

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



It has been a strange and difficult month. COVID-19 has made everyone's daily lives into more of a challenge and especially so for people with dementia. In order to support people with dementia, carers, care

professionals and national Alzheimer's associations during the ongoing COVID-19 situation, we have pulled together a range of valuable online resources in a special section on our website. We are also closely monitoring the situation and have gathered news about actions being taken by many of our member associations. It is inspiring to see how well they are all coping, ensuring the continuation of their important work, supporting people with dementia and carers, during this trying period.

At the request of the Scottish Government, Alzheimer Europe also convened an online meeting of the European Group of Governmental Experts on Dementia to discuss the responses of countries to COVID-19, with particular emphasis on how governments are ensuring that people with dementia continue to be supported. The meeting was well-attended with 13 countries being represented as well as the European Commission, the OECD and the World Health Organization. Positive news, too, from Croatia, where the parliament has decided to launch the process to adopt a National Dementia Strategy. Congratulations to our colleagues at Alzheimer Croatia, who have been instrumental in making this happen.

A number of the projects in which we are involved held online meetings this month in lieu of face-to-face events, including AD Detect & Prevent, Neuronet, PARADIGM, RADAR-AD and Recognised, while a new project, Eurofingers kicked off with an online meeting. Eurofingers will work on the prevention of dementia and will build on the work of similar existing European studies. We are excited to be a part of this new venture. On another note, one of the projects in which we have been involved since its kick-off in 2015, EPAD comes to an end this year. Project coordinators announced the closure of the Longitudinal Cohort Study and thanked everyone who helped make the project a success.

The situation has of course also had an impact on our work, but we are persevering, as are our member organisations and the members of our European Working Group of People with Dementia. Our staff is working from home, staying safe and looking after family and I am deeply grateful for their dedication in ensuring our work continues, despite the circumstances. I would also like to say thank you to Christophe Bintener, for his contributions to the team since January 2017. As of 31 March, Chris has moved on to a new position and we wish him every success!

The 30th Alzheimer Europe Conference is still planned to take place in Bucharest from 20-22 October. Our call for abstracts is open until 15 May, as are registrations, with Early Bird fees available until 15 July.

Keep healthy and well.

Jean Georges
Executive Director

COVID-19 SITUATION

17-24 March: Alzheimer Scotland issues statements on their response to the coronavirus pandemic



On 17 March, Henry Simmons, the Chief Executive of Alzheimer Scotland, issued a first statement on how Alzheimer Scotland is responding to the ongoing coronavirus pandemic. This statement, which was published on their website and shared via their social media channels, outlined the measures Alzheimer Scotland had put in place to ensure the health, safety and wellbeing of the people they support, their staff and volunteers. These included increased cleaning regimes in all their local Dementia Resource Centres and services, as well as regular monitoring of staff temperatures. Henry Simmons emphasised Alzheimer Scotland's unwavering commitment to provide support for people with dementia, their carers and families. He encouraged people to use the Alzheimer Scotland 24h Freephone Dementia Helpline as a source of support and information.

An update to this statement was released on 24 March, in response to the new UK and Scotland lockdown guidelines issued by the Prime Minister on 23 March. From 24 March, all Alzheimer Scotland office bases and Dementia Resource Centres will be closed, with staff and volunteers working from home. In addition, the level of support provided to the 24h Freephone Dementia Hotline has been increased, with the creation of a central support team aiming to help people experiencing difficulties in accessing medication, information or emotional support. Moving forwards, Alzheimer Scotland hopes to convert their Day Services into a home support service for those in greatest need, while other activities and community groups will be moved online. Further updates will be provided in due course.

19 March: Fundación Alzheimer España asserts "We won't let distance get in the way of our care"



At this time of uncertainty and anxiety, flexibility, for the lack of any alternative, is the only approach to caring for people with dementia. As one of the main bodies of reference in the field of dementia, FAE (Fundación Alzheimer España) cannot, and will not, let down its guard during the current coronavirus pandemic. The fact that our headquarters, and consequently our capacity for direct, hands-on care, has had to see its shutters pulled down indefinitely, stands no chance of getting in the way of some of the much-needed services we offer.

FAE's staff members, each from their respective home-based work stations, have got down to the nitty-gritty and have rapidly put in place a tele-assistance service aiming at providing people with dementia and their relatives and carers with some of the supports that will help them come out the other side, while preserving, in so far as possible, their overall health and general wellbeing, both mental and physical.

By providing services such as daily contact over the phone; regularly mailing out cognitive exercises and getting them returned for marking; sending out regular information circulars containing the latest news and developments, tips and advice; and, links to on-line resources, FAE is trying to relieve carers' worries about the impact of the coronavirus situation. We want to ensure that loneliness and boredom are removed from the isolation equation, and that, to the best of our expertise, all basic and non-basic needs of people with dementia are met in such a rapidly changing and oppressive context. Not losing focus on practical issues, providing tailored distance care and assistance, and offering psychological relief and tools, to both deal with the situation and properly support a person with dementia, are some of the keys to success.

We will continue to ensure we are only a phone call or an e-mail away, with our arms outstretched, and with a constant spark of hope in our hearts. We will make it through this difficult time, together as one, as has always been the case.

25 March: France Alzheimer publishes tips on managing social isolation and advice for families and caregivers of people with dementia



In response to the ongoing coronavirus pandemic, France Alzheimer has created several resources aimed at supporting people with dementia, their families and caregivers. On 18 March, France Alzheimer announced that its 99 departmental associations would be setting up additional telephone helplines staffed by trained volunteers, aiming to provide support and information to those in need.

France Alzheimer has also published advice for carers and caregivers of people living with dementia, highlighting ways in which they can provide support in the home or in care institutions. These include demonstrating good hand washing techniques, ensuring a good supply of prescription medication, and making sure that people with dementia can keep in touch with their family and caregivers via phone calls, emails or letters.

To support people with dementia who are isolated at home, France Alzheimer suggests creating a structured routine that can be followed, offering reassurance and stability and reducing anxiety. The importance of remaining physically and cognitively active is emphasised, and several suggestions for physical and cognitive activities are provided, such as doing craft projects, listening to music, doing stretching exercises

and walking on the spot. France Alzheimer also encourages people to use technology, devices and telephone conversations, where possible, to remain connected with friends and family.

For more information, visit:

<https://www.francealzheimer.org/covid-19-conseils-pour-les-aidants-et-personnes-malades-dalzheimer-ou-dune-maladie-apparentee/>

<https://www.francealzheimer.org/coronavirus-confinement-comment-prendre-soin-de-son-proche-malade/>

26 March: Association Luxembourg Alzheimer keeps on working, so others don't have to



On 26 March, Association Luxembourg Alzheimer, posted a number of photographs on its Facebook account, showing members of staff at work during these difficult times, with the slogan "we are working, so you can stay at home". Association Luxembourg Alzheimer continues to provide its vital services and also aims to raise awareness of the need for other people to stay home, to help protect vulnerable populations and care workers.

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

26 March: Alzheimer's Society provides updates on coronavirus for people with dementia and their carers



The Alzheimer's Society has set up a specific section on its website, providing advice and guidance on how to support a person with dementia during the coronavirus pandemic.

On their website, the Society provides practical tips for people living with dementia and those supporting them,

including different scenarios where a person may be living alone or where a carer may be providing support at a distance.

The Society also directs people towards its two support lines 0333 150 3456 and 03300 947 400, the latter of which is for Welsh-speakers. In addition, they also have an online

community, in which people can connect and talk with others affected by dementia, called [Talking Point](#).

For more information visit: <https://www.alzheimers.org.uk/get-support/coronavirus-covid-19>

26 March: Alzheimer Nederland publishes advice and resources for people with dementia in relation to COVID-19



**alzheimer
nederland**

Alzheimer Nederland has made a number of resources and information available on its website about the COVID-19 pandemic. Their website acknowledges the specific difficulties for people with dementia during the pandemic and offers practical advice for supporting people.

The website has online support through a [dedicated section within its forums](#) where individuals can speak with each other about COVID-19. Additionally, people can phone the helpline between 9am and 11pm on 0800-5088.

