

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



First of all, I would like to extend our most sincere condolences to Krister Westerlund's family, friends and colleagues, following his passing, on 16 May. For the past 19 years, Krister was the Chair of Alzheimer

Sweden and spent a total of 25 years working in the field of dementia advocacy. He was a dear friend and colleague and we will miss him enormously.

At the very start of May, the United Nations (UN) published a Policy Brief on the impact of COVID-19 on older persons, calling for actions that respect their rights and dignity. The brief has been very well received by Member States, with 140 of them issuing statements of support. The UN has also issued another COVID-19 related Policy Brief, on the need for action on mental health, in which governments, civil society, health authorities and others are urged to address the mental health dimension of this pandemic.

At the European level, there has been some very positive news this month, with President Ursula von der Leyen announcing the European Commission's commitment to a specific health programme, as well as indicating further support for Horizon Europe, as part of the next Multi-annual Financial Framework (MFF) for 2021-2027. The Commission has set out its vision of this future EU Health Programme, EU4Health (not associated to the EU4Health campaign), following the announcement of EUR 9.4 billion of funding in its budget proposal.

On the subject of the (not associated) EU4Health campaign, Alzheimer Europe has joined with other European health and patient-focused NGOs this month, to support this campaign, calling for health to be made a policy priority at an EU level.

Good news on the research front, as Lilly gains FDA approval for its flortaucipir PET tracer. Flortaucipir has been approved for assessing the quantity, localisation and extent of Tau neurofibrillary tangles in the brains of people with suspected Alzheimer's disease.

Supporting research is an important aspect of our work and we continue to develop our Clinical Trials Watch online resource, providing accessible information on Phase II and III dementia and AD drug trials, currently recruiting participants in at least one European country. Two new trials have just been added.

In relation to the COVID-19 pandemic and the impact it has had on our ability to hold face-to-face events, I would like to announce that the 30th Alzheimer Europe Conference #30AEC, which was planned to take place in Bucharest, will now be a virtual conference, under the banner "Dementia in a changing world". This decision was taken by our Board on 19 May. It has also been decided that, rather than cancelling it, the Bucharest conference "Building Bridges" will move to 29 November to 1 December 2021. Keep an eye on our website and social media accounts for more information about registering for the 2020 virtual conference, coming soon.

Jean Georges
Executive Director

In Memoriam Krister Westerlund, 1944 - 2020



We were very sad to learn of the passing of our dear friend and colleague, Krister Westerlund, who died suddenly from heart failure on 16 May 2020 at the age of 75. He was at home with his wife of 54 years, Kristina.

Krister, a former politician, was Chairman of Alzheimer Sverige (Alzheimer Sweden) for the past 19 years and spent a total of 25 years working in the field of dementia advocacy, speaking up for the rights of people living with dementia and their carers, and supporting research. His father, mother-in-law and father-in-law all passed away from dementia and he felt his work with Alzheimer Sweden was his “calling” in life.

Krister Westerlund is survived by his wife Kristina, with whom he has worked side-by-side at Alzheimer Sverige; by two daughters, one of whom, Karin, also works at Alzheimer Sverige and is an Alzheimer Europe Board member; by two grandchildren and by many close friends in the wider dementia community.

A firm believer in working together for better outcomes for people with dementia and carers both in Sweden and across Europe, he will be remembered as an incredible advocate, as well as for his warmth, his sense of humour and his personable approach. We at Alzheimer Europe will sorely miss him. Our heartfelt condolences go out to Kristina, Karin and to all of Krister’s family, friends and colleagues.

COVID-19 SITUATION

23 April: INTERDEM network is publishing regular COVID 19 blog posts



The INTERDEM network decided to publish a special COVID19 blog on its website twice a week, starting from 23 April.

The first post was written by person with dementia, who described how the current situation is affecting him. Read it, here: <http://interdem.org/?p=7279>

1 May: The United Nations publishes a Policy Brief on the impact of COVID-19 on older persons, calling for actions that respect the rights and dignity of older people



On 1 May, the United Nations (UN) Secretary-General, António Guterres, launched the

UN Policy Brief on the impact of COVID-19 on older persons. The goal of this policy brief is to provide analyses and recommendations that address the particular challenges facing older persons during the COVID-19 pandemic. These challenges include (among others), the higher COVID-19 fatality rate for older people, the risk of age discrimination in decisions on medical care, vulnerabilities due to living in long-term care facilities, and the disproportionate impact of physical distancing rules on older people who are socially isolated.

In the first part of its Policy Brief, the UN identifies 4 key priorities for action. Firstly, the response to COVID-19 must respect the rights and dignity of older people, in particular the

right to health. Secondly, the UN calls for improved social support and community solidarity during physical distancing, and increasing the access of older persons to digital technologies. Thirdly, the specific needs of older people must be taken into account in all socio-economic and humanitarian responses to COVID-19, particularly in developing countries and those in humanitarian crises. Fourthly, the UN calls on society to tackle the problem of ageism and stigma against older persons head-on, ensuring that their societal contribution, past and present, is valued and that their voices are heard.

The second part of the UN Policy Brief provides more in-depth analysis and specific recommendations on the four priorities for action, with dedicated sections on 1) the impact on health, rights and long-term care services for older persons; 2) the effects of physical distancing and stigma; 3) Integrating a focus on older persons in the overall socio-economic and humanitarian responses to COVID-19; and 4) Harnessing knowledge and data, sharing good practice and expanding participation by older people. The Policy Brief summary underlines the importance of addressing the disproportionate threat that COVID-19 poses to the health, lives, rights and wellbeing of older persons. Only in this way can truly inclusive, sustainable and age-friendly societies be rebuilt. The UN Policy Brief can be found here:

https://www.un.org/sites/un2.un.org/files/un_policy_brief_on_covid-19_and_older_persons_1_may_2020.pdf

7 May: Alzheimer’s Society issues response to UK Prime Minister

The Alzheimer’s Society has responded to UK Prime Minister, Boris Johnson, following comments he made during the weekly session of Prime Ministers Questions, during



which it was claimed that the situation in care homes, in relation to COVID-19, was improving.

Gavin Terry, Head of Policy at the Alzheimer’s Society highlighted that they had not seen any evidence to suggest that deaths in care homes were slowing down, and that any other implication would be dangerously complacent. Speaking further, he stated: “In the past month, we know that the number of people who have died in care homes is twice the average; in the last week alone we saw the death rate rise by 30%. And it is not only deaths due to coronavirus that we fear - we are concerned there will be a sharp rise in deaths due to dementia, not least because of the impact of isolation, when the full figures are known.

It is a terribly worrying time for everyone with dementia and their families, and we hear heart-breaking stories every day via our Dementia Connect support line from people anxious about the safety of their loved ones in care homes. Ministers have made welcome commitments to keep people safe but there can absolutely be no let up. The dreadful cost of not giving the care sector equal attention as the NHS is clear for all to see. Care staff and residents must get the regular testing they need, and adequate personal protective equipment must be available to every home until this virus is really under control.

The Government must also consider how to manage dementia more effectively in the event of a lengthy lockdown, with measures to support safe social contact. Without intervention, people with dementia will continue to die needlessly in these horrifying numbers.”

7 May: Patients’ concerns with COVID19 must be urgently addressed and voiced to Member States, says EU Commissioner Kyriakides



On 7 May, the European Patients’ Forum (EPF) met virtually with EU Commissioner for Health and Food Safety Stella Kyriakides (pictured) to discuss challenges faced by patients during COVID19.

This much needed meeting stemmed from the Commissioner’s concern that “no chronic patients should be left behind” during these unprecedented times, and in the long term that “patients need to be at the centre of the decision-making process”, which EPF strongly welcomed.

The meeting began with some opening remarks from the Commissioner, who briefly outlined how the Commission has been responding to the pandemic, highlighting weekly calls with national ministries of health, sharing guidelines and coordinating joint procurements of protective gear and ventilators.

EPF President Marco Greco highlighted that there has been little or no patient involvement in COVID19 decision-making processes. He mentioned that EPF has also strengthened its existing cooperation with the EMA, notably related to access to medicines and shortages. He then highlighted the key focus areas where the EPF has been targeting its work, namely ensuring continued access to timely treatment and care and the involvement of patients in strategies for de-confinement. Finally, he provided details on EPF’s presence and actions since the beginning of the pandemic, which included:

- issuing to-date four [statements](#),
- the creation of an online [COVID-19 Resource Point](#) containing reliable information (credible figures, research articles and reports on COVID-19 and its effects on the patient and medical community),
- showcasing our [members’ initiatives and other best practices](#),
- gathering [testimonials from patients](#) across the community.

Read EPF’s full meeting report, here:

<https://www.eu-patient.eu/News/News/patients-concerns-covid19-eu-commissioner-kyriakides/>

7 May: Activities delivered at home by family carers can have positive effects on cognitive function in people with dementia during social isolation

On 7 May, Mari Lloyd-Williams, Caroline Mogan, Sarah Russell and Karen Harrison-Dening published a brief report on behalf of the Centre for Evidence-Based Medicine at



Oxford University, summarising evidence for the beneficial effects of activities delivered at home on cognitive function in people with dementia.

The report provided an overview of studies investigating the cognitive and psychological benefits of reminiscence therapy, cognitive stimulation therapy, music-based interventions, art therapy and meaningful activities for people with dementia.

Among other findings, these studies identified a reduction in depression for reminiscence therapy, associations between listening to music and improved performance in memory tests, and improved neuropsychiatric symptoms following art therapy.

The report identified some limitations to the studies, notably the small sample sizes and paucity of evidence for home-based interventions, as opposed to interventions delivered in the group home setting. However, the overall conclusion was that engaging people with dementia in activities they find enjoyable can help provide a sense of purpose whilst in social isolation. Moreover, the fact that many of these interventions are not technology-based may have practical advantages during the COVID-19 pandemic.

The rapid review can be found here: <https://bit.ly/2ZS7L1y>

11 May: Open Letter in HRB Open Research calls for person-centred care of people with dementia during the COVID-19 pandemic



On 11 May, the journal HRB Open Research published an Open Letter from Prof. Eamon O'Shea (pictured) of the National University of Ireland Galway, in which he argues that we need to assert the personhood of people with dementia during the COVID-19 pandemic.

