

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



June began with a series of Alzheimer Europe meetings in Brussels, including a Board meeting, a roundtable with sponsors, a lunch debate on modifiable risk factors for dementia hosted by Milan Brglez MEP (Slovenia), a meeting of the European Group of Governmental Experts on Dementia, a meeting of the European Working Group of People with Dementia and a Public Affairs meeting with our national member associations. At the lunch debate, we also launched the latest edition of Dementia in Europe magazine and our 2022 Annual Report.

Speaking of our publications, we are grateful to our French and Italian member associations who decided to translate some of our recent reports into their own languages, allowing them to share these more widely in their countries. France Alzheimer translated our guidelines on ethical and inclusive communication about people with dementia, while Alzheimer Italia translated our guide aimed at raising awareness of issues around sex, gender and sexuality in dementia.

Our focus on Public Involvement activities continues to grow and, with this in mind, we would like to invite individuals who are affected by or interested in dementia and brain health to join our new European Public Involvement Pool. This platform allows members of the public (excluding health and social care professionals and service providers) to share their views on research-related topics and projects. People will participate in online or in-person

consultations, focus groups, written discussions and brief surveys.

Our work on EU-funded research projects is also on the increase. One such project, PROMINENT, a collaborative pan-European initiative funded through the Innovative Health Initiative, has just launched. It aims to create a digital platform for precision medicine to improve the diagnosis and treatment of neurodegenerative disease and co-morbidities. We are delighted to be a partner and to be leading the communication, stakeholder engagement and public involvement activities.

Another partnership which I am pleased to announce is a strategic partnership with the newly-launched Brain Health Mission, which aims to support people around the world to take care of their brain health and to improve the system for those who live under unfair circumstances, as well as pushing for equal education opportunities for doctors.

Finally, I am excited to inform you that we already have well over 800 delegates registered for the 33rd Alzheimer Europe Conference, as at the close of our Early Bird rates. The number of registrations so far has exceeded all previous years, including the previous record-setting conference in The Hague in 2019. We are excited to see everyone in Helsinki, from 16-18 October, for what promises to be another diverse and engaging conference!

Our next newsletter covers both July and August and will be released in early September. In the meantime, I wish you all a great summer ahead.

Jean Georges
Executive Director

ALZHEIMER EUROPE

6 June: Alzheimer Europe organises a Company Round Table meeting in Brussels



On 6 June 2023, Alzheimer Europe hosted a Company Round Table meeting in Brussels. The meeting was a hybrid event, with many participants attending in person and some joining remotely. It was attended by a total of 33 delegates, including company representatives from Alnylam, GE Healthcare, Grifols, Hoffman-La Roche, Novo Nordisk, Nutricia and TauRx, members of the Alzheimer Europe staff, members of the Alzheimer Europe Board and representatives from 18 member organisations of Alzheimer Europe. During the meeting, four speakers provided updates on recent policy and research developments. First, Cindy Birck, AE Project Officer, gave an update on our Clinical Trials Watch. Next, Owen Miller, AE Project Officer, shared some updates on EU policy developments, European Parliament elections and European Dementia Monitor. Simone Mohrs from MedTech Europe gave then a talk on the European Union AI Act. Finally, Jean Georges, AE Executive Director, informed participants about Alzheimer Europe's activities in 2023 and the work plan and sponsorship opportunities for 2024.

We would like to thank our sponsors and members for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting in September.

6 June: Alzheimer Europe hosts lunch debate on modifiable risk factors for dementia

Alzheimer Europe welcomed attendees to its lunch debate on 6 June 2022 in Brussels, Belgium. The session explored the relationship between modifiable risk factors and dementia, with stakeholders representing national member organisations, national ministries, industry partners, policy makers and the European Working Group of People with Dementia (EWGPWD) in attendance. A total of 85 people attended the lunch debate in person, with a further 148 joining on line.

Milan Brglez MEP (Slovenia), a member of the European Alzheimer's Alliance (EAA) hosted the session and opened by highlighting the importance of modifiable risk factors and

primary prevention in relation to dementia – especially in light of the lack of a cure or disease modifying treatment.

He further noted that as research reveals more about the underlying diseases which cause dementia, the associated risk factors become better understood, which have demonstrated that conditions such as Alzheimer's disease, physical changes occur in the brain many years before symptoms manifest – interventions therefore need to be targeted at this stage of the condition. Modifiable risk factors cover a number of key social determinants throughout the life course and are often not specific only to dementia, therefore there is a need for greater focus to be placed on primary prevention, identifying how we can minimise risk factors and decrease the risk of developing dementia.

Mr Brglez spoke of the role of decision makers and elected members at a European level, outlining the importance of their role in providing funding for research and interventions through programmes such as Horizon Europe and EU4Health, and support for initiatives to raise awareness amongst the public about risk factors and adopting a brain health approach across the life course.

Gill Livingston, Professor of Psychiatry of Older People, University College London, presented on risk factors for dementia, based on the two Lancet Commissions on dementia, noting that a third Commission was under development. Her presentation focused on why dementia can be considered as preventable, what some of the key risk factors are and what should be done in response.

Setting out the context, it was noted that there has been an increase in the number of people overall living with dementia, whilst at the same time there has been a decrease of 20% in the incidence, though in some countries it remains stable or is increasing. Improvements have mostly been in high income countries and amongst men. Key mechanisms related to this are thought to be cognitive reserve, the ability to tolerate brain changes without developing dementia.

It was noted that there is sufficient evidence to identify 12 risk factors for dementia: less education, peripheral hearing loss, hypertension, obesity, traumatic brain injury, excessive alcohol, smoking, depression, physical inactivity, air pollution, social isolation and diabetes. These risk factors account for 40% of current risk factors (as a population attributable fraction), with the largest single risk factor being hearing loss (8%), followed by education (7%) and smoking (5%).

Changing risk factors changes the outcome for developing dementia. It is especially important to target those at risk as trials have tended to take people at lower risk (i.e. those with higher education, higher income).

Based on a follow up study involving health economists, if interventions in midlife for hearing aids, hypertension and smoking cessation were undertaken in England, it is estimated there would be an 8.5% reduction in prevalence and save GBP 1.8 billion per year. However, early interventions for diabetes

were not cost effective in relation to dementia prevention alone.

The Lancet Commission’s research has been used in the USA and in 2021 a goal was added for the reduction of 10 potential risk factors, with policies developed aiming to reduce prevalence by 15% per decade. The presentation was concluded by calling for stakeholders to be ambitious in prevention, noting that the development of new treatments did not remove the need for prevention and that by tackling risk factors, it provided more years of healthy life, could prevent dementia from occurring and saved money.

Tom Russ, Consultant Psychiatrist & Honorary Clinical Reader, University of Edinburgh, presented on environmental risk factors for dementia, covering what causes dementia, why studying environmental factors is important and which matter the most.

Referring to the Lancet Commission, it was noted that in 2020 air pollution was added as risk factor. The strength of the

resource for distinguishing between potentially modifiable factors and unknown risk was highlighted, as was its adoption of a life course approach, explaining the different risk factors at different stages of life.

Citing a paper which examined Bonavista Bay, Newfoundland, Canada, which showed a north/south divide (based on place of birth) in the number of people who died from dementia, with many more people developing the condition in the north.

Additionally, he referred to his study which examined the north/south divide in Sweden, using data from the twin study, which examined people over 65 who had developed dementia, also showing significantly more people in the north had developed dementia. It was noted that this pattern has been noted in many countries.

There is a limitation to reviewing scientific literature for risk factors, as there may be risk factors which have not yet been studied. From his review of the existing evidence, some of the key environmental risk factors include: rural living, air pollution,

Impressions from the lunch debate



Our lunch debate host, MEP Milan Brglez, addresses delegates



Our first speaker, Gill Livingston presents risk factors for dementia, based on the two Lancet Commissions on dementia



Our second speaker, Tom Russ discusses environmental risk factors for dementia ,



Our third speaker, Katja Kanninen introduces the ADAIR project and some of its preliminary findings



Our fourth speaker Jan Steyaert, shares some of the work happening in Flanders



Helen Rochford-Brennan (right) gave a moving goodbye speech after her time in the EWGPWD, while Charles Scerri (left) closed the meeting



EWGPWD Chairperson Chris Roberts (left) and member Nigel Hullah, both from Wales (UK) participated in the lunch debate



The Alzheimer Society of Ireland CEO Andy Heffernan (left) deep in conversation with EWGPWD Vice-Chair Kevin Quaid (right)



Alzheimer Europe (Left to right) Dianne Gove, Director for Projects, Jean Georges, Executive Director and Gwladys Guillory, Event and Conference Coordinator

metals (aluminium, fluoride and silicon) vitamin D levels, pesticides and electromagnetic fields. In relation to policy development, it is crucial to bear in mind that some of these risk factors relate to personal choice, whilst others are outwith the control of individuals.

Examining differences between high (HIC) and low & middle income (LMIC) countries, it appears that there is greater risk for developing dementia for those in rural areas in LMICs. For air pollution, there is a useful article “The polluted brain” published in 2017 which explains how pollution affects the brain. The air pollution policy landscape is extremely complicated, however, its potential impact for health policy (not only dementia) is considerable.

In relation to water, using data from Scotland, higher levels of aluminium and fluoride, even in safe levels, are associated with a higher risk of dementia. Additionally, there appears to be an association with lower levels of vitamin D and higher risk of dementia.

Katja Kanninen, Professor, Faculty of Health Sciences, A.I. Virtanen Institute for Molecular Sciences, University of Eastern Finland, introduced the ADAIR (Alzheimer’s disease Air Pollution) project and some of its preliminary findings. The project involves eight countries across Europe and multidisciplinary researchers, aiming to:

- Identify biomarkers of air pollution
- Correlating exposure biomarkers to Alzheimer’s disease risk
- Assess air pollution exposure induced health impacts on the molecular and cellular level.

The context of air pollution and adverse health was set out, including World Health Organization (WHO) figures which suggest that 90% people breath polluted air, with air pollution linked to 6.7 million premature death. It was noted that policies to reduce air pollution offer benefits for both the climate and health. However, cellular and molecular processes altered by air pollution are not well understood, nor is the link to dementia.

Through controlled acute exposure to air pollution, the project was able to identify significant changes to blood plasma, specifically immune cells strongly reacting and, amongst other things, increasing biological processes relating to inflammation.

In relation to long-term exposure, a longer-term study of over 18,000 individuals aged over 40 showed that exposure to air pollution was associated with several metabolites in the blood, including sphinganine which is associated with inflammation and immunity, which may increase the risk of Alzheimer’s disease.

An impaired sense of smell is known to be an early sign of Alzheimer’s disease and as part of the research, olfactory mucosa samples (tissue from the top of the rooftop of the nasal cavity which is in direct contact with the brain) were collected and analysed. This tissue is already altered in individuals with persons with AD and additionally, in persons with AD, shows a stronger response when exposed to air pollution.

Concluding, it was highlighted that the project has identified new air pollutant exposure biomarkers in both acute and long-term exposure to air pollution. These are useful in identifying individuals who have been exposed to air pollutants and work is ongoing to understand how these relate this to AD.

Jan Steyaert, Scientific Officer of the Flemish Centre of Expertise on Dementia, presented on how to turn research recommendations into practical awareness campaigns and policy actions, based on some of the work taking place in Flanders. The prevalence of dementia in Flanders is approximately 125,000 and is expected to rise to 190,000 by 2040. In Flanders, as elsewhere, there is a demographic challenge. By 2040, the labour market will rise by approximately 3%, whilst the pension population will increase by 25%. In Wallonia, there will be a 3 % decrease and 35% increase respectively.