The website also highlights ways of overcoming social isolation and keeping people connected, despite the social distancing measures. People are encouraged to share examples online, through social media, using the hashtag #wevergetenjullieniet

A dedicated section of the Alzheimer Nederland website has been set up at: <https://www.alzheimer-nederland.nl/corona>

More information can be found at:

<https://dementie.nl/dementie-en-corona>

26 March: German Alzheimer's Association publishes information and guidance on COVID-19



The German Alzheimer's Association, Deutsche Alzheimer Gesellschaft, has published information and guidance in

relation to people living with dementia and COVID-19.

In relation to restrictions on nursing home visits, the Association notes that restrictions vary by state, and direct people towards: www.biva.de/besuchseinschraenkungen-in-alten-und-pflegeheimen-wegen-corona/

Additionally, the Association directs people to official guidance on COVID-19, on the Federal Center for Health Education website: www.infektionsschutz.de/coronavirus/

To ensure people maintain exercise, the "Getting older in balance" website is also suggested, which contains videos with exercise which can be performed at home: www.aelter-werden-in-balance.de/online-bewegungsangebote/uebungsvideos/

The Association also highlights that further advice and information is available on its app, entitled "Alzheimer & YOU - actively shaping everyday life", which can be downloaded free of charge:

For the iPhone: "Alzheimer & YOU - Den Alltag aktiv gestalten"

For Android devices: "Alzheimer & YOU - Den Alltag aktiv gestalten"

You can find out more information here: <https://www.deutsche-alzheimer.de/index.php?id=1128>

26 March: Spomincica Alzheimer Slovenia publishes advice on supporting people with dementia during the coronavirus pandemic



Spomincica Alzheimer Slovenia has created a resource outlining hints and tips for supporting people with dementia during the coronavirus pandemic, whether they live at home, alone or in a care setting. They emphasise the importance of keeping busy, encouraging family members and caregivers to engage

persons with dementia in activities such as household tasks, reading, drawing or playing board games. Although visits to care or retirement homes are discouraged, Spomincica highlights several ways to ensure people with dementia remain in touch with their loved ones, including phone calls, video calls, emails and letters.

The resource can be found here: <https://www.spomincica.si/?p=99117>

For further information, Spomincica Alzheimer Slovenia can be contacted via their advice helpline on +386 059 305 555, or via email at svetovanje@spomincica.si. The helpline is staffed between 9am and 6pm and a clinical neurologist is available through this helpline each day for one hour. Their Facebook page will be regularly updated with suggestions for activities that can help enhance cognitive and physical wellbeing.



ALZHEIMER EUROPE

25 March: 30th Alzheimer Europe Conference still planned to take place in October and the call for abstracts is still open



During this time of uncertainty regarding COVID-19, the 30th Alzheimer Europe Conference #30AEC is still planned to take place in Bucharest from 20-22 October 2020.

Our call for abstracts is open, as are registrations, with Early Bird fees available until 15 July 2020. Register now and benefit from the reduced registration fee of EUR 340 instead of EUR 475. Special rates are available for people with dementia, students, delegates

from lower and middle-income countries and members of Societatea Română Alzheimer.

Alzheimer Europe and Societatea Română Alzheimer welcome abstracts for oral and poster presentations, in English, in the following categories:

People: Carers of people with dementia; Minority ethnic groups; Dementia and sexuality; Involving people with dementia.

Care approaches: Post-diagnostic support; Psychosocial interventions; Assistive technologies; Palliative care.

Care services: Memory clinics and centres; Acute and hospital care; Day and respite care; Training of care professionals.

Medical and public health aspects: Diagnosis; Risk factors and prevention; Young onset dementia; Genetics.

Policy: Awareness campaigns; National dementia strategies; Supporting family carers; Legal and ethical issues.

Please read the abstract submission guidelines carefully before submitting an abstract. The submissions deadline is 15 May 2020: <https://www.alzheimer-europe.org/Conferences/Bucharest-2020/Call-for-Abstracts>

The Alzheimer Europe office is operating at a reduced level with staff working from home, but we assure you that we are still available should you need assistance or information on the conference proceedings.

We hope that you, your families and your team members are safe and well.

We are closely monitoring the situation and will keep you informed on any new decision made regarding the event in October.



28 March: To support people with dementia and carers during the COVID-19 pandemic, Alzheimer Europe launches a website section with key resources



With the coronavirus spread across European countries, various restrictions have been put in place ranging from the closure of important services such as day care

or respite care to the prohibition of visits to nursing and old people's homes. This situation and some of these restrictions also adversely affect people with dementia and their carers.

To support carers and associations providing support and help for people with dementia in these difficult times, Alzheimer Europe has collected a number of resources which we hope will prove helpful and useful.

The long list of resources that have been gathered bears testament to the important and invaluable work provided by

national Alzheimer's associations and government agencies during the COVID-19 pandemic.

We have broken down these resources into the following categories and hope to update these pages on a regular basis:

- Information for people with dementia
- Advice for caregivers and family members
- COVID-19 and mental health
- COVID-19 in numbers: epidemiology
- Global resources
- EU resources
- National country resources
- Scientific resources.

<https://www.alzheimer-europe.org/Living-with-dementia/COVID-19>

31 March: Alzheimer Europe says farewell to project officer Christophe Bintener

On 31 March 2020, Christophe Bintener left his position as project officer at Alzheimer Europe. Chris had been working for Alzheimer Europe since January 2017, with a main focus on

the MOPEAD and ROADMAP projects during 2017 and 2018, and on the NEURONET project since the start of 2019.

He decided to leave Alzheimer Europe for a new opportunity and the whole team wishes him great success in his next role and other endeavours.

The recruitment process for a new Project Communications Officer is underway, though it has had to be temporarily suspended, due to COVID-19 restrictions.



Alzheimer Europe networking

On 3 and 4 March (Amsterdam, Netherlands), Jean attended the meeting of the Patients' and Consumers' Working Party at the European Medicines Agency.

On 4 March Dianne and Ana attended the online RADAR-AD annual meeting.

On 11 March Jean, Dianne and Ana attended the online EURO FINGERS kick-off meeting.

On 16 March Ana and Cindy attended the PREFER-PARADIGM webinar.

On 17 March Angela attended the online inaugural meeting of the RECOGNISED Dissemination and Exploitation Board.

On 16 March, Dianne participated in the AD Detect & Prevent online steering committee meeting.

On 24 March, Alzheimer Europe hosted an online meeting of the European Governmental Expert Group on Dementia.

On 24 March Angela took part in the online Judging Panel for the AAL Smart Ageing Prize.


On 27 March, Dianne and Jean participated in an online meeting of Alzheimer Europe's expert working group on intercultural care and support.

On 31 March Ana and Cindy attended the online PREFER-PARADIGM workshop.

On 31 March, Jean attended the online meeting of the Dementia Panel of the European Academy for Neurology.

EU PROJECTS

26 February: Meeting of the Neuronet Working Group on data sharing is held at Johnson & Johnson headquarters in Belgium

 On 26 February, the Neuronet Working Group on Data Sharing held a meeting at the Johnson & Johnson headquarters in Diegem, Brussels. The Neuronet Working Groups (WGs) are cross-project spaces for experts to discuss common issues, priorities and opportunities for synergy and collaboration, providing Neuronet with expert advice on four identified areas

of interest: data sharing, HTA/regulatory interactions, patient privacy & ethics, and sustainability. As such, the WGs make an important contribution to Neuronet's goal of compiling and leveraging the expert knowledge that is presently scattered across the different neurodegeneration projects in the Innovative Medicines Initiative (IMI) portfolio.

Lennert Steukers, the Project Leader for Neuronet, kicked off the WG meeting with a brief overview of the structure, function and aims of Neuronet. Focusing on the WGs, he highlighted the importance of collating best practice in data sharing from the different IMI projects on neurodegeneration, as well as working together to identify – and overcome – common challenges. Presentations were then given by three

experts on data sharing, starting with Rodrigo Barnes of Aridhia DRE. Aridhia DRE is a Scottish clinical informatics company which is providing the EPAD project with its data and analytics platform. Rodrigo identified some common data sharing challenges for consortium projects that involve clinical research studies, including pseudonymisation, audits and data protection issues. Next, Nigel Hughes from Janssen Clinical Innovation (where he is Scientific Director for Patient Data in Research) spoke about his experiences of data sharing in the EMIF and EHREN projects. A focus of both of these IMI projects was the harmonisation and integration of disparate data sources, and Nigel discussed some of the regulatory, ethical and technical challenges that can arise in data-focused projects such as these. Finally, Martin Hofmann-Apitius of the AETIONOMY project presented several examples of clinical research data sharing, also suggesting some practical solutions to maximise the use and re-use of these valuable datasets.