In his Open Letter, Prof. O'Shea draws attention to the particular vulnerability of people over 70 to COVID-19, which has led to the creation of specific cocooning measures by the Irish government. These measures are aimed at keeping them apart from their families and local community, and are particularly hard on the 55,266 people with dementia in Ireland, 34,818 of whom are estimated to be living in the community. Whilst acknowledging the efforts of the Irish government, Health Service Executive and residential care units to protect nursing home residents from COVID-19, he calls for a person-centred approach to provide meaningful support for people with dementia in the care home setting. This includes offering sensory stimulation tailored to the individual, and ensuring that people remain connected to their loved ones whilst maintaining social distancing. To meet the needs of people with dementia who live with family carers in their own homes, Prof. O'Shea suggests that national television and radio networks could create public broadcasting initiatives that encourage physical activity, provide information and reminiscence-based therapy. He applauds the work of organisations such as the Alzheimer's Society of

Ireland (ASI) in supporting people with dementia and their carers.

Prof. O'Shea concludes the Open Letter by calling for all to fully recognise the inherent personhood of people with dementia, responding to their need for additional support and connection during the COVID-19 pandemic, stating "We need a strong and unbreakable social bond that we will not ration available resources by age, condition or income, but will continue to act on the basis of carefully assessed individual need and circumstances". The Open Letter can be accessed here:

<https://hrbopenresearch.org/articles/3-15/v1#referee-response-27326>

12 May: 140 Member States issue statement of support for the United Nations Policy Brief on the impact of COVID-19 on older persons



On 12 May, Member States of the United Nations (UN) issued a statement in support of the UN Policy Brief on the impact of COVID-19 on older persons, with 140 co-signatories including all EU27 countries, the UK and Norway. The Policy Brief was launched on 1 May by the UN Secretary-General, António Guterres, calling for actions that respect the rights and dignity of older people.

In the statement, Member States expressed their concern regarding the devastating impact of the COVID-19 pandemic on the lives of older persons, who are at significantly higher risk of mortality and severe disease. They noted the potential negative impacts of certain protective measures on older persons, exacerbating vulnerabilities and increasing the risk of discrimination, violence and neglect. They recognized the importance of empowering older people to remain valuable contributors to society, via measures that are inclusive of their specific needs and protect their social and economic wellbeing as equal beneficiaries compared to others. The Member States commit to fully promoting and respecting the dignity and rights of older persons, by working together to strengthen global and national responses that address the needs of these persons, thereby fostering more inclusive, equitable and age-friendly societies. The Statement of Support for the UN Policy Brief can be found here: <https://bit.ly/3gEJrpR>

12 May: As Spain emerges from its COVID-19 lockdown, CEAFA calls for actions to improve the lives of people with dementia



On 12 May, the Confederación Española de Alzheimer (CEAFA) issued a statement calling for actions to improve the lives of people with dementia as Spain emerges from its COVID-19 lockdown period.

In the statement, CEAFA draws attention to the fact that due to COVID-19, over 200,000 people living with dementia are no longer receiving the specialised services and care provided by the 315 member associations of CEAFA. The activities of Spanish Alzheimer’s associations have been severely curtailed due to the COVID-19 lockdown, closing day care and respite centres and leading to the furloughing of more than 80% of the 4,664 personnel employed by these not-for-profit associations.

CEAFA highlights the negative effects of social isolation on people with dementia, including disruption of routines, lack of access to support systems and reduced clinical care, which has led to dementia progression and deterioration for some. This also has negative repercussions for family carers, who cannot access the respite or home care services which would normally support their caregiving activities.

Consequently, CEAFA calls for the reopening of day care and respite centres as a first priority for the national and municipal authorities in the post-lockdown period, with appropriate provision of personal protective equipment (PPE), COVID-19 tests for personnel and comprehensive disinfection of facilities and transport. In addition, CEAFA calls for home care services to be reinstated and/or continued, highlighting the value of providing therapeutic services to people with dementia in their own homes. Reopening day care and respite centres and resuming home care services will also benefit family carers as they resume their professional activities. Finally, CEAFA ask that support be provided to help furloughed staff members to progressively return to work, gradually building up the operational capacities of the Alzheimer’s associations which support over 200,000 people living with dementia in Spain.

The full statement can be accessed here:

<https://www.ceafa.es/es/que-comunicamos/noticias/comunicado-la-confederacion-espanola-de-alzheimer-ante-la-nueva-normalidad>

13 May: António Guterres launches the United Nations Policy Brief on COVID-19 and the need for action on mental health

On 13 May, the United Nations (UN) Secretary-General, António Guterres, launched the UN Policy Brief on COVID-19 and the need for action on mental health, in which he urges governments, civil society, health authorities and others to urgently address the mental health dimension of the COVID-19 pandemic.



The Policy Brief describes the negative impact of COVID-19 on mental health, highlighting the associated increase in anxiety, psychological distress, emotional difficulties and depression brought about by social distancing, fears about COVID-19 and the exacerbation of work-related stressors for frontline staff.

Providing an overview of recent epidemiological and psychosocial research on COVID-19, the Policy Brief discusses the detrimental impact of COVID-19 on mental health and mental health services. Among other aspects, these include the increased risk of cognitive decline and dementia in older adults due to social isolation and reduced physical activity, and the closure of support services in the community or healthcare setting.

The Policy Brief also identifies older adults and people with pre-existing conditions as a specific population with increased mental health problems during the COVID-19 pandemic, as a consequence of their elevated risk of loneliness, social isolation and stigma.

In its Policy Brief, the UN makes recommendations around three key pillars:

- Firstly, they call for a whole-of-society approach to promote, protect and care for mental health, with mental health and psychosocial considerations taken into account when countries devise their responses to COVID-19.
- Secondly, they ask that there be widespread availability of emergency mental health and psychosocial support during and after the pandemic, including community actions, health and social care services and the provision of remote mental health support services for those in need.
- Finally, the UN calls for increased investment in mental health services, particularly emphasising the need to build up community-based services that are accessible, affordable and sustainable in the long term, by involving people with lived experience in the design, implementation and monitoring of these services.

The UN Policy Brief can be found here:

https://www.un.org/sites/un2.un.org/files/un_policy_brief-covid_and_mental_health_final.pdf

18 May: The Alzheimer’s Society calls for better protection against COVID-19 for people with dementia

On 18 May, the Alzheimer’s Society published a statement highlighting new data which shows that dementia is the most common pre-existing condition among UK deaths involving COVID-19, issuing a call for improved support of people with dementia in care homes and in the community.

In their statement, the Alzheimer’s Society draw attention to the recently-published UK Office of National Statistics figures which show that 25.3% of the 33,841 people who died with COVID-19 in March and April in England and Wales had dementia. Alarmingly, this means that dementia is the main underlying condition for COVID-19 deaths, although the link between dementia and COVID-19 has yet to be fully understood.

The Alzheimer’s Society also emphasised the importance of regular social contact with loved ones for people with dementia, stating that social distancing and shielding measures could cause a more rapid deterioration of dementia, perhaps accounting for the sharp increase in deaths due to dementia (83% higher than usual in England) during April 2020.

Issuing a call for Government to invest in measures that guarantee the support and safety of people with dementia, the Alzheimer’s Society ask that Ministers look at long-term support systems that help people with dementia remain in contact with their loved ones. The statement can be found here:

<https://bit.ly/3eFnCot>

20 May: Alzheimer Society of Finland examines impact of COVID 19 measures on its local branches and service-users

In Finland, the COVID outbreak started in March. People started working from home, care homes closed their doors to visitors and all individuals over 70 were asked to avoid contact with others. Local associations and “Muistiluotsi” expert and support centres of the Alzheimer Society of Finland cancelled all activities, events and peer support groups, temporarily. This meant a significant change for the people with memory-related diseases and their families. The Society wanted to know more and sent a survey to local associations. Responses showed that the situation is difficult in many ways:

Since visits to care homes have not been allowed, people are missing their loved ones and are worried about them. People with memory-related diseases living at home and their families are having trouble as well. Carers do not get any free time because all activities for the people needing their support are cancelled, so they are getting tired. People with memory-related diseases living alone are cut off from the world and are lonely. There have, however, been some positive sides as well. As soon as all activities were cancelled, local professionals started thinking about new ways to reach their members. Peer

support groups were organised virtually, using a variety of online platforms. These meetings were well-received. Some associations have been making videos and publishing them on YouTube, encouraging people to sing or to exercise. Others have been calling their members and asking how they are doing, as well as sending letters and work packages to help them remain active.

The “Muistineuvo” memory advice phone support answers questions regarding memory-related diseases. Before the outbreak, the phone-line was open 3 days a week. This has now been extended to 5 days a week, to ensure more coverage and support at this difficult time.



“Despite all the challenges COVID-19 has brought to both people with memory-diseases and their carers and our organisation, I feel happy and proud, when I see the agility and innovativeness of our professionals. They really are doing their best to help our clients in these difficult times”, said Katariina Suomu (pictured), Executive Director of the Alzheimer Society of Finland.

22 May: Alzheimer Athens ensures continuity of care and support for people with dementia during COVID-19

During the COVID-19 pandemic, Greece has been on total lock down. The Greek government has taken certain action, however, to ensure that people with dementia and their families continue to have access to counselling, support and remote services such as psychosocial interventions, electronic prescribing etc.



Alzheimer Athens has advised people with dementia to stay as active as possible while remaining in confinement. To achieve this goal, the association has provided physical and cognitive exercises and daily tips, through its website and social media activity. The Chair of Alzheimer Athens, Dr Paraskevi Sakka, a neurologist/psychiatrist, has developed and circulated guidelines for people with dementia, on how to handle this difficult situation in the best possible way.

Day care centres continue to operate daily, from 9.00-19.00, with a reduced staff offering counselling sessions, medical

advice, information and support sessions via telephone and videoconferences.

Alzheimer Athens also operates a national 24-hour telephone support helpline (1110), in collaboration with the administration of the region of Attica. This helpline is staffed by the experienced health professionals of Alzheimer Athens.

22 May: ISARIC study published in the BMJ identifies risk factors for severe COVID-19 in hospitalised patients



On 22 May, the UK investigators of the International Severe Acute Respiratory and emerging Infections Consortium (ISARIC) published the first results of their prospective cohort study of patients in hospital with COVID-19.