Focusing on prevention is important as there is a potential to lower the number of people with dementia, including the reduced costs in healthcare, as well as the reduction of the number of informal carers. Additionally, as the availability of medicines is still a number of years away, coupled with the ageing demographics, the need to act based on the Lancet Commission findings is evident.

However, there is a low awareness amongst the public of modifiable risk factors and there is a need to translate the findings of such research to a public campaign. There have been two such awareness raising campaigns in recent years in Flanders.

In September 2018, “SaniMemorix” was launched and was also available in Germany, Netherlands and Norway, which made vaccine boxes, 50,000 which were distributed, as well as information and resources to pharmacies, as well as information for professional bodies about how to talk to people about dementia. This campaign increase awareness about modifiable risk factors from 35% to 44% amongst 40 to 75 year olds.

A second campaign was launched called “Two for the price of one” (2 voor de prijs van 1), which focused on what is good for your heart also being good for your head. Resources and materials included postcards, paper bags distributed to pharmacies and apples with the message printed on them. All of this is open access and are invited to contact the Expert Centre if they wish to use them.

Key lessons learned during the campaign was not to blame the victim, as there are many environmental factors outwith the persons control. Additionally, choices people make are social and not necessarily individual. Additionally, Alzheimer’s organisations need to build relationship with public health organisations. Reaching out to the public is clearly important but so is reaching and engaging with intermediaries including the press, GPs and neurologists. Finally, it is essential to reaching out to high risk groups, such as people with low education, people with migration backgrounds etc., for working with GPs and health insurance companies.

Alzheimer Europe Board Member, Mary Frances Morris, asked about the mechanism in the brain behind hearing loss and dementia, citing her own experience caring for her father. Prof. Livingston explained that the mechanism is complicated, noting that people with uncorrected hearing loss experience atrophy of the temporal lobe of the brain, however, one of the main mechanisms relate to the lack of cognitive stimulation, as well as the social isolation which often comes about as a result of hearing loss. Additionally, where you have to expend energy and focus on listening, it then leaves less capacity for engaging and responding to dementia.

An online question was asked, in relation to the difference in male *versus* female risk factors for developing dementia. Prof. Livingston noted that women were more likely than men to develop dementia, however, that this was not true in some sub populations (e.g. in higher education or higher income groups). Whilst some think it is related to the menopause, people who take hormone replacement therapy are just likely or more likely to develop dementia, therefore it is not likely correlated, with socioeconomic status much more likely to explain the differences.

Alzheimer Europe Executive Director, Jean Georges, thanked all the speakers for their excellent presentations and the evidence provided for preventing dementia to be prioritised by decision makers at a European level. He asked Milan Brglez MEP, how to prioritise dementia, given that it was not given significant attention within European Commission work programmes. Mr Brglez noted that this was not an easy question and highlighted that dementia had been included in the Parliament's position on the European Care Strategy (which he was a co-rapporteur, with Sirpa Pietikäinen MEP). He noted that when Committees produce an own initiative report, it is necessary to engage early in the process. He also noted the importance of engaging with candidates who were standing for re-election and to use the opportunity to ask candidates to give their support. Additionally, he noted that the newly formed sub-committee on health would useful place for the issue to be raised, especially as dementia is an issue which is cross party.

Štefanija Zlobec, President of Spominčica, added that in the run up to the European Parliament elections in 2024, this was an important opportunity for associations to raise awareness, engage with the media and to work to prioritise dementia.

Chris Roberts, Chair of EWGPWD, noted the disparities in access to medicines and support across European countries, noting that dementia is used as an umbrella term for more than 200 different distinct conditions. He suggested that potentially there would be greater access to services and supports if the specific kinds of dementia were identified and talked about, instead of using dementia.

Alzheimer Europe Vice-Chair, Charles Scerri, thanked the four speakers for their presentations, noting that the presentations clearly set out the science and knowledge of these risk factors, as well as an example of how these messages can translate into public messages to promote prevention.

He further highlighted that is up to governments and our organisations to clearly articulate this message to the public and to shift the paradigm of prevention to younger populations. This brain health approach across the life course must become an integral part of our work.

A presentation was made, marking Helen Rochford-Brennan's time as a member of the EWGPWD (from 2014-2022), including serving as its Vice-Chair from 2014-2016 and Chair from 2016-2022.

Charles noted that Helen had been an active and passionate campaigner both in her home country and at a European level for many years highlighting her tireless work over the years, sharing her personal experience of living with dementia, her professional experience and her many talents for the benefit of Alzheimer Europe, the EWGPWD and numerous researchers and policy makers. He noted that anyone who has had the privilege of working with Helen would attest to her insight and thoughtful contributions, which has unquestionably strengthened Alzheimer Europe's work.

Helen gave a short speech recounting her time as part of the EWGPWD, noting that it had been an honour and a privilege to be part of the group, and highlighting some of the key research projects in which she had been able to participate. Helen also spoke of her immense pride in being able to discuss and raise the issue of human rights during her time with the group, including delivering speeches in the European Parliament.

She also spoke of the early meetings of the EWGPWD and her friendship with Agnes Houston, Helga Rohra and Hillary Doxford. She extended thanks to the Alzheimer Europe team for their help and support, as well as the board for their ongoing support and for fostering an inclusive environment, allowing her to thrive. She also thanked the European Parliament and Commission for its support, as well of that of the sponsors, which made Alzheimer Europe's work possible. In particular, Helen acknowledged the support of EAA member Deirdre Clune MEP (Ireland) who has long supported making dementia a priority. Finally, she thanked the Alzheimer's Society of Ireland for nominating her and providing the support to allow her to take part in the group. Helen concluded by describing her time with the EWGPWD as one of the most enriching her life and reflected on the progress that had been made and the knowledge that had been shared. She paid tribute to past members of the group, including those who were no longer with us, and their invaluable contributions. She stated that the best way to honour their legacy was by continuing to strive for advancement in dementia research, care and support.

Her final thanks were to her supporter Carmel Geoghegan who has provided support over the years. She praised her dedication and compassion despite her own challenges and noted how it had been greatly appreciated by her, her late husband Sean and her son Martin. The videos of the presentations from the lunch debate can be watched here:

<https://www.youtube.com/playlist?list=PLo-PgQHI1WQUxce6AhLko7ffp4QSBkXzO>

6 June: Alzheimer Europe publishes its 2022 Annual Report



Alzheimer Europe's 2022 Annual Report, officially launched at our lunch debate in Brussels on 6 June 2023, looks back at our activities and achievements last year.

Our core activities were funded by an operating grant awarded by the European Commission and funded through the Citizens, Equality, Rights and Values (CERV) programme. This support allowed Alzheimer Europe and

its national member organisations to continue providing a voice to people with dementia and their carers, making dementia a European priority, changing perceptions and combating stigma, raising awareness of brain health and prevention, strengthening the European dementia movement and supporting dementia research.

You can download the annual report, here:

https://www.alzheimer-europe.org/sites/default/files/2023-06/2022_annual_report_of_alzheimer_europe_final.pdf

6 June: Alzheimer Europe publishes 42nd edition of its "Dementia in Europe" magazine



The 42nd edition of Dementia in Europe magazine was officially launched at Alzheimer Europe's lunch debate in Brussels, on 6 June 2023.

This new edition is filled with important updates on European and national policy developments in the dementia field, including national dementia strategy news, initiatives on better ageing and combatting ageism, campaigning for governments

to prioritise dementia, recent developments in dementia care, long-term care and in ensuring the voices of dementia carers are heard at the European level.

We also include updates on European research projects and other areas of research related to prevention and to continence care, as well as articles related to the inclusion of people with dementia in the arts and in cultural activities.

You can download the magazine, here:

https://www.alzheimer-europe.org/sites/default/files/2023-06/dementia_in_europe_magazine_issue_42_june_2023.pdf

6-7 June: Members of the European Working Group of People with Dementia meet again in Brussels



On 6 and 7 June, Alzheimer Europe (AE) welcomed the members of the European Working Group of People with Dementia (EWGPWD) in Brussels for their first in-person meeting of this year.

On the first day, the members actively participated in discussions centred around two key topics: anti-amyloid treatments and the use of technology by people with dementia. For the first consultation, Ange Bradshaw (AE Project Officer) provided an overview of the anti-amyloid drugs currently in development, their beneficial impact on clearing amyloid plaques and cognition, as well as the side effects in participants of clinical trials involving this type of drugs (i.e. lecanemab, donanemab and aducanumab). The members' feedback will be used to shape the AE position statement on anti-amyloid drugs. Dianne Gove (AE Director for Projects) then facilitated the next session seeking input from members on different statements and recommendations developed within the Interdem project regarding the use of technology by people with dementia.

The last part of the first day was focused on the preparation of the EWGPWD plenary session of the 33rd Alzheimer Europe Conference (33AEC). Ana Diaz (AE Project Officer) and Chris Roberts (Chair of the EWGPWD) provided more information about this session which will be dedicated to presenting the work of the EWGPWD and Public Involvement and advocacy activities at national level. The speakers for this session were carefully chosen from among the members who expressed interest.

The following day, members participated in discussions about the Dementia in Europe Yearbook 2023, facilitated by Owen Miller (AE Policy Officer). After providing an overview of the topics that will be covered in the Yearbook, members provided feedback regarding legal capacity and supported decision-making for people with dementia.

The last consultation of the second day revolved around the topic of informed consent, and re-sharing and re-use of participants' data in different research projects. Soraya Moradi-

Bachiller (AE Project Officer) provided an overview of the topic, followed by a productive discussion facilitated by Dianne.

The contributions made by all members during these discussions were extremely valuable and we are looking forward to meeting them again at 33AEC in Helsinki!

6-7 June: Alzheimer Europe Public Affairs meeting brings together 18 member organisations from across Europe



On 6-7 June, Alzheimer Europe hosted its second in-person meetings of 2023 in Brussels. The organization was delighted to welcome

representatives from 18 of its members from all regions of Europe to exchange national policy developments and campaigning activities, among others. The Public Affairs meetings provide a forum for national Alzheimer's associations to share learnings, challenges, and good practices in an inclusive, open, and collaborative environment.

The meeting started with a warm welcome from Charles Scerri, Vice-Chairperson of Alzheimer Europe (Malta), followed by talks from Alzheimer Europe staff, including the European Dementia Manifesto and European Dementia Monitor by Policy Officer Owen Miller and Project Communications Officer Christophe Bintener. Next, two of Alzheimer Europe's Project Officers spoke about the advent of anti-amyloid treatment for Alzheimer's disease in Europe, with Cindy Birck providing an overview of the results of clinical trials on anti-amyloid treatments and Angela Bradshaw introducing the draft Alzheimer Europe position on anti-amyloid treatments.

The afternoon then began with presentations on risk prediction, brain health, and prevention. Here, Alzheimer Europe Project Officers Soraya Moradi-Bachiller and Daphné Lamirel spoke about their work on risk prediction in EU projects, which was followed by Soraya Moradi-Bachiller providing an overview of Alzheimer Europe's draft position on risk disclosure. The session then closed with a roundtable introduction of Alzheimer Europe's member activities on brain health and prevention.

After a coffee break, the agenda focused on the impact of COVID-19 on Alzheimer's associations, with Angela Bradshaw presenting the results of Alzheimer Europe's survey among member organizations.

Last but not least, the attendees had the pleasure of hearing from the Director of the European Disability Forum, Catherine Naughton, on how the UNCRPD reporting system could be used to improve the rights of people with dementia at the EU and national levels.

Alzheimer Europe is looking forward to meeting with its national member organizations at the next Public Affairs meeting in September.

21 June: Launch of the new European online Public Involvement pool: share your opinions and experiences about important research topics!