Going forwards, the WG will focus on developing specific guidance to aid projects on data sharing policies and tools, incentives, value propositions and infrastructural solutions, among others. This will help facilitate the sharing of and access to data, biological tools and other materials amongst IMI projects, as well as with other interested researchers at a European and global level.

2 March: PARADIGM carries out social-media campaign introducing different case study examples of patient engagement



The PARADIGM project - Patients Active in Research and Dialogues for an Improved Generation of Medicines – carried out a mini campaign on social media between 2 and 20 March, using the hashtag #PARADIGM4Real. The aim of the campaign was to show the value and challenges of patient engagement and to draw attention to the PARADIGM tools that will enable better, more meaningful engagement.

The campaign consisted of a series of six articles, shared on Twitter via the project’s @imi_paradigm account. The first was an editorial piece and the other five articles were:

- On 5 March, The Children’s Tumor Foundation shared its learning in providing training to the patient community in order to enable more involvement within the medicines research and development (R&D) area.
- On 9 March, Novartis shared its experience in embedding patient engagement at all stages of the drug development

process that was met within the company with both enthusiasm and scepticism.

- On 12 March, The Canadian Agency for Drugs and Technologies in Health (CADTH) outlined its challenges and successes of integrating patient engagement processes across all programmes from the health technology assessment (HTA) standpoint, highlighting the importance of sharing and replicating good practices from other areas within the health system.
- On 16 March, Pfizer shared how a multi-stakeholder group was formed to plan and gather more patient insights for a clinical trial and how these insights ended up influencing the changes made in the trial protocol, hopefully making the trial more manageable for patients and carers.
- Finally, on 19 March, another patient engagement project was shared by the NIHR biomedical research centre of University College London Hospital where cancer patients played an instrumental role in the development of a digital health toolkit. The patients and carers’ roles evolved and expanded as the project progressed.

PARADIGM is an IMI-funded European project with a mission to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement (PE) and demonstrates the “return on the engagement” for all players.

4 March: RADAR-AD annual meeting takes place online



On 4 March RADAR-AD consortium met online, as the planned meeting in Switzerland had to be cancelled due to the

COVID19. During the meeting, the work carried out during the first year of the project was presented as well as the planned activities for the coming months. AE presented the activities of the Patient Advisory Board (PAB) from March 2019 to date. During its first year of life, the PAB has been very actively involved with all WPs and has provided input to several activities including the patient-facing materials for the trials. It was explained that currently, in addition to members living with dementia and carers, two persons with Mild Cognitive Impairment (MCI) had joined the Board. In addition, a local group of people with MCI in Greece had also provided input to the activities related to recruitment and retention in the trials. It is hoped that PAB members will continue with this active and meaningful collaboration with the RADAR AD researchers in 2020. Dianne and Ana participated in the call.

5 March: EPAD project publishes a paper examining the relationship between cognitive performance and AD biomarkers

On 5 March, an international team of researchers from the European Prevention of Alzheimer’s Dementia (EPAD) project published an article in the journal of Alzheimer’s disease

entitled “Cognitive Functions as Predictors of Alzheimer’s Disease Biomarker Status in the European Prevention of Alzheimer’s Dementia Cohort”. The study examined the relationship between the main biomarkers of Alzheimer’s disease (AD) and the cognitive performance in the first five hundred research participants recruited into the EPAD Longitudinal Cohort Study (LCS). This cohort represents a general population-based registry of volunteers at dementia risk undergoing clinical examination prior to recruitment into the EPAD clinical trials. Analysis showed that the majority of research participants had elevated biomarker levels, with significant associations between an episodic verbal memory task and tau, while amyloid- β was associated with a central executive task.

<http://dx.doi.org/10.3233/JAD-191108>

5 March: PACE project publishes three articles aiming to guide quality improvement on palliative care in long-term care facilities



The PACE project - Palliative Care for Older People in care and nursing homes in Europe – has published three new papers in JAMDA (Journal of the American Medical Directors Association), all of which, the project says, could guide quality improvement on palliative care in long-term care facilities:

- Palliative Care Implementation in Long-Term Care Facilities: European Association for Palliative Care White Paper tinyurl.com/tr5n8v3
- Perception of the Quality of Communication With Physicians Among Relatives of Dying Residents of Long-term Care Facilities in 6 European Countries: PACE Cross-Sectional Study tinyurl.com/rwtv8p6
- Factors Associated with Perception of the Quality of Physicians' End-of-life Communication in Long-Term Care Facilities: PACE Cross-Sectional Study

tinyurl.com/r7jctez

11 March: New JPND project EUROFINGERS kicks off



On 11 March, the new JPND-funded project EUROFINGERS, kicked off in an online meeting. This replaced a planned face-to-face meeting in Stockholm which could not take place due

to current restrictions in travelling in Europe. All partners of the consortium actively participated in the online kick-off meeting which is led by the Karolinska Institute (Sweden). Over the next three years, EUROFINGERS will, by means of a precision medicine approach, work on the topic of the prevention of Alzheimer’s disease (AD) and will build on the work of similar existing European studies. During the kick-off meeting representatives from the different work packages

in the project presented and briefly discussed their planned work including amongst other activities the development of (1) a model which will help to identify people at higher risk of developing AD dementia who may be more likely to benefit from targeted preventative interventions and (2) online registries in different countries in Europe. Alzheimer Europe (AE) will be involved in the Patient and Public Involvement (PPI) activities of the project and in this context, will set up a Patient Advisory Board to provide relevant input to the researchers from the perspective of people with Alzheimer’s disease across the disease continuum. AE will also co-lead the communication activities of the project, particularly the communication of the project activities and results to lay audiences and people affected by AD. Jean, Dianne and Ana took part in the meeting.

Alzheimer Europe’s participation is supported by the Luxembourg national research Fund (FNR).



16 March: AD Detect & Prevent holds 3rd steering committee meeting virtually



On 16 March 2020, due to concerns about the spread of the coronavirus and travel restrictions of most research partners, the AD Detect &

Prevent had a full-day steering committee meeting by teleconference. Research partners and work package leaders all took part and had productive exchanges. This included updates and discussions about product development, the scientific trials, the planned database for pooling large datasets (including health, behavioural and neuroimaging data), the active control condition, Public and Patient Involvement, procedural ethics issues and steps towards acceptance and market adoption of the future product. Dianne represented Alzheimer Europe at this meeting, and emphasised the importance of pursuing the goal of ethical communication within the project and in disseminations activities after its completion. It was agreed that Alzheimer Europe and the European Working Group of People with Dementia would also continue to collaborate with the University of Nottingham on PPI work.

18 March: RECOGNISED convenes the first meeting of its Dissemination and Exploitation Board

Recognised On 18 March, the Horizon 2020-funded RECOGNISED project convened the first meeting of its Dissemination and Exploitation Board. RECOGNISED stands for “Retinal and cognitive dysfunction in type 2 diabetes: unraveling the common pathways and identification of patients at risk of dementia”. The teleconference meeting was chaired by EATRIS, the European Infrastructure for Translational Medicine, and was attended by projects partners from

academia, small and medium enterprises (SMEs) and patient organisations, including Alzheimer Europe and the International Diabetes Federation.

The four-year long RECOGNISED project will study the biological mechanisms that cause structural and functional alterations in the retina in people with type 2 diabetes at risk of developing cognitive impairment and dementia. Based around the concept of the eye being a “window to the brain”, RECOGNISED will determine whether evaluating the retina, easily accessible with current non-invasive technologies, could help in identifying earlier cognitive impairment in people with T2D, so that appropriate support can be given.

The role of the RECOGNISED Dissemination and Exploitation Board (DEB) is to help guide the effective dissemination and exploitation of RECOGNISED project results, increasing project visibility for key stakeholder audiences. During the meeting, attendees discussed the dissemination and exploitation plan, intellectual property workflows, strategies for empowering patients and families, and both internal and external project communications. The DEB will be reconvened in the summer.