COVID-19, the viral disease caused by the novel SARS-CoV-2 coronavirus, was declared a pandemic by the World Health Organisation (WHO) in early March. As of 23 May, there have been 5,105,881 confirmed COVID-19 cases worldwide, including 333,446 deaths. The ISARIC clinical characterisation protocol (CCP) was created in coordination with the WHO in the wake of the 2012 MERS epidemic, providing a standardised clinical protocol that enables data and biological samples to be rapidly collected in a globally-harmonised manner. The UK ISARIC CCP was activated on 17 January 2020, enabling UK patients admitted to hospital with COVID-19 to be enrolled. In their BMJ article, the investigators of the ISARIC CCP-UK study characterise the clinical features of hospital patients with COVID-19 up to 19 April 2020. They also describe patient outcomes and risk factors associated with COVID-19 mortality in the hospital setting.

Between January and 19 April 2020, a total of 20,133 hospital patients with COVID-19 were enrolled into the ISARIC CCP-UK study. The median age of patients was 73 years, with a range of 0 to 104 years. More men than women were admitted to hospital (59.9% vs 40.1%) and the most common COVID-19 symptoms were cough, fever and shortness of breath. The most frequently-occurring comorbidities upon admission were chronic cardiac disease (30.9%), diabetes (20.7%), chronic pulmonary disease (17.7%) and chronic kidney disease (16.2%). 13.6% of COVID-19 patients in the ISARIC CCP-UK study had a dementia diagnosis.

Overall, 41% of patients were discharged alive, 26% died and 34% continue to receive hospital care. The median age of people who died in hospital from COVID-19 was 80 years, and only 11% of these individuals had no documented comorbidity. Using a multivariate Cox proportional hazards model, the ISARIC CCP-UK investigators identified risk factors associated with COVID-19 mortality in their hospital population, although the investigators noted that their infographic based on this information should not be used for predictive tools in clinical practice, or to inform individual treatment decisions. Age on admission was by far the

strongest predictor of mortality in hospital, after adjusting for other factors. Female sex was associated with a ~20% reduction in COVID-19 mortality, while several major cardiac, pulmonary, kidney and metabolic comorbidities were associated with increased risk of mortality. Of these, chronic kidney disease was associated with a 28% increased risk of COVID-19 mortality, while obesity and dementia were associated with a ~33% and 40% increased risk, respectively.

The original BMJ article:

<https://www.bmj.com/content/bmj/369/bmj.m1985.full.pdf>

The ISARIC4C infographic on COVID-19 outcomes: <https://isaric4c.net/risk>

Further information on ISARIC: <https://isaric.tghn.org/>

22 May: The Alzheimer Society of Ireland introduces a new therapy service during COVID-19



The Alzheimer Society of Ireland (ASI) is pleased to launch a new service called Alternative Activity Therapy for people living with dementia and their family carers during the COVID-19 crisis. Due to the necessary temporary closure of its day services, The ASI wanted to extend its reachability to those who normally avail of day care services, nationally.

People living with dementia and their family carers can now access this service by engaging in Activity Therapy Calls and Social Engagement Calls, on the phone, Monday to Friday. The ASI is also providing therapeutic, meaningful, monthly Activity Packs for people living with dementia and their families. These can be used in their own homes. Additionally, the next phase of the project will soon provide online Alzheimer's Cafes, Social Clubs, Support Groups and activities.

The project team comprises Mary Bardin, Project Manager; Jamie Sherlock Walsh, Social Activities Manager; and The ASI's local community Activities Support Leads, who have been internally redeployed during COVID-19 to provide this nationwide service. The aim is that people living with dementia and their family carers who avail of this service will enjoy this interaction with their local community Activities Support Leads and that this interaction will provide stimulation, social connectedness and fun for everyone.

Watch this video for more information:

<https://bit.ly/2TWSHfj>

22 May: Alzheimer Hellas keeps up its work supporting people with dementia during the COVID-19 crisis



In these difficult days of COVID-19, Greece is trying to cope with the pandemic by staying safe at home, while at the same time continuing the support of vulnerable groups.

In an attempt to retain the activities of the daycare centres for older people with MCI or dementia as well as for their caregivers, the Greek Association of

Alzheimer Disease and Related Disorders (Alzheimer Hellas) in Thessaloniki continues to offer its services to these groups, using alternative methods.

The staff of Alzheimer Hellas offers cognitive training, physical exercises and IT learning via remote education software. The physical trainer has designed an alternative programme of cognitive-physical training for people with MCI and dementia. The staff member in charge of IT training is introducing alternative methods and different virtual platforms for the purpose of maintaining good communication during coronavirus restrictions. Experienced psychologists send cognitive tasks via email, to people with MCI and dementia, in order to maintain daily training routines. This is also supported with a weekly telephone call.

A high priority for Alzheimer Hellas is to continue to ensure solid support for caregivers, especially during this period of confinement, when some of the behavioural issues some people with dementia may have, can be increased in frequency and intensity. Online psychological support and psycho-education are provided for caregivers. Supportive group therapy is also provided, and there is weekly telephone communication and support for those caregivers who are not comfortable with using the internet. An email with educational and counselling material is provided to all caregivers on a weekly basis. This includes links to audio-visual relaxation sessions and advice for coping with anxiety. Doctors are available to provide medical advice and they can electronically prescribe any required medications.

The health professionals at Alzheimer Athens have created helpful guidelines on the specific needs of their patients and have put together some frequently asked questions (FAQs). The guidelines can be seen, here:

http://www.alzheimer-hellas.gr/images/Periodiko/Kopwvoioç_kaì_Àvoia.pdf

Finally, a 24/7 helpline is also available in order to meet the needs of caregivers and people with dementia alike.

Neurologists, psychologists and social workers are just a phone-call away, aiming to cope with urgent problems related to COVID-19.



ALZHEIMER EUROPE

7 May: Alzheimer Europe’s ethics working group holds first meeting

On 7 May, Alzheimer Europe held its first Zoom meeting of the ethics working group, which will be looking at the issue of legal capacity.

The planned full day meeting had to be cancelled because of the current situation with the corona virus pandemic. There was, nevertheless a good turnout out with experts from Germany, Luxembourg, United Kingdom, Netherlands and Portugal.

The group decided to aim for two reports. One will contain detailed background information about the topic, covering various ethical issues related to legal capacity (e.g. healthcare decision making, restrictions of freedom, guardianship measures, marriage, voting and making a will) and this will be based on discussions within the group and relevant peer-reviewed and grey literature.

The other will be a more targeted document concluding some of the key positions of the working group and will provide some practical guidance, promote ethical reflection and contain some recommendations.

These documents should be available in December 2020.

19 May: AE adds two new trials to its Clinical Trials Watch



Alzheimer Europe continues to develop and improve its Clinical Trials Watch (CTW), an innovative online resource providing up-to-date accessible information on clinical trials currently recruiting participants in at least one European country. The service provides information on phase II and III clinical trials that are investigating drugs for the prevention and treatment of dementia and/or Alzheimer’s disease. In May 2020, two new trials have been added to the service:

- The purpose of the T-817MA Phase II study is to evaluate the efficacy and safety of T-817MA (Edonerpic) in people with mild cognitive impairment due to Alzheimer’s disease or mild Alzheimer’s disease

- The Phase III LUCIDITY study is to determine the safety and efficacy of TRx0237 (hydromethylthionine) in people with mild or mild to moderate Alzheimer's disease. Further information about the CTW is available on:

<http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch>

27 May: 30th Alzheimer Europe Conference #30AEC goes virtual!



Alzheimer Europe's 30th Annual Conference #30AEC, which was planned to take place in Bucharest, will now be a virtual conference, under the banner "Dementia in a changing world". This decision was taken by the Alzheimer Europe Board at an online meeting on 19 May 2020, in light of the continuing COVID-19 pandemic. It was also decided by the Board that,

rather than cancelling it, the Bucharest conference "Building Bridges" would move to 29 November to 1 December 2021. This has the knock-on effect of moving Alzheimer Europe's scheduled Helsinki 2021 Conference up to 17-19 October 2022.

All delegates who have already registered for the Bucharest conference will be reimbursed by Alzheimer Europe.

The deadline for abstract submissions for #30AEC was in mid-May and Alzheimer Europe is pleased to have received 271 abstracts. These will now be evaluated and submitters informed by mid-June, whether or not they have been successful. At that stage, additional information will be provided as to the format and cost of the virtual conference. In the meantime, Alzheimer Europe is working to identify the best virtual conference platform to meet the needs of delegates and speakers alike.

More details about the 2020 virtual conference, which will still take place on the scheduled dates of 20-22 October, will be available on Alzheimer Europe's website as soon as matters are finalised:

<https://www.alzheimer-europe.org/Conferences>



Alzheimer Europe networking

- On 4-5 May, Owen and Angela attended EPF consultation webinars on Digital Health.
- On 5 May, Angela attended a Health First Europe webinar on AI in personalised medicine.
- On 7 May, Dianne and Jean attended the Alzheimer Europe ethics working group meeting on legal capacity (online).
- On 7 May, Owen attended an online meeting of the Core Group of the EU4Health campaign.
- On 8 May, Owen attended a webinar on disability assessment hosted by the EDF.
- On 11 May, Jean attended a virtual meeting of the European Academy of Neurology and the European Alzheimer's Disease Consortium.
- On 12 May, Jean attended a virtual meeting of the Health Advisory Board of GSK.
- On 12 May, Ana attended the PARADIGM project's virtual workshops on PE in the CEE region.
- On 13 May, Angela attended a meeting of the DataSavesLives initiative (online).
- On 14 May, Angela attended a VirtualBrainCloud webinar on data sharing.
- On 14 May, Jean attended the AD/ADRD Funder Consortium meeting convened by the US Alzheimer's Association (online).
- On 14 May, Dianne attended a virtual meeting of the EPAD ethics work package.
- On 15 May, Jean attended the global AD Advocacy Steering Committee meeting convened by Biogen (online).
- On 18 May, Jean attended a Scientific Advisory Board meeting of Roche (online).
- On 18 May, Angela attended a NEURONET Sustainability Working Group meeting (online).
- On 19 May, Jean attended an EFPIA webinar on clinical trials at the time of COVID-19.
- On 19 May, the Alzheimer Europe Board had a virtual meeting.
- On 20 May, Owen attended an online meeting of the European Non-Governmental Organisations (NGOs) hosted by the EDF.
- On 23 May, Jean attended the Dementia Panel of the European Academy of Neurology (online).
- On 23 May, Jean attended a webinar of IPA and INTERDEM on COVID-19 and dementia.