Alzheimer Europe would like to invite individuals who are affected by or interested in dementia and brain health to join its new European Public Involvement pool. This platform allows members of the public (excluding health and social care professionals and service providers) to share their



views on various research-related topics and projects. People will be invited to participate in online or in-person consultations, focus groups, written discussions and brief surveys.

What is public involvement?

To ensure that research accurately reflects the preferences, needs and priorities of members of the public, their perspectives - including experiences and concerns - need to be included in different aspects of research processes and outputs/results. Public Involvement (PI) has been shown to improve the quality of research by enabling researchers to benefit from the lived experience of people with dementia. Also, it helps ensure that research is ethical, transparent and gives people with dementia a voice, reflecting the principle of "nothing about us without us".

What can you expect from joining?

By joining this pool, members of the PI Pool will have the opportunity to provide input on different aspects of ongoing European research initiatives (e.g. on new technologies and artificial intelligence-based approaches to dementia prevention or management, palliative care, dementia risk prediction etc.)

We particularly welcome:

- people with dementia
- people at higher risk of dementia or with memory or other cognitive problems
- carers, supporters or family members of people with dementia
- Additionally, we are very keen to include the perspectives of members of minority and marginalised groups and cultures (such as people from minority ethnic groups, from the LGBTQ+ community or living in rural areas or residential care settings).

Find out more here:

<https://www.alzheimer-europe.org/research/public-involvement/alzheimer-europe-public-involvement-pool>

Sponsors of the month

Alzheimer Europe would like to express its gratitude to two new sponsors for its 2023 activities.

Read more about sponsorship opportunities here:

<https://www.alzheimer-europe.org/about-us/governance/finances/2023-sponsorship-opportunities>



29 June: Alzheimer Europe partners with new Brain Health Mission



Alzheimer Europe is pleased to announce that it is a strategic partner of the recently-launched Brain Health Mission. The Brain Health Mission, aims to support people around the world to take care of their brain health, to improve the system for those

who live under unfair circumstances, and to push for equal education opportunities for doctors. It recognises that brain health goes beyond the absence of disease or treatment of disorders or rehabilitation and encompasses preventive

measures to decrease the incidence of neurological disorders. The vision is to create a brain-healthy environment in which everyone understands how to care for their brain health and nervous system, and has the ability to do so.

Executive Director Jean Georges represents Alzheimer Europe in the strategic partnership with the Brain Health Mission.

The secretariat of the Brain Health Mission is provided by the European Academy of Neurology.

<https://www.ean.org/brain-health-mission>

30 June: Early Bird registrations for Alzheimer Europe Conference reach an all-time high

Early Bird rates for the 33rd Alzheimer Europe Conference (#33AEC) have now ended and we are delighted to announce that we already have well over 800 delegates registered, with many more expected between now and close of online registrations, on 8 October 2023. The number of registrations so far has exceeded all previous years, including the previous record-setting conference in The Hague in 2019. We are excited to see everyone in Helsinki, from 16-18 October, for what promises to be another diverse and engaging conference.

The detailed programme for the conference is available on our website:

<https://www.alzheimer-europe.org/conferences/2023-helsinki/detailed-programme>

If you missed the Early Bird deadline, you can still register for the conference, at the full rate, until 8 October:

<https://www.alzheimer-europe.org/conferences/2023-helsinki/registration-fees-virtual-attendance>



Register now!



33rd Alzheimer Europe Conference #33AEC
New opportunities in dementia care, policy and research
Helsinki, Finland
16 - 18 October 2023

ALZHEIMER EUROPE NETWORKING

On 1 June, Cindy attended the World-Wide FINGERS Network Meeting.

On 2 June (Amsterdam, Netherlands), Cindy and Jean attended the final Annual General Meeting of the PRODEMOS project.

On 5 June (Brussels, Belgium), the Alzheimer Europe Board met.

On 5 June, Dianne took part in the RADAR-AD Qualification Advice meeting with the EMA.

On 6 June (Brussels, Belgium), Alzheimer Europe organised a company round table.

On 6 June (Brussels, Belgium), Alzheimer Europe organised a European Parliament lunch debate on modifiable risk factors for dementia hosted by Milan Brglez, MEP (Slovenia).

On 6-7 June (Brussels, Belgium), Alzheimer Europe hosted a meeting of the European Group of Governmental Experts on Dementia.

On 6-7 June (Brussels, Belgium), Alzheimer Europe hosted a Public Affairs meeting.

- On 6-7 June (Brussels, Belgium), Dianne, Ana, Soraya, Daphné, Owen and Ange participated in hosting an EWGPWD meeting.
- On 9 June, Dianne and Ana met with the Chairs of the PPI session at the AAIC conference.
- On 13 June, Jean attended the Council meeting of Alzheimer’s Disease International.
- On 14 June, Jean met with representatives of TauRx.
- On 14 June, Jean, Gwladys and Cristina met with the 33AEC committee for the monthly catch up.
- On 15 June, Dianne and Ana participated in a PREDICTOM meeting.
- On 16 June, Angela participated in an EMA webinar on the revision of the EU Pharmaceutical Legislation.
- On 16 June, Ana and Dianne participated in the INTERDEM taskforce meeting on inequalities in dementia care.
- On 19 June, Gwladys met with Presence regarding the 33AEC translation system.
- On 20 June, Soraya and Ana organised a meeting with the ADIS advisory board to discuss all their contributions to the Public Involvement activities of the ADIS project.
- On 20 June, Owen attend the ENGO meeting coordinated by the European Disability Forum.
- On 20 June, Gwladys met with a representative of NH brand for our future events.
- On 21 June, Angela attended a meeting of the Davos Alzheimer's Collaborative on healthcare system preparedness.
- On 21 June, Dianne and Ana met with EVIDERA to discuss a possible collaboration.
- On 22 June, Dianne, Ana, Daphné and Soraya organised a meeting with the EDCWG on the topic of legal capacity and supported decision making.
- On 27-28 June (Amsterdam, Netherlands), Angela attended meetings of the EMA Patients' and Consumers' Working Party.
- On 28 June, Owen attended a Strategic Dialogue on the Annual Work programme of the ESF+ organised by the European Commission.

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EU PROJECTS

15-16 May: RADAR-AD consortium celebrates four years of research and achievements in a close-out project meeting and a public event



The final RADAR-AD meetings took place as hybrid events on 15 and 16 May in Amsterdam. On the first day, RADAR-AD members gathered for a consortium meeting where investigators presented findings from their research and defined next steps for the analysis of data and the sustainability of project results. On the second day, the consortium was joined by members of the public and the RADAR-AD patient advisory board to discuss project results, experiences with

patient involvement and the way forward. Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz took part in the meeting.

Read the RADAR-AD report on this event:

<https://www.radar-ad.org/newsroom/radar-ad-consortium-celebrates-4-years-research-and-achievements-close-out-project-meeting>

2 June: The PRODEMOS project hosts its final General Assembly meeting

On 2 June, the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project held its final General Assembly meeting in Amsterdam. Since January 2017, partners of this EU-H2020 project have been working together to make an evidence-based dementia prevention strategy using mobile Health (mHealth), accessible to those at increased risk of dementia.

PRODEMOS builds on an existing eHealth intervention that is adapted to an mHealth platform for dementia prevention, specifically tailored to vulnerable populations in High Income Countries (HIC) and in Low and Middle Income Countries (LMIC), and has been implemented in multiple settings in the UK and China to pave the way towards a scalable, global strategy for dementia risk reduction.

Chaired by Edo Richard and Eric Moll Van Charante from the Academic Medical Centre Amsterdam (AMC), the meeting was attended by representatives from the institutions and organisations that make up the project’s consortium, including Alzheimer Europe. Executive Director Jean Georges and Project Officer Cindy Birck attended the meeting on behalf of Alzheimer Europe.



During the meeting, partners highlighted key project developments and achievements. Trial results were presented including its efficacy, implementation and the cost-effectiveness analysis. In addition, Chinese partners presented an overview on additional measurements and shared some experiences from the trial such as challenges and opportunities. Finally, partners looked back at accomplishments and setbacks before to officially drew the meeting to a close.

Further information on the PRODEMOS project can be found here:

<https://www.prodemos-project.eu>

5 June: Manuscript on the rationale and design of the ABOARD project is published



On 5 June 2023, the manuscript on the rationale and design of the ABOARD project was published in the journal *Alzheimer's & Dementia: Translational Research & Clinical Interventions*.

ABOARD, short for "A personalized medicine approach for Alzheimer's disease", is a

public-private project which aims to prepare for a future in which Alzheimer's disease is stopped before dementia has started. Public and private partners from the entire knowledge chain work together, from universities to healthcare and knowledge institutions, companies and civil society organisations. Alzheimer Europe Director Jean Georges is a member of the project's Advisory Board.

Find out more about the project, here:

<https://www.aboard-project.nl>

See the project's published manuscript, here:

<https://doi.org/10.1002/trc2.12401>

8 June: Paper on "Living Well with Dementia: Feeling Empowered through Interaction with Their Social Environment" published by MinD project and co-authored by Alzheimer Europe



Two years after its formal end, the MinD project partners are still working together to make available all the valuable data

collected with people with lived experience during the project. MinD addresses the social needs of people with early to mid-

stage dementia living in the community. MinD has used the concepts of design and mindfulness to develop innovative design solutions that support people with dementia with self-empowerment and social engagement.

MinD had three phases: data collection, design development, and evaluation. Each stage featured user participation to help develop the project's outcomes. The paper published now summarises key insights collected during Phase 1, which have provided the basis for much of the later co-design work. These insights were not only key to the development of the project's design ideas but also a shift to a more inclusive and salutogenic perspective. The paper, "Living Well with Dementia: Feeling Empowered through Interaction with Their Social Environment", was co-authored by Alzheimer Europe Project Officer Ana Diaz.

This study was designed to advance our understanding of how feelings of empowerment in people living with dementia still residing at home can be promoted. The researchers conducted qualitative interviews with 12 participants with mild-to-moderate stages of dementia in Germany and Spain as part of a European study on mindful design for dementia.

A qualitative thematic content analysis was performed to elicit the key features of the experience reported by the interviewees. Three overarching categories were identified:

- "Experiencing changes in personal life and coping with changes in life" covered losses and coping strategies
- "Retaining a sense of usefulness" included social participation and the need for activities with others
- "Feeling empowered" covered reflections on lifetime achievements, accomplishments in the present life, being in control and self-worth.

Participants placed a strong emphasis on continuity and on the importance of making active decisions and meaningful social contributions. Empowerment within the person living with dementia was achieved through their interactions with their social environment, including the significance of communication about their needs and wishes and enabling shared decision-making and interactions with others in reciprocity.

The paper can be seen, here:

<https://www.mdpi.com/1660-4601/20/12/6080>

Further information on the MinD project is available from the project website:

<http://www.designingfordementia.eu>

For any questions or suggestions about the MinD project and its activities, please contact Professor Kristina Niedderer at:

k.niedderer@mmu.ac.uk



12 June: RADAR-AD project investigates eliciting brain waves of people with cognitive impairment during meditation exercises in a smart-home environment



Meditation fosters relaxation and can be used as a non-pharmacological intervention for cognitive impairment in Alzheimer’s disease (AD). Electroencephalography (EEG) measuring the electric activity of the brain has

been widely used as a tool for detecting brain changes even at the early stages of AD.

A recent RADAR-AD study investigated the effect of meditation practices on the human brain across the AD spectrum by using a novel portable EEG headband in a smart-home environment. The results showed the potential of digital devices to detect early cognitive decline and brain alterations in a smart-home without medical support.