Angela Bradshaw represented Alzheimer Europe at this meeting.

25 March: EPAD Longitudinal Cohort Study is closed down and EPAD coordinators thank all involved

Dementia (EPAD) project notified the closure of the EPAD Longitudinal Cohort Study to all EPAD members and study team.

The grant received by the Innovative Medicines Initiative which has funded EPAD from 2015 runs out in June 2020. The EPAD team worked hard over the past months to guarantee the funding to continue running the Longitudinal Cohort Study from July 2020. Unfortunately, they were not able to secure the necessary resources which resulted in its discontinuation. The project coordinators pointed out that although it will no longer be possible to run the Longitudinal Cohort Study, research into Alzheimer’s disease will continue through the passion and determination of the site staff across Europe. They also highlighted that the collected EPAD data will continue to provide important information and insights about the disease.

The project coordinators thanked all EPAD members and research participants for their commitment to the study and the fight to understand Alzheimer’s disease better. They also took the opportunity to thank friends and family of research participants who supported them in their visits.

The news message can be read here:

<http://ep-ad.org/2020/03/25/message-from-the-epad-coordinators-to-all-involved-in-the-epad-longitudinal-cohort-study/>



On 25 March, Serge Van Der Geyten and Craig Ritchie, the coordinators of the European Prevention of Alzheimer's



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
- EPAD** - grant agreement 115736
- Neuronet** - grant agreement 821513

- PARADIGM** - grant agreement 777450
- Recognised** - grant agreement 847749
- RADAR-AD** - grant agreement 806999

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); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtsun (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).

EUROPEAN ALZHEIMER'S ALLIANCE

1 March: Deirdre Clune MEP becomes Vice-Chair of the European Alzheimer's Alliance (EAA)



Alzheimer Europe is delighted to announce that Deirdre Clune MEP (EPP, Ireland), has agreed to become a Vice-Chair of the European Alzheimer's Alliance (EAA).

Ms Clune has been an active supporter of the EAA over a number of years and recently joined the group again after taking up her seat as an MEP in February 2020.

We look forward to working with her more closely to help ensure dementia remains a priority at an EU level.



EU DEVELOPMENTS

14 March: European Commission launches new industrial strategy



The European Commission has published an industrial strategy, focused on creating improved conditions for businesses and industry in Europe, whilst moving towards a more environmentally friendly and digital approach.

The Strategy sets out how much of the policy agenda at a European level aligns, with the stated aim of driving industrial transformation, through dedicated efforts across a broad range of industries. Proposals include:

strengthening Europe in relation to the pharmaceutical industry through a new EU Pharmaceutical Strategy supporting the development of strategic digital infrastructures and key enabling technologies

a renewed focus on innovation, investment and skills.

The full strategy can be read here:

https://ec.europa.eu/info/sites/info/files/communication-eu-industrial-strategy-march-2020_en.pdf

24 March: Governmental Experts on Dementia meet online to discuss COVID-19 and dementia



On 24 March, following the suggestion of the Scottish Government, Alzheimer Europe organised and hosted an online meeting of the European Group

of Governmental Experts on Dementia to discuss the responses of countries to COVID-19. In particular, the meeting focused on how governments were ensuring that people with dementia continued to be supported during the extenuating circumstances.

A total of 20 people were present on the call, with representatives from Austria, Belgium – Flanders, Czech Republic, Estonia, France, Germany, Ireland, Netherlands, Poland, Sweden and the United Kingdom – Scotland, all participating in the online meeting.

Additionally, observers from Alzheimer Europe, the European Commission (both DG RTD and DG Santé), the Organisation for Economic Cooperation and Development (OECD) and the World Health Organization (WHO) were present.

Countries exchanged information and resources about from their respective countries, including information on the

current context of the country and good practice examples for people with dementia or other vulnerable populations (e.g. easy read communications). Other topics of conversation included how to ensure persons with dementia and their carers did not become isolated in countries where lockdown measures had been implemented.

Alzheimer Europe collected the links and resources exchanged by members on an online platform to allow members of the group to have a single reference point for resources and actions taking place in other countries. Members will be able to share and upload resources on an ongoing basis on this platform.



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MEMBERS' NEWS

8 March: Alzheimer's Society marks International Women's Day



Dementia is the healthcare challenge of our generation. And whilst dementia doesn't discriminate, it hits women the hardest. On International Women's Day, Alzheimer's Society took the opportunity to shine a light on women's

experiences of dementia and of working in dementia research. Worldwide, women with dementia outnumber men two to one and face more severe and rapidly progressing symptoms. Women also provide a much greater proportion of unpaid care to people living with dementia. Globally, this amounts to the equivalent of 40 million full-time workers every single year.

Dementia is a women's issue and it's one that women can solve, Alzheimer's Society asserts. Evidence shows that research studies with at least one female contributor are more likely to tackle women's health issues and the differences between the genders, than studies with no female contributors. Unfortunately, women are still under-represented in research, particularly at the highest levels. Women make up only 24% of the total UK STEM (science, technology, engineering and mathematics) workforce and hold

only 14% of STEM management roles. In order to create an environment where the impact of dementia upon women is reduced, stronger supports are needed which will empower female researchers to succeed.

Alzheimer's Society is taking action to create a better world for women living with dementia, women carers and women researchers. Family-friendly policies and research funding procedures are in place to support scientists to stay in dementia research careers. Alongside this, Alzheimer's Society's grant review boards and external reviewers are proportionally split 50/50 male and female to avoid gender bias in funding decisions.

The results speak for themselves. There is a much fairer gender representation in the Society's research, with 55% of active research projects led by women. Women are also equally represented at senior level, with women leading over 51% of project-level grants.

Alzheimer's Society is also spearheading work across the UK with employees and businesses to support workers with dementia care commitments. All the while, the Society continues to strive to be there for everyone affected by dementia, via the new national support service, Dementia Connect.

In the coming year, Alzheimer's Society looks forward to doing even more to secure a fairer deal for people living with dementia and their carers, as well as addressing the gender imbalance in dementia research.

18 March: Societatea Română Alzheimer reports on its successful involvement in ERASMUS+ project "Story2Remember"



The Societatea Română Alzheimer has successfully participated (as lead partner) in an ERASMUS+ funded pilot project to create a training programme using creative drama and storytelling in dementia care. The target audience for the Story2Remember programme is health and social care professionals,

people with dementia and care providers.

A detailed training handbook has been developed for the Story2Remember programme, which is designed to provide new learning opportunities in the field of caring for people with Alzheimer's and dementia. The handbook can be downloaded from the project website in English, Romanian, Greek and Bulgarian: <https://story2remember.eu/>.

In tandem with the project's booklet "Creative drama and storytelling in dementia care: Information for practitioners", this new handbook is designed to equip health and social care professionals with all the necessary information, skills and materials to guide the delivery of the Story2Remember programme, in care settings.

The training programme itself consists of several workshops based on storytelling and creative drama that were first tested in Ireland, in May 2019, in one of the Health Service Executive Centres. Following the successful testing in Ireland, trained professionals from Erasmus+ partners piloted the programme in the United Kingdom, Romania, Bulgaria and Greece, involving over 80 professionals and over 70 people with dementia.

Some of the reported benefits are:

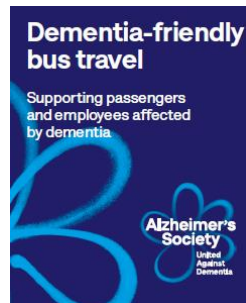
- improving social interaction
- supporting creativity
- team bonding
- improving well-being
- improving self-esteem
- learning new things
- feeling relaxed
- feeling motivated to read and write
- creating memorable experiences.

The programme was developed by the Gaiety School of Acting and the National Theatre School of Ireland and was piloted together with the Erasmus+ partners (Societatea Română Alzheimer – lead partner, Habilitas – CRFP, Alzheimer Bulgaria, Alzheimer Hellas and Bournemouth University) between September and December 2019.



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19 March: Alzheimer's Society partnered with the Department for Transport's campaign, launching dementia-friendly bus transport resources



Alzheimer's Society has partnered with Department for Transport on their current campaign – "It's everyone's journey"- to address the fact that too many disabled people do not feel confident using public transport.