From 23 May to 26 May, Jean attended the virtual conference of the European Academy of Neurology.
 On 25 May, Jean attended a Scientific Advisory Board meeting of Roche (online).
 On 25 May Ana attended the SoCaTel Advisory Board meeting (online).
 On 26 May, Jean attended the WP Leaders meeting of the PRODEMOS project (online).
 On 27 May, Owen attended a webinar on staff mental health during a pandemic hosted by MHE/EPHA.
 On 28 May, Cindy attended a virtual meeting of the EURO-FINGERS project to discuss the development of the project's website.



EU PROJECTS

29 April: Martin Rossor speaks to AD Detect & Prevent about challenges posed by Alzheimer's disease and about using digital health technologies for early detection



On 29 April, the AD Detect & Prevent project published an interview with Professor Martin Rossor, NIHR National Director for Dementia Research and Principal Research Associate at the UCL Queen Square Institute of Neurology.

In the interview, which was published on the project website, Prof. Rossor shares his perspective on the impact of Alzheimer's disease (AD) and dementia on society, and details some of the challenges scientists are facing when trying to detect AD before clear symptoms emerge. You can read the interview, here:

<https://addp.eu/interview/>

29 April: The VirtualBrainCloud project holds its General Assembly and Technical Coordination meetings



On 29 April, the H2020-funded VirtualBrainCloud project (TVB_Cloud) held its General Assembly meeting online, which was followed by a Technical Coordination meeting on 30 April. The TVB_Cloud meetings were chaired by Prof. Petra Ritter, who is leading the project, and was attended by over 50 project participants, including representatives from the 17 institutions and organisations that make up the TVB_Cloud consortium.

Jean Georges (Executive Director) and Angela Bradshaw (Project Officer) represented Alzheimer Europe at the meetings. Several members of the newly-established Technical Advisory Board (TAB) also participated, including Magali Haas

of Cohen Veterans Bioscience, Per Oster of EOSC-Hub and Thomas Schulthess of the Swiss National Supercomputing Centre.

The primary objective of TVB_Cloud is to create a decision support system for clinicians, formed around a cloud platform for personalised brain simulations based on high-quality, multidisciplinary clinical data, encompassing EEG and MRI scans, -omics and blood-based biomarker data. This decision support system will enhance the early diagnosis, prognosis and personalised treatment of neurodegenerative diseases, with an initial focus on Alzheimer's disease (AD).

During the TVB_Cloud General Assembly (GA) meeting, alongside updates describing the legal and ethical work on patient privacy TVB_Cloud work package leaders provided summaries of ongoing activities on data processing and FAIRification, the construction of AD disease progression models, computational aspects of personalised, multiscale brain simulations, and the software development that underlies these activities. Data protection is of paramount importance to TVB_Cloud, so the final part of the GA meeting was devoted to discussions on the development of a Trusted Cloud framework for TVB_Cloud, including technical and infrastructure requirements and security aspects.

On 30 April, the inaugural TVB_Cloud Technical Coordination meeting started with a question: how can we facilitate data interoperability, whilst retaining the richness (and capturing the heterogeneity) of clinical datasets? During this meeting, attendees were introduced to Indoc Research, a Canadian not-for-profit company which has been subcontracted to provide technical coordination services for TVB_Cloud. Representatives from Indoc and Codemart (an SME partner on the TVB_Cloud project) provided an update on the methodologies and processes that are being used to develop the TVB_Cloud platform. These presentations were followed by a Q&A session, as well as discussions on how best to reach out to policymakers, regulators and other key stakeholder groups. Drawing the meetings to a close, Prof. Ritter emphasised the importance of finding effective ways to rapidly and securely re-use health data, facilitating the development of platforms such as TVB_Cloud for the benefit of patients and citizens.

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



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5 May: The Horizon2020-funded PRIME project launches its website



The Prevention and Remediation of Insulin Multimorbidity in Europe (PRIME) project, which kicked off in January this year, has recently launched its website.

The goal of the 4-year PRIME project is to understand the insulin-related mechanisms that underlie metabolic disorders such as type 2 diabetes, as well as brain disorders such as Alzheimer’s disease and obsessive-compulsive disorder. PRIME brings together a multidisciplinary team that includes academic institutions in Italy, Spain and Germany as well as SMEs, NGOs and patient organisations, and is led by Prof. Barbara Franke from Radboud University Medical Center in Nijmegen, the Netherlands.

Alzheimer Europe is participating in the PRIME Scientific and Ethical Advisory Board and will contribute to the dissemination and communication objectives of the project.

The PRIME project website can be found here:

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

5 May: The PRIME project holds a webinar on Open Science

On 5 May, the PRIME project, which kicked off in January this year, held a webinar on Open Science. The webinar was hosted by Prof. Barbara Franke, who is leading the PRIME project, and was presented by Dr Michela Bertero, the Open Science advisor to PRIME.

Open Science is defined by the OECD as “making the primary outputs of publicly-funded research results – publications and research data – publicly accessible in digital format with no or minimal restriction”. Since 2017, all EU-funded research projects have participated in the Open Research Data (ORD) pilot, which aims to enable open access and reuse of project-associated research data. The PRIME webinar on Open Science was designed to demystify Open Science, defining key terms and explaining central concepts for PRIME researchers.

After an interactive Sli.Do survey session, Dr Bertero presented a historical perspective on scientific dissemination, from the times of Galileo up to the present day. Outlining key definitions in Open Science, Dr Bertero showed how Open Science is an umbrella term that encompasses multiple concepts, from Open Data and research integrity to Citizen Science and public engagement. She emphasised the importance of embedding Open Science in all stages of the research life cycle, from project planning, to data generation,

publication and long-term storage. She highlighted some of the key challenges in Open Science, such as ethical and privacy concerns, and the lack of infrastructure and robust training. However, there are also many benefits to Open Science; research quality and efficiency is increased, and it provides an ideal opportunity for societal engagement with research. Dr Bertero finished the session by describing three important Open Science concepts for PRIME: Open Access, Open Data, and Public Engagement. A recording of the webinar can be viewed here:

<https://www.youtube.com/watch?v=3tx0IZF5g9I&feature=youtu.be>

12 May: PARADIGM organises virtual workshop in CEE region

On 12 May, PARADIGM organised three parallel online workshops. The workshops aimed to provide the opportunity for participants from CEE countries to give feedback and shape the thinking about the patient engagement tools that PARADIGM is currently developing. The workshops focused on three topics:



- The development of the roadmap to making the patient engagement ecosystem sustainable;
- The recommendations on the capacity and capabilities to make patient engagement a greater reality;
- The development of the monitoring and evaluation framework to assess the value of patient engagement activities.

The session on capacity and capabilities was co-facilitated by EURORDIS and AE. During the session, participants highlighted some of the existing challenges which may affect patient engagement capabilities (e.g. lack of knowledge and resources, political instability and paternalistic approaches to patient engagement) and explored the relevance of the proposed capability framework for the CEE region. It was concluded that the framework was comprehensive but that to be applicable, it should be flexible, adaptable and affordable. Capabilities to meaningfully involve patients and patient organisations and to ensure the involvement of vulnerable populations were perceived as very valuable. AE Project Officer, Ana Diaz, attended this event.

For further information about the three sessions and future related events please see:

<https://imi-paradigm.eu/cee-patient-engagement-conference-transferability-workshops-report/>

14 May: The VirtualBrainCloud project holds a webinar on the legal and contractual aspects of data sharing

On 14 May, Prof. Nikolaus Forgó of the University of Vienna hosted a livestreamed webinar on the legal and contractual aspects of clinical data sharing in the VirtualBrainCloud (TVB_Cloud) project. Prof. Forgó and his team in Vienna lead

the legal and ethical work package of TVB_Cloud, partnering with Alzheimer Europe.

The TVB_Cloud project aims to create a cloud-based platform for targeted, precise prevention, diagnosis and prognosis of neurodegenerative diseases such as Alzheimer’s disease. Data protection forms a key part of the project, as the platform will be built around sensitive, personal data from clinical research participants and patients.

The webinar was aimed at providing an overview of the key legal and contractual frameworks that will regulate data sharing in TVB_Cloud. Emily Johnson kicked off the webinar by outlining the core data protection concepts, after which Michael Cepic highlighted the different contractual structures and agreements for data sharing. Mariana Risetto closed the webinar by presenting the data sharing workflow for TVB_Cloud, which includes identifying data availability and access mechanisms, setting up secure data transmission modalities, followed by data storage and, where necessary, data deletion. The webinar can be found here:

<https://www.youtube.com/watch?v=X4bX3EfoSsU&feature=youtu.be>

19 May: RADAR-AD project publishes “Behind-the-scenes” interview series with its researchers



To show the variety of work going on “behind-the-scenes” in RADAR-AD, the project has published a series of interviews with its

researchers.

They share the work they do for the project, what excites and challenges them the most, especially at times of the present COVID-19 pandemic, and how they see the impact of the project for the wider field of Alzheimer’s research. Read the full news story and the interviews, here:

<https://www.radar-ad.org/newsroom/radar-ad-researchers-interview-series-%E2%80%9Cbehind-scenes%E2%80%9D>



19 May: ADAIR project launches its website and social media accounts



The ADAIR project has a new website, and social media accounts have been set up:

Official website: <https://adair-jpnd.eu/>

Twitter: [@ADAIRjpnd](https://twitter.com/ADAIRjpnd)

Researchgate: <https://bit.ly/ADAIRresearchgate>

The project aims to provide mechanistic insight about the effects of air pollutants on the brain in humans and discover biomarkers for air pollution and Alzheimer’s disease risk prediction. It is funded by the JPND, and runs from 2020-2022.

Pictured: ADAIR kick-off meeting earlier this year.

22 May: RADAR-AD project reports on the impact COVID-19 is having on its work

The worldwide COVID-19 pandemic will inevitably impact the RADAR-AD project. The project management team is monitoring the situation closely and is in contact with IMI, the funder of the project.

In line with measures taken by local governments, the start of the clinical study of RADAR-AD has been postponed to later this year. Postponing the start of the study will help to reduce traffic to and from the hospitals by staff and research participants. This will help to halt the spread of the virus, and helps in protecting project staff and participants.