Read the full RADAR-AD report, here:

<https://www.radar-ad.org/newsroom/eliciting-brain-waves-people-cognitive-impairment-during-meditation-exercises-smart-home>

14 June: Revolutionising precision medicine - PROMINENT project will enhance diagnosis and treatment of neurodegenerative diseases, improving patients' lives across Europe



On 14 June 2023, partners of the PROMINENT project announced the launch of a collaborative pan-European initiative funded through the Innovative Health Initiative (IHI). PROMINENT will create a digital platform for precision medicine to improve the diagnosis and treatment of neurodegenerative disease and

co-morbidities. The overriding objective is to assist clinicians with individualised decision support in the evaluation of patients with suspected cognitive impairment.

PROMINENT is a public-private partnership funded by the IHI for a period of five years. The PROMINENT consortium brings together experts in neurodegenerative diseases and clinical neuroscience, artificial intelligence (AI), health economics, and patient advocacy. Project partners also include some of Europe’s leading medical centres for the diagnosis and treatment of cognitive disorders.

Alzheimer Europe will be leading the communication, stakeholder engagement and public involvement activities in PROMINENT.

The first application for PROMINENT will be in Alzheimer's disease (AD), which encompasses the [Alzheimer's disease continuum](#) and affects over 20 million people in Europe. The prevalence of AD is expected to double over the next three decades. However, diagnosis and management are challenging due to the high incidence of comorbidities, such as cardiovascular and psychiatric conditions. By taking into account individual differences in patients’ genes, lifestyles and clinical parameters, precision medicine has the potential to dramatically improve diagnosis, prognosis and treatment of AD.

“With a large ageing population and an ambition to maintain good health into the higher ages, Europe has a great need for precision medicine systems that can support clinicians with diagnosing and treating neurodegenerative conditions, and provide support to patients and their care partners.” said Principal Investigator, Dr Linus Jönsson. “PROMINENT will leverage digital tools and biomarkers together with advanced analytics to increase the accuracy of AD diagnosis and prognosis, paving the way for the introduction of new health technologies that will improve the lives of patients and care partners.”

A core outcome for PROMINENT will be its digital platform, which will leverage existing tools for AI-based image analysis developed by project co-Principal Investigator, Dr Jyrki Lötjönen from Combinostics. Building on these tools, PROMINENT will develop an open, interoperable platform capable of interacting with a wide range of systems to integrate multi-modal diagnostic data.

Powered by innovative prognostic and diagnostic algorithms, the PROMINENT platform will enable personalised prediction of patient-relevant outcomes as well as evidence-based recommendations for clinical management. Patients and care partners will receive understandable, personalised information on their brain health, and clinicians will benefit from these novel decision support tools that will guide them on the optimal diagnostic and therapeutic pathways.

Beyond establishing a digital platform for precision medicine, PROMINENT will pave the way for implementation in healthcare systems across Europe, using established co-creation approaches to meaningfully involve clinicians, patients and care partners along with representatives of regulatory agencies, health technology assessment bodies (HTA), and payers.

A prospective evaluation study led by the University of Cologne will assess how well the decision support system provides relevant, actionable information to clinicians, patients and care partners. Detailed feedback from interviews and surveys will facilitate iterative improvements to the PROMINENT system and user experience. A prospective validation study (led by Region Stockholm) will determine the diagnostic and prognostic accuracy of the platform, and assess clinical confidence in diagnosis before and after accessing the PROMINENT platform. With new disease-modifying therapies for AD on the horizon, there is a real need to support the introduction and optimal use of these novel drugs, and provide evidence for regulators, HTA

bodies, and payers. PROMINENT will rise to this challenge by supporting clinicians to ensure adherence with appropriate use guidelines, and by developing a framework for real-world evidence generation, delivering measurable improvements in clinical diagnosis, patient management, uptake of novel health technologies, and cost-effectiveness.

"Precision medicine is the future of healthcare, and with the PROMINENT project, we are taking a significant step forward in enhancing the diagnosis and treatment of neurodegenerative diseases. Our goal is to provide clinicians with individualised decision support and improve patient outcomes through personalised prediction models as well as evidence-based recommendations. With the collaboration of our esteemed partners, we are confident that PROMINENT will transform the way we approach cognitive impairment and ultimately improve the lives of patients across Europe." - Dr Linus Jönsson, Professor of Health Economics at Karolinska Institutet, PROMINENT Principal Investigator.

The PROMINENT project has a budget of EUR 11,069,750 from which EUR 6,069,750 is funded by IHI and EUR 5,000,000 is committed by the contributing partners. They are: Karolinska Institutet, Combinostics Oy, Combinostics US Inc., Synapse Research Management Partners SI, Alzheimer Europe, Region Stockholm, BioArctic AB, Klinikum der Universität Zu Köln, IHE, Institutet för Hälso- och Sjukvårdsekonomi, Fundació Barcelonabeta Brain Research Center, CHU Hôpitaux de Bordeaux, Univerzitetni Klinicni Center Ljubljana, University of Eastern Finland, Stichting Vumc.

Follow the project on Twitter @IHI_PROMINENT to stay up-to-date.

15 June: Paper on digital endpoints in clinical trials of Alzheimer's disease and other neurodegenerative conditions published by RADAR-AD and co-authored by Alzheimer Europe



A new RADAR-AD consortium publication investigates the value of remote monitoring technologies in the assessment

of neurodegenerative conditions, as well as the usability and feasibility of such digital assessments and the learnings from the project's public involvement and regulatory interactions. The paper, which was published in the journal

Frontiers in Neurology on 15 June 2023, concludes that the digitalisation of endpoints allows for objective, immediate and continuous measurement in both clinical and home settings, the reduction of visits to research or clinic facilities, better stratification and more personalised interventions, among others. Alzheimer Europe Project Officer Ana Diaz is a co-author. The paper is available here:

<https://doi.org/10.3389/fneur.2023.1210974>

Further information on RADAR-AD is at:

<https://www.radar-ad.org/>

19 June: Two papers published by IDoService project on insights into meaningful activities and experiences and on co-designing the service

Two papers about the IDoService project investigations have just been published and are available open access. As a reminder, this project aimed to support people living with mild dementia to better identify opportunities for participation in meaningful activities. [The I Can Do Pathway](#)



was developed to explore people's strengths and preferences to offer concrete guidance about how to access these activities.

The I Can Do Pathway was designed following inputs from various stakeholders collected first during interviews and focus groups, and next during co-design workshops. Details about these two research stages are shared in the two following open-access publications:

- "An Investigation of the Wishes, Needs, Opportunities and Challenges of Accessing Meaningful Activities for People Living with Mild to Moderate Dementia" in the International Journal of Environmental Research and Public Health: <https://doi.org/10.3390/ijerph20075358>

As part of the IDoService project, this study has investigated people's needs and wishes, barriers and facilitators to identify opportunities for improving access to meaningful activities. Individual and focus group interviews were conducted with people living with mild to moderate dementia, familial and professional care partners, as well as people working in the field of dementia and/or community activities. Thematic analysis has highlighted the benefits of participating in meaningful activities, such as empowerment and pride, social contacts, and feeling useful to others. A number of barriers to participation relating to individual and environmental factors were reported. Even where participants praised dementia-friendly activities and facilities, they advocated activities inclusive for all.

- "I Can Do: Co-Designing a Service with and for People with Dementia to Engage with Volunteering" in the MDPI-published journal of Social Sciences: <https://doi.org/10.3390/socsci12060364>

The initial data collection (see above) into opportunities and barriers in Greater Manchester provided key insights as a starting point for the service concept development. For its development, seven co-design workshops were held: two with people with dementia and five with carers and health, care and volunteer professionals. The outcome was the development of the concept and criteria of the I Can Do Pathway to support people with a dementia diagnosis in identifying their interests and strengths and to connect them with relevant volunteer opportunities. The article

explains the transformative co-design process and its results, followed by a reflection of the insights of designing a new service within an existing service system.

More information, see: www.idoservice.org

For any questions or suggestions contact Dr Isabelle Tournier by email idoservice@mmu.ac.uk or Twitter [@idoservice4dem1](https://twitter.com/idoservice4dem1).

This project built on the work done in the MinD project, in which Alzheimer Europe was involved.

20 June: Members of the ADIS advisory board gathered online to discuss the Public Involvement activities of the ADIS project



On 20 June, Cristina, Kina, Pilar, García and Ricard (members of the ADIS-advisory board (ADIS-AB)), and their supporters, gathered online. The meeting was organised by Alzheimer Europe (AE), facilitated by AE Project Officers Soraya Moradi-Bachiller and Ana Diaz and was attended by neuropsychologist Andrea del Val Guardiola and neurologist Neus Falgàs (Fundació Clínic per a la Recerca Biomèdica, Spain), as well as Jesús Rodrigo (Confederación Española de Alzheimer, Spain). Contrary to previous meetings, this one aimed at providing the members of the ADIS-AB with a summary of all their contributions to the Public Involvement activities during the first half of the year and the impact that their feedback had on the ADIS project.

Soraya started the meeting by giving an overview of the discussions and feedback obtained in previous consultations relating to the topic of the informed consent process, and the terminology used in the ADIS informed consent form. After this overview, Neus, who is part of the ADIS research team, explained the changes that were made to the ADIS informed consent form, based on the feedback received from the ADIS-AB. These changes include the replacement of the term "patient" with "participant" when referring to everyone who participates in the ADIS study, regardless of whether that person has Alzheimer's disease (AD) or not, and the addition of a paragraph acknowledging the value of participation to research participants.

Soraya then summarised the feedback provided by the ADIS-AB on the topic of the value of knowing an AD diagnosis in the early stage of the disease (i.e. Mild Cognitive Impairment (MCI)).

According to the ADIS-AB, an early diagnosis of AD has a huge value, as this is essential to plan and make important decisions regarding someone's future needs, to access clinical trials and appropriate medication, and to take part in activities to maintain psychological wellbeing. However, an early diagnosis of AD, still to this day, represents a challenge in employment and healthcare systems that cannot be ignored.

Lastly, Soraya gave some details about the first face-to-face consultation with the members of the ADIS-AB, which will take place in November in Luxembourg, where they will have the chance to meet each other in person.

26 June: AI-Mind continues successful enrolment in its clinical study and its follow-up visits

AI-Mind, a 5-year EU-funded project aiming to provide better and personalised diagnoses for future patients, was launched in March 2021. The members of the AI-Mind consortium are glad to announce that its study is approaching its enrolment goals, with over three-quarters of recruited participants.



The AI-Mind research study is at the heart of the project and will help collecting invaluable data to develop and validate artificial intelligence (AI)-based tools to predict, at an early stage, who is likely to develop dementia. The AI-Mind study, launched in January 2022, is the largest European study of this kind and is aiming to recruit 1,000 participants across four countries in Norway, Finland, Italy and Spain. Almost 900 research participants have been enrolled so far. Participants, aged between 60 and 80 years, who either have a diagnosis of Mild Cognitive Impairment (MCI) or who are experiencing memory and concentration problems, are asked to visit the clinical sites for four appointments over two years, resulting in an appointment every eight months.

Project partners are pleased to share that the first participants enrolled in the study get back to their study site for their second or third visit. This milestone is a significant accomplishment for the study team, who expressed gratitude to all those who joined them. Their participation in the project involve standardised assessments including a short interview, digital cognitive tests (i.e. memory, thinking, language) and a procedure to measure electrical activity in the brain (EEG and MEG tests).

If you are interested to learn more about the study, please visit the dedicated sections on the [AI-Mind website](#) with new visualisations, as well as watch the [explanatory video](#) developed to inform potential participants about the AI-Mind study procedures. You can also subscribe to the new quarterly study newsletter [here](#) to stay informed. By subscribing, you'll gain a deeper understanding of the project's progress and its potential impact on dementia research.