The campaign runs from 25 February to the end of March 2020. It aims to show the impact that other

passengers' unconscious behaviour can have on disabled passengers, and encourages a change in behaviour. Alzheimer's Society and people with dementia have provided feedback on the issues being highlighted during the campaign and also on the materials which will be advertised at railway stations, bus stops, on buses and trains across the country.

Two-thirds of people living with dementia in the UK live in the community but less than half (47%) feel like they are a part of it. Transport is a lifeline; helping people retain their independence, combat loneliness and live well with dementia.

Alzheimer's Society have launched two resources for the bus sector, setting out best practice and key actions the bus industry can take to become more dementia-friendly. They are in the form of an information card for bus organisations and a 'Top 10 Tips' booklet for bus drivers, providing advice on how they can support and assist people living with dementia.

The resources have been created by consulting directly with people living with dementia, through regional Focus on Dementia groups and alongside organisations in the sector such as Bus Users UK, Blackpool Transport and Brighton & Hove Buses; all of whom lead the way in accessibility and working towards a more dementia-friendly bus sector.

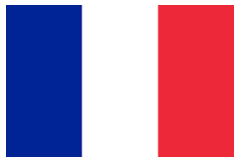
There are regional pockets around the country where bus operators are engaging with Alzheimer's Society to be more dementia-friendly and where some partner organisations have over 5000 Dementia Friends. However, the aim of these resources is to help support the sector to increase the number of Dementia Friends, on a national scale and help them take steps towards ensuring the services they offer are fully accessible and dementia-friendly.

Making clear announcements to keep passengers informed, providing signposts to show them where to find support when routes are disrupted, and producing easily accessible timetables are some examples of actions that can support people living with a wide range of disabilities, including dementia. Both individuals and organisations can collectively create a more supportive travel environment for people living with dementia.

To download the resources, visit: alzheimers.org.uk/bus

POLICY WATCH

18 March: France calls on international experts to evaluate the implementation of its recent neurodegenerative diseases plan



The French neurodegenerative diseases plan for 2014-2019 ended in December 2019. For France Alzheimer, this national strategy, which started with almost one year of delay, was deployed unequally on the French territory. Despite some significant progress in the diagnostic pathway and the therapeutic patient education, its global budget of EUR 470 million and the lack of mobilisation of some public operators, made it difficult to implement all of its 96 measures.

Nevertheless, after multiple calls to action from France Alzheimer, the French Ministry of Health finally invited all the stakeholders to meet on 13 February 2020. At this meeting, the government took the time to listen to the associations' priorities and concerns about the future. It was also announced that two international experts have been nominated to lead the evaluation of the Plan.

It appeared to be a great opportunity for all the associations and foundations involved (France Alzheimer, France Parkinson, the French League for people living with multiple sclerosis, Fondation Médéric Alzheimer...) to work closely on the identification of the remaining priorities in terms of healthcare pathways, support of informal caregivers and a more inclusive society.

This collaborative document was presented to the two chosen experts, by the stakeholders, on 18 March 2020. The experts will send their final report to the government before the end of June, pending possible changes due to the current international situation. In any event, France Alzheimer will keep lobbying the authorities in the coming months. It remains essential that the French Government understands the issues at stake, when it comes to the needs of people living with dementia and their caregivers. As Alzheimer Europe's "Dementia in Europe Yearbook 2019" shows, the estimated prevalence of dementia in France will almost double by 2050, and the country's current health system is not yet fully prepared to address everyone's needs.

18 March: Croatian parliament unanimously decides to launch National Dementia Strategy



The Croatian Parliament has unanimously adopted two conclusions proposed by Alzheimer Croatia and a number of societies of the Croatian Medical Association, during a thematic session of the

Parliament's Committee on Health and Social Policy. The conclusions of Parliament are as follows:

- It is necessary to develop a National Strategy for the Fight against Dementia in the Republic of Croatia in view of the increasing incidence of dementia and the needs of persons with dementia, in accordance with the recommendations of the World Health Organization.
- A Commission should be established to develop a National Strategy for the Fight against Dementia (composed of experts, representatives of the Ministry of Health and the Ministry of Demography, Family, Youth and Social Policy, and representatives of non-governmental organisations).

Alzheimer Europe is delighted that the work of Alzheimer Croatia, health professionals and family carers of people with dementia has resulted in such a positive outcome.

We look forward to seeing dementia prioritised as a public health matter in Croatia and to the development of a national strategy to improve the lives of people living with the condition.

19 March: France Alzheimer's national campaign for a more inclusive society is supported by over 200 cities/departments



Last year, France Alzheimer and related diseases chose to focus its message on inclusiveness and the necessity for all citizens to take into consideration people living with dementia and their caregivers. The organisation's main objective is to raise awareness among society and to dismantle the stigmas

around the disease and its consequences.

France Alzheimer launched a national campaign on World Alzheimer's Day 2019, which will have a long-lasting impact. The campaign has three main axes:

- raising awareness and training the major local actors (police, fire departments, etc.), with the help of France Alzheimer's nationwide network
- broadcasting a unifying symbol of recognition to signal support for people living with dementia
- inviting mayors of every French city to sign the France Alzheimer pledge "Alzheimer Caring City" and engage in an inclusive approach.

The unifying symbol (pictured) has been shared repeatedly and will continue to be broadcast as widely as possible. It is a useful tool to spread awareness and emphasise the necessity to show more support to people living with dementia and their caregivers.

So far, more than 200 cities and/or departments have signed the pledge "Alzheimer Caring city" and after the local elections of March 2020, we will keep on spreading the need for more understanding and active cities, villages, departments...

Concerning the training of major local actors France Alzheimer has been able to contact national or local federations and is still working on developing a specific training offer.

19 March: Alzheimer’s Society releases new animation on Dementia Care highlighting the impact of the UK’s broken and unfair social care system



After delivering a letter to the UK Prime Minister signed by 112,000 people calling on him to fix dementia care last year, Alzheimer’s Society has been focusing its efforts on calling for urgent immediate investment in the care system in order to stabilise it.

Ahead of the March 2020 Budget, thousands of Alzheimer’s Society campaigners urged their MPs to contact the Chancellor and call for immediate investment in the social care system to support people living with dementia.

As part of this activity, the Society launched an animation telling the story of Isobel and John, and their experience with the social care system after John was diagnosed with dementia.

Narrated by Oscar-nominated actress and Alzheimer’s Society supporter Lesley Manville, the animation tells the story of Isobel and John’s family not only having to come to terms with John’s dementia diagnosis, but also having to struggle with an unfit and unfair social care system. The family could not find any support from the care system and were left to fend for themselves until Isobel was overcome with the pressures of caring for John and fighting the care system. You can watch the animation [here](#).

Although the 2020 Budget did not mention social care, Alzheimer’s Society is proud of the great response from supporters and their feedback that the animation had really resonated with them and their own stories. Ultimately, 14,000 people contacted their MPs, which is a fantastic result.

Alzheimer’s Society will now be focusing on the long-term reform of social care, ensuring that it works for people with dementia, who are the foremost users of the care system. A system that works for them, works for everyone.

For more information on the Fix Dementia Care campaign, visit: www.alzheimers.org.uk/fixdementiacarecampaign

24 March: The rights of people with dementia in Portugal are being better respected and promoted, thanks to a new legal framework



Although Portugal is still waiting for the implementation of the 5 Regional Dementia Plans in the field of Health and in spite of its Health Strategy for Dementia focusing solely on healthcare issues, and not at all on social issues, rights and research, a very important achievement happened in what concerns the rights of people with dementia, with the

implementation of a new legal framework for persons with diminished capacity (“Regime do Maior Acompanhado”) that is line with the New York Convention (Convention on the Rights of People with Disabilities).

This is a completely new paradigm based on autonomy.

The new legal framework came into force on 10 February last year and since then, Alzheimer Portugal is pleased to report that people become much more aware of the need to plan in advance.

In any individual situation, the measures are to be enacted in the perspective of restricting rights as little as possible, in order to respect as much as possible the person’s autonomy. For example, a person experiencing difficulties in dealing with money, taking complex decisions about their real estate or about how to manage savings, but who is still capable of taking other personal decisions, they can ask the court to appoint them a person “acompanhante”, to help them taking those decisions they are struggling with, but continuing to have autonomy in other areas. The person requesting this (the person with “diminished capacity”) has the right to choose the “acompanhante”. This is a big difference compared to the former framework that stated that the guardian should be the spouse or, if not possible, the eldest son or daughter.