Read the full news story, here:

<https://www.radar-ad.org/newsroom/impact-covid-19-pandemic-radar-ad>

EU project acknowledgement



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:

AD Detect & Prevent - grant agreement 820636

PRIME - grant agreement 847879

PARADIGM - grant agreement 777450

RADAR-AD – grant agreement 806999

VirtualBrainCloud - grant agreement 826421

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **94**, 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 Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alamestä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (ALDE); Matt Carthy (GUE/NGL); Deirdre Clune (NI); Ciàran 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 Blinkevičiute (S&D). **Luxembourg:** Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Nicolas Schmit (S&D); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Clàudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estaràs 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).

EU DEVELOPMENTS

25 April: EPF hosts its Annual General Meeting online



On 25 April, members of the European Patients' Forum (EPF) gathered online for the 17th Annual General Meeting (AGM). This was the first ever virtual AGM for EPF, adapting to the current COVID-19 circumstances while upholding fundamental governance standards for EPF and its members.

During the event, members of EPF's Board and Secretariat reported on 2019 activities and gave an overview of current and upcoming work for 2020-2021. The event also saw the election of the Board, the approval of new member organisations, and the election of members for the newly-created EPF Ethics Committee.

The annual report and the financial report for 2019, as well as the budget and work plan for 2020 were all approved during the meeting.

Jean Georges, Executive Director attended the EPF AGM on behalf of Alzheimer Europe. You can read the full meeting report, here:

<https://www.eu-patient.eu/News/News/EPFS-AGM-2020/>

8 May: Chair of Health Committee writes to European Commission on dedicated Health Programme



Pascal Canfin MEP, the Chair of the Environment, Health and Food Safety Committee (ENVI) in the European Parliament, has written a letter to the European Commission demanding that the Commission ensure a dedicated Health Programme in the Multi-annual Financial Framework (MFF) 2021-2027.

In the letter, Mr Canfin sets out three key demands in relation to health policy within the future MFF:

- The first relates to the need for a strong and ambitious Health Programme.
- The second is to articulate the need for a reinforced Union Civil Protection Mechanism (UCPM), which builds on the lessons of the current crisis.
- The final demand is for greater competence and resources for the European Centre for Disease Prevention and Control (ECDC) and the European Medicines Agency (EMA).

You can read the full letter here:

<https://www.europarl.europa.eu/resources/library/media/20200511RES78809/20200511RES78809.pdf>

11-15 May: European Public Health Week counts 147 events in 31 countries, uniting Europe to promote public health



The second edition of the European Public Health Week (EUPHW) took place between 11 and 15 May 2020. Despite the current pandemic and challenges faced by the public health community, individuals and organisations across Europe and beyond embraced this year's motto of "Joining forces for healthier populations" by hosting 141 events in 31 countries.

The main theme was "COVID-19 Collaboration, Coordination, Communication" in addition to 5 daily themes. You can find summaries of each day's activities below:

- Promoting health through the Global Goals (Monday 11 May) including the kick-off webinar
- Primary care in the digital age (Tuesday 12 May)
- Staying together for mental health (Wednesday 13 May)
- Equal health for all (Thursday 14 May)
- Grow old, grow healthy (Friday 15 May).

For more information, visit:

www.eupha.org/EUPHW

12 May: Socialists and Democrats call for stronger EU competence on health

The Socialists and Democrats (S&D) group in the European Parliament have called for an increase in the European Union's competence in relation to health policy, in a statement outlining a number of key asks.

In the statement released by the group, the S&D group highlighted that the COVID-19 pandemic had exposed the weaknesses of the instruments and powers available at an EU level to deal with matters relating to health.

They highlight that Article 168 of the Treaty stipulates that "a high level of human health protection shall be ensured in the definition and implementation of all Community policies and

activities". The statement further notes that the European Court of Justice has ruled on numerous occasions that the EU can pursue public health objectives through internal market measures. In addition, it identifies existing EU engagement in health policy including regulation of pharmaceuticals and medical devices, as well as through its own research and health programmes. In the statement, the S&D calls for the creation of a European Health Union, which covers:

- Stress-testing of EU healthcare systems
- A new Directive for Minimum Standards for Quality Healthcare
- A European Health Response Mechanism
- Strengthened Joint Procurement Mechanism under a regulation
- Revision of the Transparency Directive for pricing and reimbursement of medicines
- Full implementation of the Cross Border Healthcare Directive and Clinical Trials Regulation
- Strengthened EU health agencies and strengthened civil protection capacities
- A European Health Data Space
- A new approach to European health research.

You can read the full call here:

<https://www.politico.eu/wp-content/uploads/2020/05/European-Health-Union-SD-Position-FINAL1.pdf>

14 May: European Commission President commits to an EU health programme



European Commission President, Ursula von der Leyen, has committed to a specific health programme, as well as indicating further support for the EU's next research programme, Horizon Europe, as part of the next Multi-annual Financial Framework (MFF) for 2021-2027.

Addressing the European Parliament, President von der Leyen outlined some of the details of the "recovery plan", which aims to strengthen the economy of the EU following the COVID-19 pandemic. The recovery plan will be based on the EU's budget (the MFF), which will be increased through use of

a recovery instrument, which will be “funded through a larger headroom”.

However, President von der Leyen did not unveil the size of the recovery instrument or the updated EU budget, while the European Parliament is asking for a package worth EUR 2 trillion (double that of the Commission’s previous proposal for the MFF 2021-2027).

Speaking about the recovery plan, President von der Leyen explained that the Commission intended to strengthen elements which had “proved their worth” during the COVID-19 pandemic, citing the Horizon Europe research and innovation programme as an example. In addition, she stated that a dedicated health programme would also be created. You can read President von der Leyen’s speech here:

https://ec.europa.eu/commission/presscorner/detail/en/SPEECH_20_877

18 May: European Parliament passes resolution on future EU budget



European Parliament

The European Parliament has passed a resolution on the future of the Multiannual Financial Framework (MFF), setting out its vision on the focus of the EU’s budget for 2021-2027. The

resolution was adopted on Friday by 505 votes in favour, 119 against and 69 abstentions.

The resolution stressed that European citizens must be at the heart of the proposed recovery strategy, incorporating a strong social dimension, which addresses the social and economic inequalities of people most affected by the crisis. In total, the resolution calls for a total spend of EUR 2 trillion, financed through recovery bonds, primarily disbursed through grants, as well as loans.

Of particular interest in relation to health matters, the resolution calls for the creation of a new standalone European health programme, as well as highlighting the importance of a strong social dimension, aligned with the objectives of the European Pillar of Social Rights and the United Nations Sustainable Development Goals (UN SDGs). You can read the full call here:

https://www.europarl.europa.eu/doceo/document/TA-9-2020-0124_EN.pdf

20 May: European Commission publishes health related Country Specific Recommendations



The European Commission has published Country Specific Recommendations (CSRs) as part of the European Semester process, providing policy guidance to all EU Member States in the context of the

COVID-19 pandemic.

Of interest to the work of Alzheimer Europe and its members, the CSRs in this round of the Semester cover areas such as investing in public health and the resilience of the health

sector, in addition to covering areas such as employment, support for small and medium enterprises, and focus on digital and green transitions.

The CSRs reflect the need for countries to strengthen the resilience of national health systems, including their ability to deal with crisis situations, as well as implementing longer-term structural changes needed for future sustainability. It is further noted that existing challenges around resilience, accessibility and efficiency of health systems have been exacerbated by the COVID-19 pandemic.

Additionally, the working conditions of clinicians, shortages of health workers, out-of-pocket payments and high levels of unmet medical care needs, were further issues identified by the CSRs. The full recommendations can be found on the European Commission website:

https://ec.europa.eu/commission/presscorner/detail/en/ip_20_901

26 May: EU4Health campaign relaunches to prioritise health at EU level

Alzheimer Europe has joined with other



European health and patient-focused Non-Governmental Organisations (NGOs) to support calls for health to be made a policy priority at an EU level.

Coinciding with ongoing discussions around the new Multiannual Financial Framework (MFF) in the EU, 17 organisations have issued a joint statement indicating their support for the EU4Health campaign, calling for stronger and more ambitious European health policies. The statement outlines three key themes for action, including:

- Boosting funds and resources for health in the EU
- Strengthening EU health action under the current mandate
- Re-thinking EU healthcare competencies and vision for the future.

As part of these themes, the statement specifically calls for a standalone EU health programme (including increased resources), ensuring health is a key focus of the health and research agenda, and establishing health in all policies as a new norm in policymaking. The full statement can be found on the EU4Health website:

<https://eu4health.eu/covid-19-has-shown-eu-action-on-health-is-more-urgently-needed-than-ever/>

27 May: European Commission proposes new budget

The European Commission has set out its proposals for the future budget of the EU, announcing measures totalling EUR 1.85 trillion. This combines EUR 1.1 trillion of the Multiannual Financial Framework (MFF), along with EUR 750 million of one-time recovery instrument, the Next Generation EU.

Of particular relevance for dementia policy at an EU level, the European Commission’s proposed standalone Health

Programme, EU4Health, has been allocated a budget of EUR 9.4 billion. This is a significant increase on the original EUR 414 million allocated for a health strand of the European Social Fund Plus package in the Commission’s original MFF proposal.

Additionally, the new proposals have allocated EUR 94.4 billion for the future European research programme, Horizon Europe. This represents a marginal increase on the EUR 94.1 billion proposed in the Commission’s original MFF proposal.

Additionally, a new initiative, REACT-EU, will provide a top-up for cohesion funds to support Member States, with a budget of EUR 55 billion. This will be distributed according to a new allocation key which takes into account the impact of the crisis, supporting workers and Small and medium business, health systems and the green and digital transitions.

Furthermore, the document sets out broader aims in relation to investment in health systems, greater roles for the European Medicines Agency and the European Centre for Disease Control, as well as the creation of a European Health Data Space.

You can read the European Commission’s proposal here:

<https://bit.ly/36Rf0bK>

28 May: European Commission sets out vision for future Health Programme

The European Commission has set out its vision of the future EU Health Programme, EU4Health (not associated to the EU4Health campaign), following the announcement of EUR 9.4 billion of funding in its recent budget proposal.