EU project acknowledgements



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

AI-MIND - grant agreement 964220

PROMINENT - grant agreement 101112145

PRODEMOS - grant agreement 779238

RADAR-AD – grant agreement 806999



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Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **87**, representing **26** out of 27 Member States of the European Union and seven out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **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 (Renew Europe); Deirdre Clune (EPP); Ciarán Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (EPP); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens/EFA); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Peter Lundgren (ECR).



EU DEVELOPMENTS

6 June: Alzheimer Europe co-signs Civil Society Europe manifesto for EP elections 2024



A coalition of 69 civil society organisations have co-signed a Civil Society Europe manifesto, “Civil Society for EU”, aiming to use the

forthcoming European Parliament elections in 2024 to turn the tide of shrinking civil society space and limited civil dialogue all over Europe.

The manifesto notes that civil society has the potential to become a permanent, empowered and engaged actor in future European governance, providing a voice and a role to some of the most marginalised groups in society.

The manifesto calls for the strengthening of civil dialogue and civic space across the EU through better recognition, involvement and resourcing of civil society. Additionally, it calls on the European Parliament and Commission to take concrete steps to create an empowering environment for civil society during the next five-year term, starting from the development of a European Civil Society Strategy and of a Civil Dialogue Agreement. The manifesto can be accessed at:

<https://drive.google.com/file/d/1UASTO8wj-9-qB7D1RQuT3u4zDGCsPK--/view>

6 June: European Commission publishes communication on mental health

The European Union has published a Communication on a “comprehensive approach to mental health”, with 20 flagship initiatives and EUR 1.23 billion in EU funding from different financial instruments. The EU action on mental health will focus on three guiding principles:

- Adequate and effective prevention
- Access to high quality and affordable mental healthcare and treatment
- Reintegration into society after recovery.

The initiative looks at mental health across all policies, including prevention, care and treatment, with efforts made to:

- Promote good mental health through prevention and early detection
- Invest in training and capacity building that reinforces mental health across policies and improves access to treatment and care
- Ensure good mental health at work by raising awareness and improving prevention

- Address vulnerable groups by providing targeted support to those most in need, such as older people or people in difficult economic or social situations.

The full Communication is available at:

https://ec.europa.eu/commission/presscorner/detail/e%20n/ip_23_2955

6-7 June: European Group of Governmental Experts on Dementia meets in Brussels



The European Group of Governmental Experts on Dementia held its first meeting of 2023 on 6 and 7 June in Brussels, Belgium and online. 16 European countries were represented at the meeting, in addition to representatives from the World Health Organization (WHO), from the European Commission’s European Health and Digital Executive Agency (HaDEA) and DG Research & Innovation (DG RTD) and from Alzheimer Europe. Over the course of the two-day meeting, the group heard about national dementia strategies and policies, as well as European and international policy developments.

At the national level, representatives from health ministries updated the group on recent developments in their countries, including the development and implementation of dementia strategies in Austria, Belgium (Flanders), Czech Republic, Germany, Iceland, Ireland, Slovenia and the United Kingdom (Scotland), a new awareness campaign in Norway and other dementia policy developments in Cyprus and Poland.

At the European level, representatives from the European Commission shared information about funding for dementia research and dementia policies, with presentations on “Dementia as a priority of the EU research programmes Horizon2020 and Horizon Europe” and on “The EU4Health Programme and its focus on mental health and dementia”. Jean Georges, Executive Director, Alzheimer Europe discussed the EU Joint Actions on Dementia, giving participants an overview of the ALCOVE and Act on Dementia projects.

Regarding global developments on dementia, the WHO updated delegates on some of its ongoing dementia initiatives and participants also heard about the activities of the World Dementia Council, the G7 and about the Dutch High Level Meeting on Dementia planned for October 2023.

The European Group of Governmental Experts on Dementia was formed in 2018 by Alzheimer Europe, the Dutch Ministry of Health, Welfare and Sport, the Italian Ministry of Health and the Scottish Government and is facilitated by Alzheimer Europe. It is scheduled to meet again on 14 December 2023.

14 June: European Parliament adopts negotiating position on Artificial Intelligence Act

The European Parliament has adopted its negotiating position on the Artificial Intelligence (AI) Act, ahead of talks with Council on the final law. The rules would ensure that AI developed and used in Europe is fully in line with EU rights and values, including human oversight, safety, privacy, transparency, non-discrimination and social and environmental wellbeing.

The position sets out a risk-based approach and establishes obligations for providers and those deploying AI systems. Where there would be unacceptable level of risk to people’s safety, the use of AI systems would be prohibited, such as those used for social scoring (classifying people based on their social behaviour or personal characteristics). MEPs expanded the list to include bans on intrusive and discriminatory uses of AI, including:

- Real-time remote biometric identification systems in publicly accessible spaces
- Biometric categorisation systems using sensitive characteristics (e.g. gender, race, ethnicity, citizenship status, religion, political orientation)
- Emotion recognition systems in law enforcement, border management, the workplace, and educational institutions
- Untargeted scraping of facial images from the internet or CCTV footage to create facial recognition databases.

The position also stipulates that high-risk applications include AI systems that pose significant harm to people’s health, safety, fundamental rights or the environment. Additionally, AI systems used to influence voters and the outcome of elections and recommender systems used by social media platforms (with over 45 million users) were added to the high-risk list.

The full position can be read at:

https://www.europarl.europa.eu/doceo/document/TA-9-2023-0236_EN.html

POLICY WATCH

31 May: The Model of Care for Dementia in Ireland is launched at The Department of Health in Dublin

The Alzheimer Society of Ireland advocates, staff and supporters attended the Launch of The Model of Care for Dementia in Ireland at The Department of Health in Dublin on 31 Ma 2023. With over 64,000 people currently living with dementia in Ireland, it is a life changing condition. This Model of Care provides an integrated framework to bring together a wide range of services for people living with Dementia and is underpinned by the following:

- People living with dementia are at the centre of considerations relating to service design and recommendations related to care practices.
- They receive timely and equitable access to assessment, diagnosis and post-diagnostic support regardless of the location of a service, the type of dementia they have, their age, their ethnicity, any other disability or co-morbidity, or their gender.

The Alzheimer Society of Ireland welcomed the plan as it ensures people living with dementia are involved in the process of their service design. To learn more, please visit:

<https://www.hse.ie/eng/services/news/media/pressrel/hse-enhanced-community-care-programme-launches-new-model-of-care-for-dementia-in-ireland.html>



Pictured: The Alzheimer Society of Ireland advocates, staff and supporters pictured with Minister Mary Butler TD at the Launch of The Model of Care for Dementia at The Department of Health in Dublin on 31 May 2023

15 June: Environmental Protection Scotland’s Clean Air Day 2023 campaign urges the public to “Clean up our air to look after your mind”

15 June 2023 marked Clean Air Day, the largest air pollution campaign in the United Kingdom. Environmental Protection Scotland noted that the event was a huge success, with hundreds of events taking place across the country, engaging thousands of people nationwide and reaching millions more through the media.

Clean Air Day is coordinated on an annual basis by Global Action Plan, with support from a number of partners nationwide. Environmental Protection Scotland has been granted the responsibility to coordinate the campaign north of the border (i.e. in Scotland) since 2018, in partnership with Global Action Plan and on behalf of the Scottish Government.

“We were delighted to see a range of actors involved in coordinating activities and events to mark the campaign, including schools, community groups, health boards, local authorities, and more, making fantastic use of our free



resources available online”, said Emma Eusebi, Policy & Communications Officer, Environmental Protection Scotland.

The theme for the campaign this year was focused on raising awareness and on increasing our understanding of how air pollution can affect the brain and the mind. This followed emerging research that people who breathe polluted air are more likely to develop mental health and brain problems, such as depression, anxiety and dementia.

Clean Air Day aims to drive a positive shift in public knowledge and action and Environmental Protection Scotland wanted to use the campaign to make sure the public are aware of the actions they can take to reduce their exposure and their contribution to air pollution, not only protecting their physical health, but their brain health too.

21 June: Davos Alzheimer’s Collaborative calls for key actions to drive early detection and healthcare system preparedness



On 21 June 2023, the Davos Alzheimer’s Collaborative (DAC) Healthcare System Preparedness Learning Laboratory convened more than 350

stakeholders from over 50 countries and 300 organisations to share lessons based on the 19 early detection initiatives in 12 countries across DAC flagship pilot sites and grant programmes. Inspired by these discussions, the DAC and partners are now calling on national governments, healthcare system leaders, private-sector innovators, global organisations, and other stakeholders to collaboratively act on these lessons to expand early detection and strengthen healthcare system preparedness.

Speakers at the Learning Laboratory included: Kristina Malzbender, Gates Ventures; Mark Roithmayr, Alzheimer’s Drug Discovery Foundation; David Bates, Linus Health; Tom O’Neill, Cognivue; Brad O’Connor, Cogstate; Joel Braunstein, C2N Diagnostics; Hilary Evans, Alzheimer’s Research UK and Dame Barbara Windsor Dementia Mission; Kosuke Wada, Ministry of Health, Labour, and Welfare, Japan; Simon Njuguna, Ministry of Health, Kenya; and Kristine Galstyan, Ministry of Health, Armenia.

They highlighted four areas for action:

- Harness a “toolbox” to support early detection across geographies, contexts, and needs.
- Advance implementation science to drive adoption, scalability, and impact.
- Enact bold dementia policy to scale a proven patient pathway for early detection.
- Strengthen global collaboration for enduring policy commitment, shared lessons, and inclusive research.

Read more about the Learning Laboratory and the Call to Action, here:

<https://mailchi.mp/9c222abed71b/dac-learning-lab-call-to-action-june2023>



SCIENCE WATCH

30 May: New study investigates the link between flavanol deficiency and memory

In a new study published in the journal Proceedings of the National Academy of Sciences, researchers in the US and UK investigated whether a balanced diet including foods rich in flavanols could help to improve memory in older adults. Dietary flavanols are food constituents found in certain fruits and vegetables.



Participants of the study were part of a larger ongoing study of more than 21,000 adults looking into the health benefits of flavanols from cocoa. Characteristics of over 3,500 healthy US adults with an average of 71 years old were included in this study. Participants received either a daily cocoa flavanol supplement pill (500 mg of cocoa flavanols per day) or a placebo for three years. Researchers assessed the participants’ memory and thinking skills, quality of diet and levels of the flavanol indicator in their urine. They showed that the flavanol supplement, after three years, boosted memory test scores among participants who originally had the lowest-quality diet and lowest amounts of urine biomarker.

<https://doi.org/10.1073/pnas.2216932120>

1 June: Expert panel calls for concrete actions to enable access to innovative Alzheimer’s disease therapies for people with intellectual disability and Down Syndrome

People with Down Syndrome (DS) have a 90% risk of developing Alzheimer’s disease (AD) over their lifetimes, with most receiving an AD diagnosis by the time they’re 54 years of age.

This is thought to be linked to the fact that people with DS have an extra copy of the amyloid precursor protein (APP) gene, which resides on chromosome 21, and promotes the build-up of amyloid plaques in the brain. However, current prescribing criteria for innovative, anti-amyloid immunotherapies in the US explicitly exclude people with Down Syndrome and other intellectual disabilities.

In their consensus statement, an international panel of experts convened by the National Task Group on Intellectual Disabilities and Dementia (the NTG) and the LuMind IDSC Foundation call for policy changes to urgently address inequitable access to AD drugs.

The consensus statement was developed as a result of deliberations between 20 international experts on AD and DS. The panel calls for adaptation of the current inclusion criteria for anti-amyloid immunotherapies to enable equitable access for people with DS and AD. These criteria do not currently account for the young age of people with DS and AD; inappropriately exclude of people with intellectual disability; and are designed around the use of cognitive tests that are not adapted for people with DS. To address this issue, the panel provide recommendations for modifications to prescriber guidelines, such as reducing the minimum age for treatment; consulting with DS or intellectual disability specialists; and using DS-appropriate measures of cognitive decline.