As a person’s capacity may diminish further as their condition progresses, the court decision may be reviewed, at any time, as the circumstances change, and at least every five years.

Of course, there are people that are not cognitively in a condition to apply for their own measures, and in these circumstances, the judicial procedure may be initiated by another person (the spouse, cohabiting partner, or other close relative). This can only be done with sufficient reason given, in the eyes of the court, as to why it is necessary.

This is just one example of the positive changes taking place in Portugal, since the implementation of this new legal framework. There are many other aspects of this legislation that are helping to ensure the rights of people with dementia are being upheld.

The former legal framework was basically a one-size-fits-all. The current one is a custom made suit, which makes for a much more appropriate, practical and fair system.

There has been great interest from all the stakeholders to discuss and learn about this new legal framework and Alzheimer Portugal has organised several training initiatives, stressing the importance of respecting and promoting the rights of people with dementia.



SCIENCE WATCH

26 February: Study examines Dutch centenarians who maintained high levels of cognitive performance

On 26 February, Dutch researchers published a paper identifying centenarians who were able to maintain high levels of cognitive performance for a period of at least two years. Findings were published in the journal JAMA Network Open.

In the published study, researchers analysed data from the 100-plus study of 340 centenarians. It is a cohort study including Dutch centenarians enrolled between 2013 and 2019 who had annual visits until death or participation was no longer possible. Cognition was assessed using the Mini-Mental State Examination (MMSE).

At baseline, participants had a median age of 100.5 years and scored a median MMSE score of 25. Results showed an 82% survival rate per year across participants who scored 26 to 30 points on the baseline MMSE. Only 79 of the 340 participants were followed up for 2 years and no cognitive changes were observed for 73% of these centenarians. This group is likely representative of less than 10% of the Dutch centenarians. In contrast, participants who had a baseline MMSE score less than 26 had a lower percentage rate of survival and experienced a higher cognitive decline per year.

In addition, the researchers investigated the prevalence of the protein apolipoprotein E (ApoE) as a risk factor associated with cognitive decline. They found that 18.6% of the centenarians who scored 26 or higher on the MMSE had at least one ApoE-4 allele compared with 5.6% of those with lower and/or declining cognitive performance. They also pointed out some limitations of the study including that the 100-plus is a cohort cognitively intact, not representative of the overall centenarian population and that the MMSE might be controversial as a test to evaluate cognitive health in centenarians.

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

27 February: Biogen and Sangamo announce collaboration to develop gene regulation therapies for AD



On 27 February, the biotechnology companies Biogen and Sangamo Therapeutics

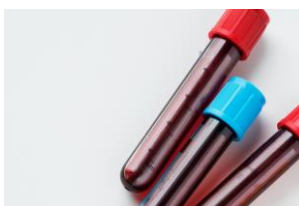
announced that they have signed a partnership agreement to develop therapies for neurological diseases including Alzheimer's disease (AD).

The partnership will initially focus on three gene therapy candidates. Biogen gets ST-501 targeting tau, a protein found in neurons which is abnormally hyperphosphorylated and present in excess in brains with AD. The agreement also includes rights for ST-502 for synucleinopathies such as Parkinson's disease and another undisclosed neuromuscular target. Moreover, Biogen has the exclusive rights to select up to nine additional undisclosed neurological targets.

Sangamo aims to address neurological diseases at a genomic level by developing therapies to selectively activate, repress or replace key genes involved in these diseases. Financial terms of the agreement include an upfront payment to Sangamo from Biogen of about USD 350 million. Sangamo will be eligible for up to USD 2.37 billion in milestone payments and royalties.

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

2 March: Two studies published in Nature Medicine show the diagnostic value of blood tests for pTau181 in Alzheimer's disease



On 2 March, two articles published back-to-back in Nature Medicine demonstrated the diagnostic and prognostic value of blood tests that measure pTau181 in Alzheimer's disease.

The two studies were carried out by research groups based in the US and in the EU, with first authors Shorena Janelidze and Niklas Mattsson (first study), and Elisabeth Thijssen (second study).

The accumulation of disordered Tau proteins in the brain is a defining neuropathological feature of Alzheimer's disease (AD). In healthy individuals, Tau is a fairly simple, filamentous protein that supports microtubules, molecular tracks that transport cargo inside brain cells. However, in AD, Tau becomes misfolded and misshaped, accumulating in squash racket-shaped knots called neurofibrillary tangles. One of the causes of Tau tangling in AD is a process called "phosphorylation", thought to happen as a knock-on effect of increased amyloid beta levels in the brain. Accumulating amyloid beta creates a microenvironment which favours Tau hyperphosphorylation, and this in turn alters Tau shape and function - leading to aggregation and tangling. One of the sites within the Tau protein that is particularly prone to hyperphosphorylation is residue 181 in the Tau protein chain: Tau that is hyperphosphorylated at this site is denoted as "pTau181". Research has shown that hyperphosphorylated forms of Tau such as pTau181 are released into the blood stream, and can be detected in blood plasma using antibody-based tests. Importantly, studies indicate that blood tests for pTau181 are correlated with PET imaging scans for amyloid beta and Tau, suggesting that blood tests for pTau181 may represent a minimally invasive and less costly way to diagnose

AD. However, it is not yet known whether plasma pTau181 can differentiate between AD and other neurodegenerative diseases - or whether it can accurately identify healthy individuals at risk for progression to AD.

To answer these questions, the two research teams studied plasma pTau181 across several different cohorts of healthy individuals, people with mild cognitive impairment (MCI), AD dementia and non-AD neurodegenerative diseases. In the first study, Shorena Janelidze, Niklas Mattsson and colleagues compared plasma pTau181 levels to measures of pTau181 in cerebrospinal fluid (CSF) and Tau PET brain imaging scans. Studying two prospective cohorts with 526 individuals, as well as a cohort of 63 individuals with autopsy-confirmed AD, the researchers found that plasma pTau181 was increased in the presymptomatic stages of AD, continuing to increase as disease progressed. In contrast, pTau181 was not increased in individuals with non-AD dementia, showing the utility of this blood test to differentiate AD from non-AD conditions, and to track disease progression – and disease risk - in AD.

In clinical practice, it can be hard to determine whether a patient has AD or frontotemporal lobar degeneration (FTLD) as both conditions are similarly prevalent in certain age groups and share several clinical features. In the second study, Dr Thijssen and colleagues therefore focused on the ability of pTau181 plasma tests to distinguish between individuals with FTLD and AD. To do this, the researchers evaluated a cohort of 362 participants with MCI, AD or non-AD forms of dementia, including FTLD-associated conditions such as corticobasal syndrome and behavioural variant frontotemporal dementia. Comparing plasma pTau181 tests to other biomarkers, PET and MRI, the researchers showed that plasma pTau181 was increased 3.5-fold in participants with AD compared to individuals without AD. Plasma pTau181 tests were able to discriminate between AD and FTLD at a level of accuracy similar to CSF pTau181 tests, which are much more invasive than plasma tests due to the requirement for spinal taps to obtain the CSF. Similar to the first study, Dr Thijssen and colleagues found that plasma pTau181 measurements were correlated with the amounts of Tau protein in the brain, as measured by Florbetapir Tau-PET brain scans.

Together, these two studies highlight the utility of minimally-invasive plasma tests for pTau181 as a surrogate measure of Tau accumulation in the brain. Each study overcomes a limitation of the other; the small size of the non-AD disease subgroup in the first study, and the low number of controls and participants with MCI/AD in the second study. Importantly, both studies consistently show that plasma pTau181 measurements can predict the risk of developing AD dementia, providing a way for researchers and clinicians to identify those who may most benefit from therapeutic interventions at an early stage.

4 March: Study investigates association between specific combinations of drugs and Alzheimer’s dementia risk



On 4 March, an international team of researchers from US and UK published a study in the PLOS One journal, reporting the association between dementia risk and combinations of frequently used drugs for

dyslipidemia and hypertension.