The new funding proposal for the standalone EU4Health Programme is a substantial increase on the previous proposal, which saw EUR 413 million for a health strand as part of the European Social Fund+.

The EUR 9.4 billion will comprise of EUR 1.7 billion from the EU budget, as well as EUR 7.7 billion from external assigned revenues from the EU Recovery Instrument Regulation.

The EU4Health Programme has three general objectives:

- Protecting people in the EU from serious cross-border health threats and improving crisis management capacity
- Making medicines, medical devices and other products, available and affordable
- Strengthening health systems and the health care workforce, including by investing in public health.

Beyond crisis preparedness and responses, the EU4Health Programme will address other long-term challenges for health systems, including:

- Inequalities in health status among population groups, countries and regions, as well as access to affordable, preventive and high-quality treatment
- Non-communicable diseases, in particular cancer, mental health, rare diseases and risks from health determinants
- Uneven distribution of health system capacity

- Obstacles to the uptake and scaling of digital innovations in health
- Growing health burden from environmental factors, as well as from demographic changes.

You can read the Commission’s outline for the Health Programme here:

https://ec.europa.eu/commission/presscorner/detail/en/qanda_20_956

28 May: European Patients Forum (EPF) issues statement on health in the EU

The European Patients’ Forum (EPF) has issued a statement, “High time for enhanced European coordination and competence on health”, calling for greater action on health at the EU level.

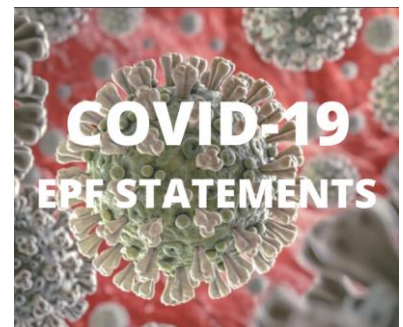
The statement highlights that the COVID-19 pandemic has exposed gaps and weaknesses in national health systems, noting that the patient community has long been aware of such issues.

Additionally, the EPF highlights the need for enhanced European collaboration and competence to strengthen health systems, as well as outlining the importance of health as both a European and global health policy priority. The EPF statement explored issues around:

- A coordinated European approach to protect health
- Better utilising existing EU mechanisms and instruments
- More investment in health, coordinated by a dedicated EU health programme
- A stronger mandate and resources for the European Commission, European Medicines Agency and the European Centre of Disease Control
- An enhanced and meaningful role to allow for the contribution of civil society, patient and health organisations.

You can read the EPF’s full statement here:

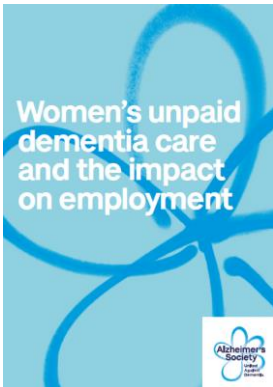
<http://pr.euractiv.com/pr/high-time-enhanced-european-coordination-and-competence-health-203873>



MEMBERS’ NEWS

30 April: Alzheimer’s Society explores how unpaid dementia care disproportionately impacts women in the workplace

Alzheimer’s Society’s latest report; “Women’s unpaid dementia care and the impact on employment”, explores how unpaid dementia care disproportionately impacts women’s ability to continue paid work. The report draws on the findings via Alzheimer’s Society’s international networks, gathering



evidence relating to the gender dynamic of unpaid dementia care and includes the experiences of women in the UK, providing dementia care support to family members while balancing paid work.

Globally, 71% of unpaid dementia care is provided by women - typically wives, daughters or daughters-in-law of a person with dementia - while they juggle jobs

and often other care responsibilities in the home. In the UK, 63% of unpaid dementia care supporters are women. The nature of the care they provide is likely to be less flexible than that of men's, for example women in the UK are 2.5 times more likely to provide 24-hour care to someone with dementia, making it harder to juggle their paid work.

The women Alzheimer's Society spoke to said that the most supportive employers and managers were those who had experienced dementia in their own family and understood the long-term and progressive nature of the condition. For most of the women, they relied on using annual leave, flexible working and carer's leave to help them juggle their dementia care commitments and the pressures of their jobs, alongside childcare and support to other family members.

This report calls on governments and businesses to recognise the disproportionate impact long-term dementia care (and elder care in general) is having on women in the workplace.

"Support must be ensured through the provision of longer-term carer's leave, flexible working and wellbeing support. If we ensure women affected by dementia, with their multiple care roles, get the right support in the workplace, we will get it right for all employees with care commitments" wrote the Alzheimer's Society.

Read the new report: "Women's unpaid dementia care and the impact on employment":

<https://www.alzheimers.org.uk/media/29161>

22 May: The Alzheimer Society of Ireland pays tribute to advocate Helen Rochford-Brennan on her 70th birthday

The Alzheimer Society of Ireland (ASI)'s wonderful advocate, Helen Rochford Brennan marked her 70th birthday together with her grandnephews and close loved ones, with an article in her local newspaper, the Sligo Champion.

In the article, Helen talks about living with Alzheimer's disease, the great community spirit that has helped her during the COVID-19 public health emergency, and about her advocacy work with the Irish Dementia Working Group (IDWG), which is supported by The ASI.



Helen, who was diagnosed with Alzheimer's disease in 2012, is the current Chairperson of the European Working Group of People with Dementia (EWGPWD) and is on the Board of Alzheimer Europe; she is a former Chair of the IDWG and continues to sit on the group's steering committee.

Helen is passionate about research and has engaged in many Irish and international research projects. She has had a remarkable journey so far, from research participant to research leader and is now mentoring and training other advocates living with dementia as part of The ASI's Patient and Public Involvement (PPI) work.

Happy birthday, Helen and thank you for all the work that you do! Full article here: <https://tinyurl.com/ybr53l8l>



SCIENCE WATCH

20 April: Researchers develop a new molecule that can reduce levels of amyloid plaques in mouse models

On 20 April, a group of researchers reported the development of a new molecule that can reduce brain inflammation and the number of amyloid plaques in Alzheimer's disease (AD). Scientists tested the compound known as L1 in mouse models genetically predisposed to develop AD. Results showed that L1 had high affinity for beta-amyloid and metal ions. A significant reduction (up to 50%) of the levels of amyloid plaques was described in the brain of the treated mouse models. In addition, L1 alleviated the brain inflammation response and reduced the amount of tau aggregates surrounding the amyloid plaques. L1 also exhibited antioxidant properties. Findings were published in the journal ACS Chemical Neuroscience. The researchers are planning to evaluate the ability of L1 to have a beneficial effect on the learning and memory performance of AD mouse models.

<https://pubs.acs.org/doi/10.1021/acscchemneuro.0c00114>

22 April: A new study reports an association between long-term flavonoid-rich foods and a reduced risk of Alzheimer’s disease and related dementias



On 22 April, US researchers from the University of Boston published a paper in the American Journal of Clinical Nutrition reporting a lower risk of developing Alzheimer’s

disease (AD) and Alzheimer’s disease and related dementias (ADRD) in people who consumed high amounts of flavonoid-rich foods. Flavonoids are natural substances found in plants, including fruits and vegetables. There is ongoing research into the association of flavonoids and various health benefits.

In the published study, researchers used data from the Offspring Cohort Study of 2,800 people aged 50 and older. They analysed six types of flavonoids and compared long-term intake levels with the number of AD and ADRD diagnoses later in life. Results showed that people with high long-term intakes of three flavonoids (flavonols, anthocyanins and flavonoid polymers) had a lower risk of ADRF relative to people with lowest intakes. Results were essentially the same for people with AD.

<https://bit.ly/2XOWwnZ>

27 April: Axsome Therapeutics announces top-line results for its ADVANCE-1 Phase II/III trial in AD agitation

On 27 April, the company Axsome Therapeutics, which develops therapies for the management of central nervous system disorders, reported top-line results of its ADVANCE-1 trial of AXS-05.

The Phase II/III ADVANCE-1 study was designed as a multicentre, randomised, double-blind and controlled trial, enrolling 366 US participants with agitation associated with Alzheimer’s disease (AD).

The company announced that the ADVANCE-1 trial met its primary endpoint by demonstrating a statistically significant improvement in AD agitation at week 5. The improvement was determined using the Cohen Mansfield Agitation Inventory (CMAI) total score. Results showed a statistically significant mean reduction from baseline of 48% for AXS-05 and 38% for placebo. In addition, AXS-05 was reported to have rapidly and significantly improved agitation symptoms at week 3 in people with AD starting to receive the full dosing of AXS-05 at week 2 as compared to placebo. AXS-05 was well tolerated. The most commonly reported adverse events were somnolence, dizziness and diarrhoea.

The company expects to present detailed results at upcoming medical meetings.

<https://bit.ly/2Bgyr1G>

27 April: Shanghai Green Valley Pharmaceuticals gets approval from FDA for Phase III study of Oligomannate in mild to moderate Alzheimer’s disease



On 27 April, it was reported that Shanghai Green Valley Pharmaceuticals had gained approval from the US Food and Drug Administration (FDA) for a Phase III study of its Alzheimer’s disease (AD) drug.

In November 2019, the company received approval from China’s National Medical Products Administration (NMPA) for Oligomannate as a new oral treatment for mild to moderate AD. The decision followed the results of a Phase III clinical trial enrolling 818 participants in China. Oligomannate was found to be safe, well tolerated and showed a statistical significant improvement in cognitive function in people with mild to moderate AD compared to placebo. The new drug called Oligomannate or GV-971 is derived from marine brown algae, a seaweed, and works by restoring balance to the gut microbiota.

On 8 April 2020, the company received approval from the FDA to start a Phase III clinical trial with Oligomannate in the US with more than 2,000 people with mild to moderate AD. The randomised and placebo trial will be conducted for a year and will be followed by six months of open study when all the participants will receive the drug. The company expects to complete the Phase III trial in 2024.

<https://prn.to/3doMtMS>

29 April: Life & BRAIN GmbH has filed a patent application for a technique generating high numbers of human microglia

LIFE & BRAIN GmbH, a German development-stage biomedical enterprise, has filed a



patent application with the European Patent Office for an improved protocol for generating high numbers of human microglia, implicated in Alzheimer’s disease (AD), from induced pluripotent stem cells (iPSCs).