The panel also highlighted the need for improved guidance and education for primary care physicians and prescribers of anti-amyloid therapies, to ensure equitable access to these drugs for people with intellectual disability or DS; and called on pharmaceutical companies to include people with intellectual disability or DS in clinical trials, starting with the conduct of safety trials with FDA-approved anti-amyloid therapies. Read the consensus statement:

<https://lumindidsc.org/expert-panel-addresses-inequitable-access-to-alzheimers-drugs-for-adults-with-down-syndrome>

6 June: Analysis of electronic health records from people in Wales finds a link between shingles vaccination and dementia risk

Shingles is caused by the reactivation of the chicken pox virus, leading to a painful, itchy rash on the skin. The chance of getting shingles increases with age, as does the risk of severe side-effects. The Welsh shingles vaccination programme was launched on 1 September 2013, offering free vaccination against shingles to anyone aged over 70 and below 80 years. This age cut-off was determined based on the efficacy of the vaccine, which was shown to be lower in adults aged 80 and over. The stringent eligibility cut-off for the vaccination programme allowed researchers to compare the incidence of dementia in two similar groups of older adults: people who were born on or after September 2, 1933 (and were eligible for shingles vaccination) and people who were born just one week earlier, and were therefore not eligible for vaccination. According to their analysis of electronic health records from

282,541 people in Wales, receiving a vaccination for shingles may reduce the risk of developing dementia.

In their study, which was recently released on the medRxiv preprint server, a team of researchers led by Pascal Geldsetzer at Stanford University (California, USA) analysed the electronic health records of 296,603 people born between 1925 and 1942, evaluating several health outcomes including the diagnosis of dementia. Just under half of those who were eligible received the shingles vaccine in the 7-year period that was analysed. Statistical analyses of health data showed that people receiving shingles vaccination were 19.9% less likely to develop dementia, compared to people who did not receive the vaccine. Closer inspection of the health records revealed that the vaccine's effect on dementia diagnosis was much greater in women than in men. However, dementia experts have cautioned that clinical trials are now needed to confirm the observed effect, and eliminate possible causes of bias that may affect the validity of the results. Read the article on medRxiv:

<https://www.medrxiv.org/content/10.1101/2023.05.23.23290253v1.full-text>

9 June: FDA Advisory Committee endorses traditional approval of lecanemab, paving the way for broader access in the US

Since 6 January, the anti-amyloid drug lecanemab has been available to US-based patients with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease (AD). However, the national coverage determination by the Centers for Medicare and



Medicaid Services (CMS) limits access to participants enrolled in approved clinical research studies. On 9 June, a US Food and Drug Administration (FDA) Advisory Committee unanimously recommended traditional approval of lecanemab, which is expected to pave the way for broader access to the drug.

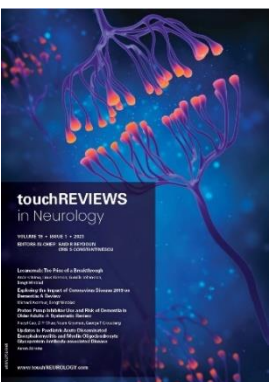
Lecanemab is an antibody that targets plaques of amyloid-beta proteins, which accumulate in the brain during the development of AD. Lecanemab was authorised via the FDA accelerated approval pathway, which covers medicines for serious conditions where there is an unmet medical need, and where the drug has an effect on a surrogate endpoint that is likely to predict a clinical benefit to patients. FDA approval of lecanemab was based on the positive results of a Phase 2b, randomised and placebo-controlled clinical trial, which recruited 856 patients with MCI or mild dementia due to AD. In January this year, Eisai and Biogen filed for traditional FDA approval based on the results of their confirmatory Phase 3 study, CLARITY-AD. This study similarly showed a substantial reduction in brain amyloid, as well as a 27% slowing in clinical decline after 18 months of lecanemab treatment.

During the Advisory Committee meeting, six experts including Collette Johnson, a patient advocate, discussed the findings of CLARITY-AD, with presentations from Eisai, and overviews of clinical efficacy, safety, and statistics from FDA reviewers. The advisors unanimously agreed that CLARITY-AD verified the clinical efficacy of lecanemab, showing a clear, statistically-significant slowing of clinical decline that would represent a meaningful benefit for patients. On safety, the Committee discussed the risk of brain bleeds and swelling (also termed ARIA), which are particularly high for individuals carrying the APOE4 risk allele. They recommended that the FDA provide clear labelling to inform patients and caregivers on the risk of ARIA, and strengthen the suggestion to undergo genetic testing for APOE4.

The FDA now has four weeks to consider the recommendations from the Advisory Committee, with a final decision due by 6 July. Access information and briefing documents for the Advisory Committee meeting:

<https://www.fda.gov/advisory-committees/advisory-committee-calendar/updated-information-june-9-2023-meeting-peripheral-and-central-nervous-system-drugs-advisory>

20 June: touchNEUROLOGY publishes new edition of its journal touchREVIEWS in Neurology, including three expert interviews with Alzheimer Europe



Welcome to the latest edition of touchREVIEWS in Neurology which features a diverse range of free-to-view, topical articles covering therapeutic areas relevant to neurologists and other practitioners involved in the care of patients with neurological illness. The new journal includes three interview pieces with Alzheimer Europe staff.

In the first interview, Alzheimer Europe Policy Officer Owen Miller discusses the Dementia in Europe Yearbook 2022: Employment and Related Social Protection for People with Dementia and their Carers:

<https://touchneurology.com/alzheimers-disease-dementia/journal-articles/dementia-in-europe-yearbook-2022-employment-and-related-social-protection-for-people-with-dementia-and-their-carers/>

The second is on our report on sex, gender and sexuality in the context of dementia. In this expert interview, Director for Projects Dianne Gove Executive Director Jean Georges discuss the defining aims and goals of the guide, including how it contributes towards challenging the assumptions and inequalities in dementia and about people living with dementia, and its take-home messages:

<https://touchneurology.com/alzheimers-disease-dementia/journal-articles/sex-gender-and-sexuality-in-the-context-of-dementia-a-guide-to-raise-awareness-amongst-health-and-social-care-workers/>

The third interview is on our recently-published Guidelines for the Ethical and Inclusive Communication About/Portrayal of Dementia and People with Dementia. In this piece, Dianne Gove and Project Officer Ana Diaz discuss the current challenges in ethical and inclusive communication about and portrayal of dementia and people with dementia, the defining aims and goals of the guide, and the key messages:

<https://touchneurology.com/alzheimers-disease-dementia/journal-articles/guidelines-for-the-ethical-and-inclusive-communication-about-portrayal-of-dementia-and-people-with-dementia-and-people-with-dementia/>

The journal touchREVIEWS in Neurology is a peer-reviewed, free-to-access, bi-annual journal that aims to provide insightful and topical articles relevant to the day-to-day practice of physicians in the field of neurology and provides practical advice relevant to the clinical setting on the diagnosis and treatment of neurological conditions. Explore the new edition of touchREVIEWS in Neurology, here:

<https://touchneurology.com/journals/touchreviews-neurology/touchreviews-in-neurology-volume-19-issue-1-2023/>

27 June: Novel immunotherapy for Alzheimer’s disease from AC Immune receives Fast Track designation from the FDA

The US Food and Drug Administration (FDA) has awarded Fast Track designation to the biopharmaceutical company AC Immune, for its investigational immunotherapy ACI-24.060.

ACI-24.060 is a liposome vaccine that is designed to elicit an immune response against the toxic forms of amyloid beta proteins that build up in the brain during the development of Alzheimer’s disease. It is currently being investigated in ABATE, a Phase 1b/2 double blind, randomised, placebo-controlled clinical trial in adults with mild cognitive impairment due to Alzheimer’s disease, and in adults with Down Syndrome.

Individuals with Down Syndrome possess a third copy of the amyloid precursor protein (APP) gene, which is thought to cause the accumulation of amyloid plaques in the brain. In a press release issued in January this year, the company announced interim safety, tolerability and immunogenicity results for ACI-24.060, explaining that the drug was generally safe, well tolerated, and could induce an antibody response two weeks after administration.

The Fast Track designation is aimed at expediting the development and review of drugs to treat serious conditions and fill an unmet clinical need. Drugs that receive Fast Track designation may be eligible for more frequent meetings or communication with the FDA, and for accelerated approval and priority review, if relevant criteria are met. Initial PET scan data on amyloid plaque reduction by ACI-24.060 are expected in early 2024. Read the press release:

<https://www.globenewswire.com/news-release/2023/06/27/2695157/0/en/AC-Immune-Receives-FDA-Fast-Track-Designation-for-Anti-Amyloid-beta-Active-Immunotherapy-ACI-24-060-to-Treat-Alzheimer-s-Disease.html>

28 June: New study investigates the link between menopausal hormone therapy and dementia



A new article entitled “Menopausal hormone therapy and dementia: nationwide, nested case-control study” has recently been published in the journal The BMJ. Researchers from Denmark conducted a nationwide study on the association between menopausal hormone therapy and

development of dementia. Drawing on national registry data, they identified 5,589 cases of dementia and 55,890 age matched controls between 2000 and 2018 from a population of all Danish women aged 50-60 years in 2000 with no history of dementia or contraindications for use of menopausal hormone therapy.

Results showed that, people who had received oestrogen-progestogen therapy had an increased rate of developing all cause dementia, late onset dementia and Alzheimer’s disease, even in women who received treatment at the age of 55 years or younger. Rates were higher with longer use. In addition, oestrogen-progestogen therapy was positively associated with development of dementia for both continuous and cyclic treatment regimens.

This is an observational study with strengths and weaknesses in relation to other studies. Authors recommend further studies to explore whether these findings “represent an actual effect of menopausal hormone therapy on dementia risk, or whether they reflect an underlying predisposition in women in need of these treatments.”

<https://www.bmj.com/content/381/bmj-2022-072770>

MEMBERS’ NEWS

29 May-4 June: Scottish Dementia Working Group and National Dementia Carers Action Network support Alzheimer Scotland's campaign for Dementia Awareness Week 2023



Members of both the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) supported and helped to shape the content of Alzheimer Scotland’s week-long Dementia Awareness Week (DAW) campaign— particularly **Talking our language** which aims to challenge the stigma and preconceptions people with dementia often face.

SDWG member Stuart Dougall played a key role in Alzheimer Scotland’s national DAW communications, as one of five people who shared their experiences of young-onset dementia through a short film and a blog. Stuart also appeared on the cover of the **Dementia Awareness Week edition of Dementia in Scotland Magazine**, and wrote about why dementia didn’t stop his recent South American adventure. SDWG member Margaret McCallion also appeared in the magazine, sharing what she’d like people to know about life with a diagnosis of young-onset dementia.

Throughout our week of activities SDWG and NDCAN members promoted Alzheimer Scotland’s key DAW message that dementia is "One thing, not everything" about a person. They demonstrated that a person can continue to live well following a dementia diagnosis, and they played their part in tackling the stigma of dementia.

1 June: Scottish Dementia Working Group involved in work on dementia research including a Junior Doctors Learning Session and a research-themed "Tea & Blether"



The Scottish Dementia Working Group (SDWG)’s commitment to ensuring workforce knowledge and practice are informed by people with personal experience was at the heart of a learning session with first year junior doctors from Wishaw General Hospital on 1 June 2023. Group members Margaret McCallion, Stuart Dougall and Kenny Moffat spoke about their diagnosis journeys, their experience of receiving a dementia diagnosis in their 50s, their life since and how they are living the best life possible with dementia, including through their work with the SDWG. They took the opportunity to highlight the key things the junior doctors should keep in mind when giving a dementia diagnosis.

