event Coordinator: Gwladys Guillery; 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 Tomasinii.
## AE CALENDAR 2020

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<tr>
<td>12 November</td>
<td>Meeting with PAVE</td>
<td>Jean</td>
</tr>
<tr>
<td>13 November</td>
<td>Meeting with Biogen</td>
<td>Jean</td>
</tr>
<tr>
<td>16 November</td>
<td>Association happy hour – EU CVB (Convention Bureau) Network introduction</td>
<td>Gwladys</td>
</tr>
<tr>
<td>16 November</td>
<td>Meeting of EMA PCWP on COVID-19</td>
<td>Angela</td>
</tr>
<tr>
<td>17 November</td>
<td>Information meeting with Nutricia</td>
<td>AE members and staff</td>
</tr>
<tr>
<td>18 November</td>
<td>IEEPO Virtual World Café</td>
<td>Ana</td>
</tr>
<tr>
<td>18 November</td>
<td>EWGPWD meeting</td>
<td>Ana and Dianne</td>
</tr>
<tr>
<td>24 November</td>
<td>Alzheimer’s Association Academy Workshop “Health data governance and sharing”</td>
<td>AE members and staff</td>
</tr>
</tbody>
</table>

## CONFERENCES

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>4-7 November</td>
<td>13th Clinical Trials on Alzheimer’s Disease (CTAD) <a href="https://www.ctad-alzheimer.com/">https://www.ctad-alzheimer.com/</a></td>
<td>Boston, US</td>
</tr>
<tr>
<td>16-18 November</td>
<td>2nd Krems Dementia Conference, <a href="https://www.donau-uni.ac.at/dementia-conference">www.donau-uni.ac.at/dementia-conference</a></td>
<td>Krems, Austria</td>
</tr>
<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="https://www.alzheimer-conference.gr">www.alzheimer-conference.gr</a></td>
<td>Thessaloniki, Greece</td>
</tr>
<tr>
<td>9-14 March 2021</td>
<td>AD/PD 2021 - The 15th International Conference on Alzheimer’s &amp; Parkinson’s Diseases, <a href="https://aat-adpd.kenes.com/">https://aat-adpd.kenes.com/</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>29 Nov-1 Dec 2021</td>
<td>31st Alzheimer Europe Conference</td>
<td>Bucharest, Romania</td>
</tr>
</tbody>
</table>
31st Alzheimer Europe Conference
Building bridges
Bucharest, Romania
29 November to 1 December 2020

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