Microglia – a type of immune cells located in the brain- are thought to play an important role in the development and progression of AD. To understand more about their function, researchers in the PHAGO project, an IMI project devoted to the development of immunomodulatory therapies for AD, looked at genetically distinct iPSCs generated from the blood of people with AD and microglia derived from them. It was reported that this technique is challenging and cumbersome.

LIFE & BRAIN GmbH, a partner in the IMI PHAGO project, has now developed an improved method that involved new types

of materials. This technique might offer new perspectives for a possible immunotherapeutic approach to treat people who have a genetic disposition to develop AD.

In the PHAGO project, 40 iPSC lines have already been generated from donors that carry specific genetic mutations. These cell lines are accessible for researchers via the “European Bank for Induced pluripotent Stem Cells” (EBiSC).

<https://bit.ly/2LOjeH4>

29 April: Landmark study reveals a link between APOE4 and blood-brain barrier defects, contributing to cognitive decline in AD



On 29 April, Dr Axel Montagne and co-investigators published an article in Nature, showing that APOE4 is linked to breakdown of the blood-brain barrier (BBB) contributing to the cognitive decline observed during the

development of Alzheimer’s disease (AD).

APOE4 is the leading genetic risk factor for AD, increasing the risk of developing AD up to 4-fold in people who carry one copy of the gene, and 15-fold in those who carry two APOE4 copies. Recent studies indicate that APOE4 may accelerate breakdown of the blood-brain barrier, the vascular layer that separates the brain from the peripheral blood circulation, by activating an inflammatory pathway that injures BBB cells called pericytes. However, it was unclear whether there was a connection between the vascular damage caused by APOE4, and the cognitive impairment that characterizes AD.

To address this important question, Dr Montagne and colleagues investigated the permeability of the BBB in 245 people with or without mild cognitive impairment, using a sophisticated brain imaging technique called dynamic contrast-enhanced MRI. These analyses revealed an APOE4-dependent pattern of BBB breakdown in the hippocampus and medial temporal lobe, two areas of the brain that are particularly important for memory and cognition. Although BBB breakdown was worse in APOE4 carriers with cognitive impairment, evidence of BBB breakdown was still present in cognitively unimpaired APOE4 carriers. In addition, the BBB changes in the hippocampus and medial temporal lobe appeared to precede tissue loss in these areas – suggesting that BBB breakdown is an early event in the development of AD. Interestingly, these findings did not seem to be associated with amyloid or Tau pathology, as measured by PET scans or in cerebrospinal fluid samples. Finally, the researchers investigated whether the BBB changes were associated with inflammatory pathways that had previously been linked to pericyte damage. They found higher levels of two inflammatory proteins, MMP9 and CypA, in CSF samples from APOE4 carriers with cognitive impairment, pinpointing a

mechanism that links inflammatory molecules, pericytes, BBB damage and APOE4 with cognitive decline in AD. The original article was published in Nature and can be found here:

<https://go.nature.com/3d2W4s6>

30 April: Annovis Bio plans to launch a Phase II clinical trial with ANVS401 in Alzheimer’s and Parkinson’s disease

On 30 April, Annovis Bio, a clinical-stage drug platform company developing novel treatments for neurodegenerative diseases such as Alzheimer’s disease (AD) and Parkinson’s disease (PD), announced plans for a new Phase II clinical trial investigating its lead compound ANVS401 in AD and PD. ANVS401 is a small orally administered brain penetrant inhibitor of neurotoxic proteins.

The company has received comments from the US Food and Drug Administration (FDA) and can advance with the launch of its Phase II clinical trial, expecting to enrol 68 people with AD and PD at 10 sites across the US. They will receive ANVS401 for one month. The clinical trial is planned to start enrolment in May. However, due to the COVID-19 pandemic, the recruitment may be delayed until this summer.

<https://bit.ly/3ckwttV>

1 May: Researchers develop and validate an AI algorithm for more accurate risk prediction of Alzheimer’s disease



On 1 May, Dr Shangran Qiu and colleagues published an article in Brain, detailing the development and validation of an AI-based framework for predicting the risk of developing Alzheimer’s disease (AD).

The last two decades have seen the rapid development of multimodal diagnostics for AD, involving biomarker tests, analyses of brain scans and genetics alongside more traditional cognitive assessments. Whilst offering the potential for highly precise diagnoses and risk estimation for AD, the accuracy of these multimodal tests currently depends on clinicians having the skills to interpret a diverse range of complex data sources. Artificial Intelligence (AI)-based approaches such as machine learning and neural networks could help clinicians rapidly perform in-depth analyses of multiple health data sources,

enabling more uniform and accurate diagnosis of AD. However, there is a lack of external validation of AI-based algorithms, as well as a paucity of clear decision-making frameworks that clinicians can apply based on these algorithms.

To overcome these challenges, Dr Qiu and colleagues aimed to develop and validate a deep learning framework for creating high-resolution visualisations of AD risk by linking two types of neural networks: a fully convolutional network (FCN) and a multilayer perceptron (MLP). The framework was developed and validated using four case-control clinical datasets from participants with AD (cases) or cognitively unimpaired controls: the AD Neuroimaging Initiative (ADNI) dataset, the Australian Imaging, Biomarker and Lifestyle Flagship Study of Ageing (AIBL) dataset, the Framingham Heart Study (FHS) dataset, and the National Alzheimer’s Coordinating Centre (NACC) dataset.

The first step of the framework involved the random sampling of patches from MRI images in these datasets, leading to the creation of participant-specific disease probability maps in step 2. The third and final step of the framework resulted in an overall AD prediction, based on an integrated analysis of brain imaging data alongside factors such as age, gender and cognitive test scores. Validation tests of the framework showed that it displayed good predictive performance across the different clinical cohorts, despite between-cohort variations in MRI protocol, geographic location and recruitment criteria. Further studies are now required to test the accuracy of the AI framework in more diverse populations, with a range of comorbidities and potential neurodegenerative disease diagnoses. The original article was published in *Brain* and can be found here:

<https://academic.oup.com/brain/advance-article/doi/10.1093/brain/awaa137/5827821#203273794>

13 May: Study in mice reveals that retinal imaging technology could detect an early warning sign of Alzheimer’s disease



On 13 May, Dr Ge Song from Duke University published a paper in *Scientific Reports*, showing that a novel retina scanning technology could be used to detect early retinal changes in a mouse model of Alzheimer’s disease (AD).

Recent technological advances have led to the development of non-invasive retinal imaging techniques such as Optical Coherence Tomography (OCT), which uses a long-wavelength light source to generate high-resolution, 2D or 3D images of the retina. Studies now suggest that Alzheimer’s disease may be accompanied by changes in the retina, including deposition of amyloid plaque around the retinal nerve and altered retinal blood vessel structure. In this paper, Dr Song and colleagues

investigated whether angle-resolved low-coherence interferometry (a/LCI) guided by OCT can provide a more detailed and sensitive detection of retinal changes in transgenic mouse models of AD. Using these complementary methods *ex vivo*, the researchers hoped to extract both textural and structural information on the retina.

In their paper, Dr Song and colleagues showed that complementing OCT with a/LCI enabled the simultaneous assessment of retinal structure and retinal thickness, providing sufficient resolution to visualise retinal texture in the different layers of the mouse retina. They observed significant differences in the structure of three retinal areas of AD mice compared to wild-type controls, which may be related to AD-associated plaque deposition. Further studies are now required to evaluate whether this technique works in the *in vivo* and clinical settings. The original *Scientific Reports* article can be found here:

<https://www.nature.com/articles/s41598-020-64827-2>

15 May: Cassava Sciences announces that its Phase II clinical trial of PTI-125 in mild-to-moderate AD did not meet the primary endpoint

On 15 May, the biopharmaceutical company Cassava Sciences, developing novel solutions to detect and treat neurodegenerative diseases such as Alzheimer’s disease (AD) reported top-line results from its Phase II study of PTI-125 in AD. PTI-125 is a small molecule drug targeting the altered form of filamin A found in the AD brain to restore its normal shape and function.

Top-line results showed that the study did not meet its primary endpoint, which was a statistically significant effect of PTI-125 on cerebrospinal fluid (CSF) levels of tau protein and other biomarker assessments from baseline to Day 28. The drug was safe, well-tolerated and significantly reduced a secondary endpoint, CSF levels of IL1-beta, a core biomarker of neuroinflammation, from baseline to Day 28. The company reported that analyses of biomarker data revealed high variability in levels of CSF biomarkers over 28 days.

The Phase IIa clinical study was a double-blind, randomised and placebo-controlled study evaluating PTI-125 in people with mild-to-moderate AD. A total of 64 participants (50-85 years old) received PTI-125 or placebo twice a day for 28 days.

<https://bit.ly/3g17sML>

19 May: Meta-analysis reveals that reducing the blood pressure of older people with hypertension can reduce the risk of dementia

On 19 May, Dr Diarmaid Hughes and collaborators published a systematic review and meta-analysis in the *JAMA* journal, showing that treatment of hypertensive patients with blood pressure-lowering medication can reduce the risk of dementia and cognitive impairment.

Clinical studies have identified a link between elevated blood pressure (or hypertension) and dementia, with studies



showing that people with hypertension in middle age and later life are almost 50% more likely to develop dementia compared to people with normal blood pressure. Hypertension is a risk factor for multiple forms of dementia including vascular dementia and Alzheimer’s disease, due in part to the vascular damage caused by high blood pressure. However, the benefit of blood pressure-lowering medication for the prevention of dementia or cognitive impairment is unclear, as two recent large-scale trials (the SPRINT MIND and HOPE-3 studies) found opposing results. In undertaking their systematic review and meta-analysis, Dr Hughes and colleagues hoped to determine whether blood pressure lowering using antihypertensive drugs was associated with a reduced risk of dementia.