This was followed by a research themed "Tea & Blether" event, at which SDWG members got together with Professor Debbie Tolson and Dr Louise Ritchie from the Alzheimer Scotland Centre for Policy & Practice. The Group has enjoyed working closely with the Centre since its inception 10 years ago, so it was great for members to meet with Prof. Tolson and Dr Ritchie in the Glasgow Brain Health & Dementia Resource Centre, to review the work they’ve done together and look forward to future research opportunities. Members chatted about the ways in which they can participate in research – from receiving information on research projects; to being consulted on and participating in research; and to working with the Centre on a co-production basis. Conversations took place about possible

areas for future research, and around how the Group can identify and develop project ideas that align with their renewed priorities and focus areas. Members agreed to establish a research group to build upon their research partnerships with the Centre for Policy & Practice, Brain Health Scotland and the Scottish Dementia Research Consortium.

2 June: Alzheimer Italia translates Alzheimer Europe guide aimed at raising awareness of issues around sex, gender and sexuality in dementia



An Italian version of Alzheimer Europe's guide to help raise awareness of issues around sex, gender and sexuality in dementia has been published, translated by Alzheimer Italia.

The guide is about the experience and wellbeing of men, women and non-binary people with dementia who are living alone or with a partner and who may or may not be sexually active. We draw attention to inequality,

discrimination and lack of sensitivity towards their needs and wishes, both from other people and through structures and procedures within society, also towards their families, carers and in some cases health and social care workers. The guide is not limited to the experience of LGBTQ+ people but their experience is often qualitatively different to that of non-LGBTQ+ people and they encounter several issues that others do not, hence the frequent reference to this group in the guide. The new Italian version of the guide can be downloaded from the Alzheimer Europe website, at:

https://www.alzheimer-europe.org/sites/default/files/2023-07/guide_on_sex_and_gender_-_italian_-_final_version_-_1_page_format.pdf

16-18 June: Alzheimer Poland hosts Annual General Meeting in Warsaw, including a conference on "The Current Approach to Treatment and Care for Persons with Dementia in Poland"

On 16 -18 June 2023, Alzheimer Polska organised and hosted an Annual General Meeting (AGM) of its member organisations in Warsaw. Almost 70 people attended, representing local Alzheimer's associations from around Poland, as well as invited officials from the Ministry of Health and other institutions.

The main event of the AGM was a conference on "The Current Approach to Treatment and Care for Persons with Dementia in Poland", at which there were two debates that participants could listen to and learn from. The first debate, moderated by Marlena Meyer, President of the Dementia Action Alliance



Polska, gathered family and professional carers who shared their personal stories relating to care.

During the next debate, chaired by Edyta Ekwinska (pictured, left), Vice-president of Alzheimer Polska, seven notable Polish neurologists, psychiatrists and psychologists who specialise in diagnosis and treatment in dementia, presented their experiences and views on present and future developments and Innovations in the field.

21 June: The Alzheimer Society of Ireland launches Alzheimer's Memory Walk 2023

On 21 June 2023, The Alzheimer Society of Ireland (The ASI) Ambassadors, Local Champions and ASI staff gathered in Merrion Square, Dublin to launch the Alzheimer's Memory Walk 2023, proudly supported by Payzone. The Alzheimer's Memory Walk will take place at 30 locations across Ireland on 24 September.

The nationwide, annual event gives families, friends and those living with dementia the opportunity to come together, honour, celebrate and raise funds for the vital support services that The ASI provides.

The Alzheimer's Memory Walk (#ASIMemoryWalk2023) is a family-friendly event suitable for all ages and walking abilities to unite friends, families and communities to raise awareness and funds for dementia supports. The ASI is aiming to secure over 3,000 walkers across Ireland to participate and help raise funds for vital services that support so many people living with dementia and those who care for them.

The ASI is pleased to welcome their Alzheimer's Memory Walk 2023 Ambassadors: leading business entrepreneurs Pamela Laird and Ellen Kavanagh Jones, Comedian Neil Delamere, TV personality Martin King, Actor and member of The Irish Dementia Working Group Bryan Murray and Miss Cork Rachel O'Leary. Each Ambassador has a personal connection to dementia.

Speaking at the launch, Mairéad Dillon, Head of Fundraising for The ASI said: "The Alzheimer's Memory Walk for 2023 is set to be our biggest and best to date and the number of ambassadors, staff, and local champions gathered at the launch today is testament to that. I'd like to say a heartfelt thank you to our partners Payzone who are supporting the event and are in attendance today. We are really looking forward to September 24th this year to get people together supporting people with dementia." Registration for Alzheimer's Memory Walk 2023 is open now at:

www.memorywalk.ie



Pictured: Mairéad Dillon, Head of Fundraising at The Alzheimer Society of Ireland and Andy Heffernan, CEO at The Alzheimer Society of Ireland with Alzheimer's Memory Walk 2023 Ambassadors.

24 June: The Alzheimer Society of Ireland marks Pride Month 2023



The Alzheimer Society of Ireland (The ASI) proudly marks Pride month in support of LGBTQIA+ friends, colleagues, supporters and people affected by dementia and their loved ones. On 24 June, ASI staff and supporters joined thousands of people to march in the Dublin Pride

Parade, led by members of The ASI's LGBT+ Pilot Group. The LGBT+ Pilot Group is a group of ASI Staff who help to identify and shape workplace practices that can be made to better support LGBT+ people living with dementia. It was a day of joy and inclusivity as a rainbow of colours filled the streets of Dublin. This was the first year that the charity took part in the Dublin Pride Parade.

On 13 June, the DemTalks Podcast; Series One, the Dementia Carers Campaign Network (DCCN) launched, featuring a panel discussion on Caring in the LGBT+ Community. The first episode of the podcast is also dedicated to the same topic. The DCCN, supported by The ASI, is an advocacy group of people who have experience caring for a loved one with dementia. The podcast is proudly sponsored by Hidden Hearing.

27 June: Spominčica Alzheimer Slovenia receives generous donation from largest bank in Slovenia

Spominčica Alzheimer Slovenia has received a generous donation from NLB Group, the largest bank in Slovenia. NLB Group decided to donate EUR 1.35 million to all markets in their home region where they operate. Their employees put forward

nominations for nearly 100 organisations, associations, and humanitarian organisations and, by means of a vote, they selected over 30 recipients for the fund donation. In Slovenia, 10 organisations received donations and Spominčica was among them. This recognition is an acknowledgement of Spominčica's ongoing dedication and the impact it has in assisting individuals and families affected by dementia.

During an event, Blaž Brodnjak, President of the Management Board of NLB Group, extended his congratulations to all the organisations receiving donations. President of Spominčica, Štefanija L. Zlobec, had the honour of presenting him with Spominčica's latest publication, the Dementia Guide for Families: Living with Dementia at Home. Mr Brodnjak expressed interest in future cooperation, as people with dementia are often no longer able to manage their money and finances. Spominčica feels that it is therefore beneficial to work together to prevent potential abuse and make it easier for people with dementia to manage their finances.



Thanks to the generous donation from NLB Group, Spominčica will be able to strengthen its support services for individuals with dementia and their carers. Its comprehensive programmes, such as Dementia Friendly Points, helpline, support groups, lectures, informative brochures, Spominčica newsletter and Alzheimer Cafés contribute to the creation of a dementia-friendly environment throughout Slovenia.

Spominčica remains committed to raising awareness and reducing the stigma associated with dementia in society and extends its deepest appreciation to NLB Group for its generosity and belief in Spominčica's mission.

28 June: Six new day centres and mobile units for people with dementia and their families have been inaugurated in Greece

The inauguration of six new structures, which offer free-of-charge services to people with dementia and their families, funded by the Greek Department of Health and the Recovery and Resilience Fund, was completed over the past few days.

Alzheimer Athens inaugurated three new Day Care Centers and Mobile Units for people with dementia in Piraeus, Heraklion Attica and Arta, while Alzheimer Hellas opened a new Day Care



Center in Katerini, Alzheimer Chalkida opened one in Chalkida and the Alzheimer Association “Solidarity” opened a new centre and mobile unit in Heraklion, Crete.

29 June: France Alzheimer has translated Alzheimer Europe's guidelines on ethical and inclusive communication about people with dementia into French



A French version of Alzheimer Europe's new set of guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia has been published, translated by France Alzheimer. The guidelines were developed in tandem with the European Working Group of People with Dementia (EWGPWD) and are targeted at the media, researchers, journalists, policy makers and anyone

responsible for the portrayal of or communication about dementia in the public domain. Originally launched (in English) in January 2023, the guidelines are structured around 14 statements, each constituting a piece of advice and followed by a more detailed explanation, and in some cases by a few quotes from members of the EWGPWD and one from a supporter.

Alzheimer Europe is delighted that its member association France Alzheimer decided to translate this document and to share it on the France Alzheimer website and via its social media channels.

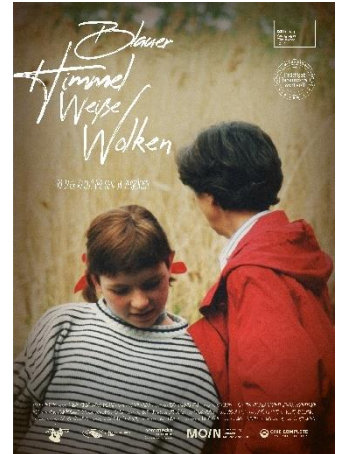
The new French version of the guidelines can be downloaded from the Alzheimer Europe website:

https://www.alzheimer-europe.org/sites/default/files/2023-06/alzheimer-europe_francealzheimer_respectfulcommunication_fr.pdf

DEMENTIA IN SOCIETY

5 June: German documentary film “Blue Sky White Clouds” takes a look at what it means to care for a loved one, and what matters most in life

Blauer Himmel Weiße Wolken (Blue Sky, White Clouds) is a German-language documentary film featuring a grandmother who is exhibiting the signs of dementia and her two grandchildren. Since the death of her husband, the gaps in her memory are getting bigger and bigger and her disorientation is increasing. Director Astrid Menzel made a decision together with her brother, to go on a ten-day canoe trip across northern German waters with their 86-year-old grandmother. It was an adventure with an uncertain outcome, a fact which the three travellers had to face anew at each stage of their journey together. The trip was documented on film and the end result was “Blue Sky, White Clouds”.



After its successful premiere at the documentary film festival DOK Leipzig, the film was shown in select cinemas all over Germany, between 24 May and 5 June 2023, as part of a tour with Astrid Menzel. “Blue Sky White Clouds” is a feel-good-movie, which shows the emotional turmoil and intimacy of its protagonists; a larger-than-life grandmother and her two endlessly patient and loving grandchildren.

For further information, please contact ACROSS NATIONS at: info@across-nations.de

<https://across-nations.de/projekte/blauer-himmel-weiße-wolken/>

26 June: “Music, Meaning & Memory” cultural event aims to open up conversations and combat stigma around memory problems and dementia in the UK’s South Asian community

On 26 June 2023, Dr Naaheed Mukadam (Principal Research Fellow, Mental Health of Older People, Division of Psychiatry, University College London) hosted and performed in a cultural event to open up conversations around memory problems and dementia in the South



Asian community and combat stigma. The show was titled “Music, Meaning & Memory” and used song, instrumental music and kathak dance to explore the experience of having

memory symptoms or caring for someone who has dementia. Dr Mukadam partnered with Akademi (a dance organisation) and Soumik Datta, an award winning sarod artist, to create this event.

Through music and movement workshops in a care home and day centre, and conversations with participants, Dr Mukadam, dance artist Jesal Patel and Soumik Datta were able to observe how music sparks connections and memories and to listen to personal experiences of attendees. All professionals also spoke to each other throughout the process, reflecting on Dr Mukadam’s clinical experience in speaking to patients with dementia and their families.