The research team investigated data from 694,672 beneficiaries from the US- funded health insurance company, Medicare. The beneficiaries were all at least 67 years old and used both statins and antihypertensive drugs. Findings showed that specific combinations of statins and antihypertensive drugs may reduce risk for Alzheimer’s disease and related dementia (ADRD). The authors reported that two statins in particular, pravastatin and rosuvastatin, combined with angiotensin II receptor blockers (ARBs) or angiotensin converting enzyme (ACE) inhibitors were associated with reduced risk of ADRD. The risk was lower for people using pravastatin and rosuvastatin in combination with ARBs and the risk reduction was more apparent in men than in women.

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0229541>

16 March: Study suggests link between inflammation in the brain and frontotemporal dementia

On 16 March, researchers from the University of Cambridge published a paper reporting that inflammation in the brain may be linked to frontotemporal dementia. This type of dementia preferentially affects two parts of the brain: the frontal and temporal lobes (at the front and side of the brain respectively). Previous research has linked brain inflammation - known as neuroinflammation - with disorders such as depression, psychosis, Parkinson’s and Alzheimer’s disease.

In the study, published in the journal *Brain*, the research team recruited 31 research participants with three different types of frontotemporal dementia and 14 healthy participants (control group). They underwent brain scans to identify areas of inflammation and aggregated proteins called tau and TDP-43, which play a role in dementia. Findings showed that areas of the brain with inflammation correlated with presence of aggregated proteins, which are linked to the disease. An increase in neuroinflammation corresponded with an increase of aggregated proteins in all three types of frontotemporal dementia. This was not the case for the people in the control group.

In addition, scientists analysed the brains of 12 people who had died of frontotemporal dementia. They had donated their brains for research to the Cambridge Brain Bank. Results showed that microglia (brain immune cells) markers were

more common in areas with aggregated proteins, which also suggest a link between neuroinflammation and protein aggregation across the frontotemporal dementia spectrum.

<https://academic.oup.com/brain/advance-article/doi/10.1093/brain/awaa033/5803192>

18 March: Critical Path Institute and H.Lundbeck A/S announce data sharing collaboration to advance drug discovery research for Alzheimer’s disease

On 18 March, the Critical Path Institute (C-Path) and H.Lundbeck A/S (Lundbeck) announced a new data sharing collaboration, with Lundbeck contributing clinical trial data from over 2,500 participants to the Critical Path for Alzheimer’s Disease (CPAD) consortium database. The data contribution agreement between C-Path and Lundbeck is supported by Gates Ventures.

C-Path is a non-profit public-private partnership with the US Food and Drug Administration (FDA), formed in 2005 with the aim of advancing medical innovation and creating new tools to speed up the drug development process. CPAD, a C-Path programme focused on Alzheimer’s disease (AD) and related neurological disorders, manages a patient-level database that currently contains data and information from more than 14,500 patients and clinical trial participants. The contribution of Lundbeck datasets will expand this database, and CPAD aims to add further patient-level datasets over the coming months. The Lundbeck datasets are particularly valuable as they stem from Phase II and Phase III trials that evaluated idalopiridine (a selective 5-HT₆ antagonist) as an adjunct to cholinesterase inhibitor therapy in mild to moderate AD.

Together with the other patient-level datasets in the CPAD database, data contributed by Lundbeck will help CPAD create

new disease progression models across the timecourse of AD development. In addition, datasets will be made securely available to qualified researchers upon request.

20 March: Axsome Therapeutics accelerates the completion of its ADVANCE-1 trial of AXS-05 in AD agitation

On 20 March, the company Axsome Therapeutics, which develops therapies for the management of central nervous system disorders, announced that it is accelerating the completion of its ADVANCE-1 trial of AXS-05.

The Phase II/III ADVANCE-1 study is a multicentre, randomised, double-blind and controlled trial to evaluate the efficacy and safety of AXS-05 in people with agitation associated with Alzheimer’s disease (AD). In the original protocol of the trial, approximately 435 research participants over 65 years old were to be enrolled to receive the drug or the placebo for 5 weeks.

To ensure the safety of research participants during the COVID-19 outbreak, the company is concluding participant’s enrolment early. The decision was made in compliance with the new guidance from the US Food and Drug Administration, which reports the potential impact of the COVID-19 pandemic on the conduct of clinical trials and the safety of research participants.

More than 90% of research participants are estimated to have completed the study. Topline results should be available in the second quarter of 2020.

<https://bit.ly/3awZx1s>



LIVING WITH DEMENTIA

3 March: Petri Lampinen, a member of the EWGPWD, shares a frightening experience



I recently had a scary and quite dangerous experience which I would like to share.

It was a crisp frosty day in January. I had just come home and decided to have a warm shower. After my shower, I decided to light a fire in the fireplace. I was wearing a bathrobe which was made of synthetic fibre. As I was squatting before the fireplace, I lit a match in the same way as always, with one swift stroke. But this time, something went wrong.

I smelt burning. I looked to my right and noticed the shoulder of my bathrobe was on fire. I got up, startled. My whole bathrobe caught fire and I remember thinking “What am I supposed to do?” Luckily, I have a scout background so I was instinctively able to act quickly. I ran across the living room with a burning bathrobe on, opened the terrace door and threw the burning bathrobe onto the snowy terrace. I then picked up a shovel leaning against a wall and quickly put out the fire.

Then, I immediately went back inside the house to check there weren’t any embers smouldering. Nothing was found and all I had to do was to switch off beeping fire and carbon monoxide alarms, and ventilate the apartment. My home care staff came early that day and I told the whole story with shaking hands. I still have no idea how my bathrobe caught fire.

After that experience, I am more careful with the fire. Also, I do not burn candles at home because I would surely forget to keep an eye on them. I am very careful in the kitchen and avoid any kind of distraction that could interrupt what I am doing and perhaps cause a dangerous situation. I recommend that everybody has a safe switch for the stove and to always keep a fire blanket nearby.

I can tell this story with some humour now but on that particular day I got a terrible fright and I could not sleep well for a few days after the incident. I felt unsafe for a while but luckily things turned back to normal quite quickly.

I want to thank Suomen pelastusalan keskusjärjestö (Central Organisation of Rescue Services in Finland) who collaborate closely with The Alzheimer Society of Finland to ensure a safer way of living for people with memory-related diseases.

13 March: Tomaž Gržinič, member of the EWGPWD, reflects on the importance of timely diagnosis, discipline and living fully every day

Tomaž Gržinič, member of the European Working Group of People with Dementia (EWGPWD), recently had an interview for a well-known media webportal, siol.net. His statements were informed by his own personal experience and challenges, since his diagnosis of early onset dementia. He says that dementia has become his life partner, and with smile on his face, continues: "I am a sociable and active person". These are his words:

Dementia has not interfered with my daily routine in a harmful and dysfunctional way. I still have control over all aspects of my life and I am sure that dementia has helped me to organise my activities even more. The first symptom that I experienced of dementia was poor orientation in unfamiliar places. But I was still not overwhelmed, as orientation was always one of my weakest skills. The most dramatic reduction in my spatial orientation was the day that I realised that I had lost my way on a very popular trail near Ljubljana. I realised that it was better for me not to go for long walks on my own and I made the decision to rearrange my walking habits.



Several years ago, my father was also affected by Alzheimer's disease. So I am sure that education about dementia plays a crucial part in timely diagnosis. A decade ago, you barely heard a word about dementia. Also, cognitive decline was understood to be a normal part of ageing. I first noticed gaps in my memory in 2016 and knew that it was time to make an appointment at the doctor. In order to know whether I had mild dementia or whether the cause lay elsewhere, my neurologist proposed a CT image, but to be 100% accurate, he also tested for possible biomarkers. The results showed me that I was in the initial stages of dementia. I was referred for an MR scan, which showed a normal state of brain matter.

Finding out that I had dementia was a very emotional event. I am so thankful for the support of the EWGPWD, where other members are also sharing their experiences of the potential risks and benefits of living with dementia. However, I have taken a very positive outlook and I feel that my quality of life might even have improved. Since my diagnosis, I have become less stressed and angry. I take my time and am patient with myself. I am very disciplined in my life. I never risk putting my personal belongings in different spots. Keys, wallet, mobile phone are always on the same shelf in the hall. Dementia has affected my driving a bit, so I only drive to destinations that I am familiar with.