In total, fourteen studies were selected for inclusion in the meta-analysis, comprising 96,158 participants who were followed up for an average duration of 49 months. At baseline, none of the trial participants were known to have dementia or cognitive impairment, and all trials included a treatment and control arm. The mean age of trial participants was 69, and the mean baseline systolic and diastolic blood pressures were 154/83 mmHg. Analysis of the trials that reported dementia or cognitive impairment outcomes revealed a 7% reduction in dementia and 7.5% reduction in cognitive impairment in participants receiving antihypertensive drugs. In trials that reported on progressive cognitive decline over the follow-up period, blood pressure-lowering treatment was associated with a 20.2% reduction in cognitive decline. Overall, blood pressure lowering with antihypertensive agents was associated with a statistically significant reduction in dementia or cognitive impairment. The original article in JAMA can be found here: <https://bit.ly/2ZIB4DS>

20 May: TauRx Therapeutics Ltd reports that hydromethylthionine could slow clinical decline and brain atrophy in behavioural variant Fronto-Temporal Dementia

On 20 May, the company TauRx Therapeutics Ltd, based in Aberdeen (Scotland), published analysis of its drug hydromethylthionine (TRx0237) in the Journal of Alzheimer’s Disease. Hydromethylthionine acts by blocking abnormal accumulation of Tau protein in the brain.

TauRx conducted a randomised, controlled, double-blind and parallel-group Phase III study in 220 people with behavioural variant Fronto-Temporal Dementia (bvFTD) between 2013 and 2016. The 52 week Phase III trial study recruited participants younger than 80 years of age with a diagnosis of bvFTD at 70 sites in Canada, United States, Australia, Asia and Europe. Research participants received the drug, taken as a tablet, at doses of 8 or 200 mg/day. Findings showed that hydromethylthionine had statistically significant effects on clinical decline and brain atrophy. There were no significant differences on any of the outcomes at 52 weeks between the participants receiving the drug at 8 mg/day and those receiving 200 mg/day. The company is planning to conduct a confirmatory placebo-controlled trial.

TauRx is also developing this drug for the treatment of Alzheimer’s disease (AD) in a Phase III trial. The LUCIDITY trial is a randomised, double-blind and placebo-controlled study evaluating the safety and efficacy of hydromethylthionine in people with mild to moderate AD in US, Canada and Europe.

<https://content.iospress.com/articles/journal-of-alzheimers-disease/jad191173>

28 May: FDA approves flortaucipir PET tracer to support Alzheimer's diagnosis

On 28 May, the US Food and Drug Administration (FDA) approved flortaucipir for intravenous injection prior to positron emission tomography (PET) scanning of the brain. The flortaucipir tracer, which was developed by a wholly-owned subsidiary of Eli Lilly & Co, has been approved for assessing the quantity, localization and extent of Tau neurofibrillary tangles in the brains of people with suspected Alzheimer’s disease.



A 2018 Phase III study that included post-mortem evaluation confirmed the sensitivity and specificity of flortaucipir, a radioactive tracer that specifically binds to Tau within neurofibrillary tangles. Using PET scans to detect the presence of intravenously-delivered flortaucipir in the brain, study investigators were able to accurately identify individuals with cognitive impairment or dementia due to Alzheimer’s disease. Availability of flortaucipir will initially be limited but will expand in response to commercial and clinical demand.

The press release can be found here:

<https://investor.lilly.com/news-releases/news-release-details/lilly-receives-us-fda-approval-tauvidtm-flortaucipir-f-18>



LIVING WITH DEMENTIA

28 May: Idalina Aguiar, a member of the European Working Group of People with Dementia, talks about her new project “COFIQue a Rir”

COVID-19 has been a difficult time for everyone. For those with Alzheimer’s disease, other dementias or indeed any chronic illness or disability, this period of confinement has been exceptionally confusing, stressful and lonely. People need and crave human interaction and stimulation and without it, they become lost and depressed. Although I was obliged to stay at home, and even though the usual supports were gone, I still had the privilege of being part of a supportive community. Volunteers and professionals from Alzheimer Portugal, "Lugar de Memórias" and "Garouta do Calhau" have kept me stimulated and given me daily or weekly support and challenges that keep me motivated and encouraged.

Aware that not everyone receives this kind of necessary emotional support, I decided that, with the support of my wonderful family, my daughter Nélide and another friend, we would create a way to share “smiles instead of hugs”. We created a new Facebook page called "COFIQue a Rir". The object of this project is to share home videos, of kids and adults, with music, exercises, theatre, dance, ballet, and any other material we can find that will engage and benefit others in similar circumstances. Our motto is: “Laughter is the music of the spirit”. If we can make people laugh, that already has made a positive difference. So far, our efforts were reported in the Local and National newspapers and we know that we have reached 8 institutions. We challenge our friends and followers to join us and publish and share their small contributions, in order to bring a little more joy to those who are alone and isolated.

Please like our Facebook page of "COFIQue a Rir":

https://www.facebook.com/COFIQue-a-rir-113137576987737/?modal=admin_todo_tour

Idalina is supported by her daughter Nélide, to whom we are grateful for her help in translating Idalina's words to English.



JOB OPPORTUNITIES

6 May: University of East Anglia seeks health professional with Master’s Degree to embark on dementia care PhD exploring hydration difficulties in care homes



The University of East Anglia (UEA) has an opportunity for a health professional with a Master’s Degree to undertake a fully-funded PhD to support people with dementia living

in care homes to drink well, preventing dehydration and the ill health associated with it. The PhD will start from October 2020.

Full details can be found here: buff.ly/2yAzFDV

For further information, contact Diane Bunn, Lecturer in Health Sciences, UEA: d.bunn@uea.ac.uk

Closing date for applications is **30 June 2020**.



EDUCATION

28 May: Free online course in “Foundations in Dementia” is available for professional and family carers



A free online course that provides dementia carers with tools and advice to better support the people they care for is now open for registration.

The eight-week course, Foundations in Dementia, run by FutureLearn for the University of Nottingham, is open to both the general public and professionals, and will explore the signs and symptoms of dementia, interventions, support networks and more.

The University's online programme, which has contributions from 30 University dementia experts as well as family carers, offers those taking the course to learn to understand people with dementia and to care appropriately as a professional or family supporter. The course spans six topics, from prevention and diagnosis to end of life care, as well as offering insights from recent research.

It is the second time the course has been run after launching in January this year, with 3,500 people registering worldwide following its launch, ranging from nurses, people living with dementia and their families, care workers and health and social care students.

By engaging with the resources, which includes about 30 videos, and exchanging views with others, those taking the course will gain knowledge, skills, and confidence in dealing with people with dementia. Key achievements will include the ability to:

- Identify how lifestyle changes may reduce the risk of dementia
- Assess the signs and symptoms that may indicate dementia and describe the pathway to diagnosis and treatment
- Identify communication approaches which can support the person with dementia to communicate their needs
- Compare the impact of different interventions including medication and psychosocial approaches.
- Understand the needs of a person with advanced dementia and respond well.

Course organisers suggest it will best suit health and social care professionals, such as nurses, doctors, therapists and social workers and will also interest students, carers of people with dementia, individuals with a recent diagnosis, volunteers, and dementia researchers.

Find out more:

<https://www.futurelearn.com/courses/dementia-awareness-training>

29 May: University of Worcester offers fully online Postgraduate Certificate in Person Centred Dementia Studies



University of Worcester

The University of Worcester (United Kingdom) is offering a fully online Postgraduate Certificate in Person Centred Dementia Studies, starting in September 2020. This is the second year the course is being run, and it went very well the University reports that it went very well, despite the COVID-19 disruptions. The closing date for applications is **20 July 2020**. The following fully distance-learning modules will be available:

Semester one – 2020/21: September 2020

- Person-Centred Leadership: the VIPS Approach
- Supporting People Living with Advanced Dementia
- Enabling Environments for People Living with Dementia

Semester two – 2020/21: January 2021

- Engagement and Empowerment in Dementia Studies
- Dementia in the Family Context
- Expert Practice in Delivering Person Centred Dementia Care

The course is designed to be flexible and engaging for busy people. Further information and contact details for each module can be found at:

<https://www.worcester.ac.uk/study/find-a-course/?term=dementia>

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 Pietikäinen (Finland), Jesús Rodrigo (Spain), Karin Westerlund (Sweden).

Alzheimer Europe Staff:

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

AE CALENDAR

Date	Meeting	AE representative
2-3 June	Patients and Consumers' Working Party of the European Medicines Agency (online)	Jean
4 June	European Group of Governmental Experts on Dementia (online)	Jean, Ange and Owen
5 June	MIRIADE project meeting (online)	Jean
8 June	Alzheimer Europe Board (online)	AE Board and staff
9 June	Alzheimer Europe Company Round Table meeting (online)	AE Board, sponsors, members and staff
9 June	ADAIR General Assembly (online)	Ana
10 June	EFID Webinar - People living with dementia. Challenges and solidarity during the Covid-19 emergency	Dianne
10 June	Alzheimer Europe public affairs meeting (online)	AE Board, members and staff
11 June	European Working Group of People with Dementia (online)	Dianne and Ana
11 June	Roche digital workshop (online)	Jean
15-16 June	Workshop on prevention of Alzheimer's dementia (online)	Jean
17 June	Meeting of European Academy of Neurology and the European Alzheimer's Disease Consortium (online)	Jean
19 June	RECOGNISED project meeting (online)	Angela and Jean
25 June	Neuronet IMI project review meeting (online)	Jean
25 June	PARADIGM Patient Engagement Open Forum (online) - Ana	Ana
29-30 June	PRODEMOS General Assembly (online)	Cindy and Jean

CONFERENCES

Date	Meeting	Place
26-30 July	Alzheimer's Association International Conference (AAIC), https://www.alz.org/	Online
31 August-1 September	Conference "Dementia Care and Policies in extended Danube Region", www.alzheimerbih.org	Sarajevo, Bosnia & Herzegovina
2-5 October	The 14 th World Congress on controversies in neurology, http://cony.comtecmed.com/	London, UK
20-22 October	30 th Alzheimer Europe Conference "Dementia in a changing world"	Virtual Conference
16-18 November	Second Krems Dementia Conference, www.donau-uni.ac.at/dementia-conference	Krems, Austria
10-12 December	34 th International Conference of ADI "Hope in the age of dementia", https://adi2020.org/	Singapore
9-14 March 2021	AD/PD™ 2021 - The 15 th International Conference on Alzheimer's & Parkinson's Diseases, http://lp.kenes.com/index.php/email/emailWebview	Barcelona, Spain
26-29 June 2021	Brain & Brain PET 2021, http://brain2021.scot/	Glasgow, UK
29 November - 1 December 2021	31 st Alzheimer Europe Conference	Bucharest, Romania

30th Alzheimer Europe Conference

Dementia in a changing world

Virtual Conference

20–22 October 2020

www.alzheimer-europe.org/conferences

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