Speaking of tasks and activities, my normal week is very busy. On Monday afternoon, I play tennis and the evening is reserved for a traditional dinner with 10 lifelong friends. We have been hanging around together for almost 40 years! On Tuesday morning, we hike up the nearest hill, Orle, and have lunch and chat together. On Tuesday evening, I play table tennis. On Wednesday morning, I play tennis again, while in the afternoon, I have free time. On Thursday evening, I play table tennis again. Friday is a day for myself. During the weekend, I regularly drive to my weekend house in Kurešček, where I have a small garden of vegetables. I cultivate almost all types of vegetables by myself. Since my diagnosis, the state of my disease is more or less the same.

Sharing the diagnosis with my friends was a very comfortable experience. They are very tolerant and often make jokes that they are even more forgetful than me. So I am never ashamed of my disease. Friends are a huge support for me. It means a lot, when you're not alone and can always call your "buddies", when you need to talk to someone, ask for advice or just make an afternoon more interactive. To be engaged with different activities also helped me get through a time of grieving, when my wife passed away. I was determined, I had to find ways to make my long afternoon hours active, sociable and productive. I followed through on this idea, as when I am with friends, I do not have time to overthink or analyse everything too much. I always apply for all annual regional competitions for table tennis or tennis just to stay busy and fit. Regularly, I make short trips into neighbouring countries with my son. From my experience, dealing with dementia is better done with humour, rather than without. I am not overly occupied with thinking about what the future will bring. I live for the moment, for each day. I am also

sure that my activities will slow down the progression of the disease. Honestly, I am a little afraid to reach a severe stage of dementia as my father did. But I am trying to stay optimistic for now.

Dementia can interfere with your personality as it can strengthen some behaviours and reactions. But even so, everyone must be treated with respect and dignity. Accepting dementia is also very important and helps to overcome stigma, anger and fear. People with dementia still have feelings and it is OK to show them, not to suppress them. It is much better to know what to expect rather than live in denial, believing that “dementia cannot happen to me”. Timely diagnosis is beneficial in every sense. It takes a lot of courage, to step forward and adapt your lifestyle, but sooner or later you will accept it as a part of your life and make every day meaningful for you. I believe that every country should develop screening tests for dementia for everyone after the age of 65. Medical staff should encourage all older people to follow a healthy lifestyle and prevention techniques, even if no signs of dementia have been detected.

17 March: Helen Rochford Brennan, Chairperson of the EWGPWD, writes about how she recently called upon the Irish government to “Deliver on Dementia”



During the recent General Election in Ireland, The Alzheimer Society of Ireland (ASI) launched a huge campaign to demand that the new Irish government must finally deliver on promises to end the dementia crisis. Their campaign slogan read: “Deliver on Dementia - Time to End the Crisis”.

Showcasing the lived experience of people with dementia and their family carers was a central part of this campaign. The Irish Dementia Working Group (IDWG) and the Dementia Carers Campaign Network (DCCN) were key to the success of encouraging members of the public to engage with the campaign. Everyone worked hard to also ensure that all election candidates heard the clear message that it was finally time to end the crisis.

As an advocate, I was proud to support the work of The Alzheimer Society of Ireland to raise public awareness of the campaign on a national and local level. I spoke openly about my own personal challenges of living with dementia. I also spoke about my life experiences as a carer for my husband Sean, who lives with a number of chronic illnesses. I receive no dementia services and Sean receives only three hours a week.

I took part in videos, national print/online articles and national/local radio interviews to highlight the current crisis in dementia care. I also highlighted the need for progress on the National

Dementia Strategy which needs to be fully implemented to improve the quality of life of all people living with dementia in Ireland. I was delighted that many of my colleagues in the IDWG made videos to support the pre-election campaign and we had a huge impact. My online videos on The ASI’s Facebook page had over 2,500 views alone. I know my media work and that of my colleagues in the IDWG and DCCN during the Election campaign, made a real difference in conveying the real-life difficulties that people with dementia and their families are currently experiencing in Ireland.

To people living with dementia throughout Europe, I call upon you to speak up and have your voice heard while you can. Our politicians must hear our voice.

19 March: Idalina Aguiar, a member of the European Working Group of People with Dementia, shares her personal experience of the impact of COVID-19

On 7 March, I celebrated my 80th birthday, on the neighbouring paradise island of Porto Santo. My family and friends were by my side and made this day so very special and memorable for me. Things were normal and I was coping well.

Now, however, times are changing so fast. Difficult days are ahead, where every day, we are being put to the test.

Despite living with dementia, I found that with the help of my family, I could still live with a degree of quality. I was in a day centre, specifically organised for people with dementia, where I spent every day of the week. I was with other people, all with varying types of dementia, in an environment where we were properly stimulated and helped.

With the COVID-19 pandemic, the little I have left has already been stripped away. With the declaration of the State of Emergency in my country, extreme measures are being taken to prevent the spread of the virus. For me, the direct and heart-breaking consequence is the closure of all the day centres. I have been home now for several weeks, cut off from my friends, without any certainty about when this trial of humanity will be over.

Even though I know it is for the good of all, it has been very difficult personally, but at least I can still write you these words and so my voice can still be heard.



JOB OPPORTUNITIES

9 March: University of East Anglia seeks PhD student for project on “Transitioning into the caregiver role following a diagnosis of dementia”



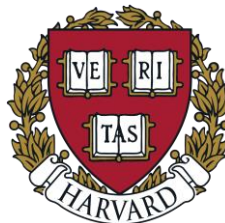
Receiving diagnosis of dementia can be a difficult experience for people with dementia but also family members. The project aims to understand the needs of this particular population to

improve their well-being. This project is suitable for candidates with interest/experience in dementia care or mental health research. Please find the further details about the project and how to apply for this PhD studentship here: <http://bit.ly/2v91otM>

Applications close on 17 April 2020.

EDUCATION

2 March: Harvard University offers free e-courses in neuroscience



Three e-courses are being offered by Harvard University, available to anyone with an interest in neuroscience.

The courses, Fundamentals of Neuroscience, parts 1, 2 and 3, are completely free.

Find you more and follow the courses:

<https://online-learning.harvard.edu/subject/neuroscience>



Contact Alzheimer Europe:

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

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AE CALENDAR

| Date | Meeting | AE representative |
|-----------------|---|----------------------|
| 1 April | PARADIGM WP3 scientific writing team meeting (online) | Ana |
| 2 April | PARADIGM WP3 metric-consensus workshop (online) | Ana |
| 2 April | Meeting with AE members to discuss COVID-19 situation for people with dementia (online) | AE staff and members |
| 21 April | PARADIGM WP4 meeting (online) | Ana |
| 25 April | General Assembly of the European Patients' Forum (online) | Jean |
| 29 and 30 April | VirtualBrainCloud General Assembly meeting (online) | Jean and Angela |

CONFERENCES

| Date | Meeting | Place |
|--------------------|--|----------------------------------|
| 2-5 April | International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders (AD/PD), https://aat-adpd.kenes.com/general-information/ | Online |
| 12 May | 28ième colloque Alzheimer: Nos droits et nos réalités - Ligue Alzheimer ASBL, https://alzheimer.be/colloque-2/ | Libramont, Belgium |
| 23-26 May | Congress of the European Academy of Neurology (EAN), https://www.ean.org/paris2020/6th-Congress-of-the-European-Academy-of-Neurology-Paris-2020.3833.0.html | Online |
| 12-13 June | "Dementia Care and Policies of extended Danube Region", www.alzheimerbih.org | Sarajevo; Bosnia and Herzegovina |
| 26-30 July | Alzheimer's Association International Conference (AAIC), https://www.alz.org/ | Amsterdam, Netherlands |
| 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 "Building bridges" | Bucharest, Romania |
| 10-12 December | 34 th International Conference of ADI "Hope in the age of dementia", https://adi2020.org/ | Singapore |
| 26-29 June 2021 | Brain & Brain PET 2021, http://brain2021.scot/ | Glasgow, UK |
| 11-13 October 2021 | 31 st Alzheimer Europe Conference | Helsinki, Finland |

30th Alzheimer Europe Conference

Building bridges

Bucharest, Romania

20–22 October 2020

www.alzheimer-europe.org/conferences

 #30AEC