These conversations and themes were used to create pieces of music and dance to express them in art form:

- Dr Mukadam composed a song in Urdu, “to show the disorientation experienced when a loved one’s memory varies day to day, leaving their family feeling as though they catch glimpses of their loved one, only for them to be swept away again”. Similarly, another song in Bengali “described

the feeling of trying to connect and keep your loved one with you, while they are swept away by the ravages of memory loss”.

- Soumik Datta performed pieces which included musical fragments and echoes. In his words, “the musical equivalent of a memory is an echo, a partial fragment of the original”.
- Jesal Patel composed an original dance piece with a partner, using different coloured scarves to represent different emotions and playing with themes of time and disorientation.

The show was performed at the Bloomsbury theatre at UCL and the audience was a mix of academics, students, people with experience of dementia and those with an enthusiasm for South Asian music. The event was a huge success, raising almost GBP 900 (EUR 1,040) for Alzheimer’s Society and sparking plans for future workshops and events.

You can view the full event, here:

<https://www.youtube.com/watch?v=wZ0Djoly-Ns>

LIVING WITH DEMENTIA

19 June: Kevin Quaid, Vice-chairperson of the European Working Group of People with Dementia, shares his experience of walking the Camino de Santiago in 2023



I took part in “Walking the talk for Dementia”, on the Camino de Santiago, in May 2023. It was, for me personally, quite simply a miracle because the Camino was something that I always dreamed of doing, but shortly after my diagnosis, I could only walk with the aid of a walking frame and the doctors advised me to get my house ready for a wheelchair, because that was the next step and the natural progression for the way my life was going. The Camino never left my mind and although I could perhaps have done it in a wheelchair, to me that was not good enough, I wanted and I had to walk it.

Because I have such a wonderful medical team, I was reduced from nineteen different medications to six different medications, I got rid of my walking frame and began to walk with the use of a walking stick, so instead of getting worse I felt my condition was improving. All the while, I kept wondering: Could the Camino be possible? How would I do it? Who would I go with? But the one thing I never gave up on was the dream of doing it and, sure enough, a call came to me from Fernando Peres, to know would I be interested in walking the Camino with him and a group of people. I said, “you know that I walk with the aid of a walking stick?” and he said to me, and I quote “if you want to do it we will make it happen together”. I cried and I didn’t question how we were going to manage it, but here was the opportunity that I wanted, being offered to me. I wasn’t going to let it go!

I went to Spain and found that the Camino journey is almost impossible to explain. For me, it affected me, mentally, physically and spiritually, in ways that I could never have imagined. I

found that inner part of me that I thought I had already found. Please let me explain: After my diagnosis, I became an advocate, an author, a motivational speaker, a storyteller sharing stories about my life. I found that I could engage with people, young and old, academics and scholars and others alike, from the most highly intelligent people who spent years dealing with dementia to people who had such misconceptions about dementia. While I was on the Camino, however, I went deeper into myself, deeper into who I was, and found strengths that I never thought possible. Sometimes, this was when there were a group of us together, sometimes when there might be just two of us together and a lot of the time when I was alone, by myself - alone with Kevin.

I found I was forgiving myself for the way I was feeling at times. I found a type of love that I never knew existed and I found that I needed to feel that self-love. All too often, we bury our feelings, we try to stop crying, we try to stop feeling the way we do. But

for me, that's not the way to do it. We need to feel those feelings and to acknowledge them, and we need to reassure ourselves that it's ok to feel the way that we do.

There were so many times when I could look around and just appreciate where I was, whether it was just for a moment or for longer. I can honestly say that I could have never expected in my wildest dreams to feel the way that I felt and to share what I shared, with some of the most wonderful people who have ever walked this planet.

I think back to before I went on the Camino and I look at my life today. It took me weeks to try to get back to normal, to get back to my normal life, but I have come to realise that this is my new life and this is my "new normal". These are my new feelings and they are taking a lot of getting used to!

I am no longer as hard on myself as I used to be. I no longer consider my Lewy Body Dementia as a disease, I consider it a gift, because without it I probably would never have done the Camino and I certainly would not have met the people I met on that glorious week in Spain.

There were so many wonderful moments, so many brilliant things that happened, but for me, the standout day was when I was having a chat with a member of the group and I was able to share things that were so personal to me, things that I would never tell anybody, things that I thought that would never be shared, but I shared them and that person understood and was able to give me advice. That is just one amazing example of the trust and love that I found on the Camino, that amazing power of being able to completely trust another person - someone who I hardly knew before going on that trip. That's the power of the Camino. I hope, from this personal message, that you can just get a glimpse and a feel of what it was like for me on this journey-of-a-lifetime, something that I could have only imagined a few years ago. Dreams do come true. For those of you who have dementia or are caring for a loved one, don't ever give up on a dream!

26 June: Lieselotte Klotz, member of the EWGPWD, tells us about her involvement in the 1st Annual Conference of the State Department for Dementia in Mecklenburg-Vorpommern, Germany

Mecklenburg-Vorpommern (M-V), my home since 2020, is a region with a lot of culture, charm, and nature, located directly on the Baltic Sea in Germany and home to around 1.7 million people. Between Schwerin and Hamburg lies the UNESCO Biosphere Reserve Schaalsee with its lakes, forests, and numerous cultural landscapes. The old residential cities of Ludwigslust and Schwerin attract tourists from all over the world with their historic buildings.

Districts and municipalities are overwhelmed with the needs of older people and people with dementia, due to demographic change, an ageing society, supply gaps, lack of care places, excessive costs in care, hyper-individualisation, disappearance of classic family structures, bleeding out of informal care in families, overburdened communities in the sense of a welfare care society, and governing administrations which are not familiar with the issues. This also applies to M-V.



At the end of 2021, around 1.8 million people with dementia (65+) lived in Germany; in 2050 there will be 2.4 to 2.8 million. I am one of around 32,000 people affected (with an unreported figure of around 2%) in my region, with a current population of around 1.6 million. But M-V faces the problems and moves on! As of the start of 2023, M-V has a State Department for Dementia, which is sponsored by the German Alzheimer Society Landesverband M-V e. V. Self-help dementia (DALzG LV M-V) and is funded by the Ministry of Social Affairs, Health and Sport M-V. This makes it the first and currently the only federal state to have a State Department for Dementia, which - in contrast to the specialist departments of other federal states - sees itself as a special strategic interface between implementation processes within the framework of the national dementia strategy and the stakeholders, municipalities and districts.

The first Annual Conference of the State Department for Dementia M-V took place on 12 May 2023 under the motto "We. Together. Living actively with dementia - for a dementia-friendly society" in Schwerin". Numerous participants from municipalities, welfare associations, senior citizens' councils, but also from research and the medical and nursing sector accepted the invitation. Throughout the conference, the multiple facets of caring communities were considered.

At this kick-off event, I had the honour of giving a speech and also taking part in a panel discussion. My speech, which took a critical look at the system, was titled "Dementia-friendly community from the perspective of an affected person?"

As a person with early dementia, I reported very critically that I unfortunately do not live in a dementia-friendly community and gave an insight into my challenging everyday life.

"We people with dementia are grateful and happy when we belong, are allowed to participate and are allowed to share aspects of our everyday reality with other unaffected people." Unfortunately, it is often not possible for us to participate. Stigmatisation, loneliness, lack of care management, excessive demand and a lack of specialist knowledge on the subject of dementia among doctors and in clinics tend to be the norm. This is where the quality and the professional and content-related framework for action by the employees of State Department for Dementia M-V come into play.

The State Department for Dementia M-V and the DALzG LV M-V draw on extensive experience and knowledge as well as tried and tested methods, instruments, and activities to support people with dementia and their relatives and provide some respite.

"We don't have a lack of ideas; we have a lack of implementation!" comments Daniel Lichy, project manager at State Department for Dementia M-V.

The bottom line is that the municipalities, more than before, should have a special responsibility in designing dementia-friendly structures. This is vital in providing the basic conditions for life, the opportunities for self-fulfilment and quality of life for all.

Of course, like so many people affected by dementia, in my region, I would like to have more opportunities to participate in our society; at all levels and wherever possible. I still want to contribute. The prerequisite is that we are allowed to step out of the shadows, are encouraged and shown acceptance and respect.

Watch the panel discussion here: <https://youtu.be/W7Yht3j7jCU>

Watch my speech, here: <https://youtu.be/kN0zVjWP04c>

In closing I want to say that I truly admire the work of the team at of State Department for Dementia M-V and Nele Kristin Meincke in particular. Nele is part of the project team at the State Department for Dementia and she kindly supported me in writing this article for Alzheimer Europe.

<https://alzheimer-mv.de/landesfachstelle-demenz/jahresauftaktveranstaltung-der-landesfachstelle-demenz/>

Pictured (previous page): Panel discussion with (left-to-right) Lars Krychowski (first chairman of the DALzG LV M-V), Kerstin Mieth (head of department of department 330 of the Ministry for Social Affairs, Health and Sport M-V), Lieselotte Klotz (person with lived experience), Hendrik Nolde (deputy project manager FAPIQ), Lars Prahler (Mayor of Grevesmühlen)

26 June: Liv Thorsen, member of the European Dementia Carers Working Group writes “A carer’s considerations”



It is now nine years since my husband received his Alzheimer's diagnosis. This was very early in the process, and we have now had nine years with a good quality of life. We chose to be open about this, both with family and friends, and in the local environment. As a nurse, I had experience from psychiatry and for many years I was also teaching patients and carers how to cope and live with a chronic disease. The knowledge I had about dementia and Alzheimer's helped me a lot in how to cope with the challenges in everyday life.

We continued to live our life as normally as possible. I was at the end of my professional career and my husband, who was retired, managed just fine at home. Short-term memory gradually disappeared, and he had challenges with orientation, but this did not bother him. We were both determined to focus on the day-to-day, make the most of what we enjoyed, not putting anything off. We stopped traveling to new places, but went back to the places my husband liked, booking the same hotels, the same rooms, which creates security, so we can enjoy our stay from day one.

Focusing on everything that is intact and not on what isn't working helps me. A lot of functions are still fresh and his personality has not changed. I never think that I live with a "diagnosis", but rather a person who has some challenges because of a diagnosis.

I am a local politician, which is both interesting and rewarding, and a place where I can influence what concerns elderly care and services for people with dementia. I want to continue with this even when the disease progresses for my husband, so we have to cooperate with family, friends and our network, to get assistance when needed.

I think I am a better wife and carer when I can do what makes sense to me. We both have a strong belief that it makes us feel good to have good experiences, even if they are forgotten immediately, as they settle in the body and leave a good feeling. We live one day at a time – and nobody knows what the next day will bring.

28 June: Scottish-born singer-songwriter, author and translator Malcolm Duff shares his experiences of being his wife’s carer in France and the soothing power of music

I am a translator and singer-songwriter, raised in Scotland, now living in Normandy, not far from the beaches. I met my wife here fifty years ago, a beautiful, dark-haired girl with shining eyes and a sunlit smile, the daughter of Spanish refugees from the civil war. But a dozen years ago, she was diagnosed with Alzheimer's disease. So, I retired early to protect and take care of her, and ended up serving as her escort – for a day came when she no longer knew who I was, other than a faithful servant. She lived on happily and peacefully in our home until the very end, surrounded by fields and the forests beyond. She died last May.



Those years were neither happy nor peaceful for me, despite our helper, a wonderful woman whom I employed for the last five years of my wife's life, and who took care of her as if she was her own child. During the final six months, I had to tell what had happened to us all, how the illness acts as a catalyst, accelerating peoples' reactions without being consumed, in some even turning love to hate, and managed each week to write a chapter of a book now entitled "The Escorts". It is to be released this year in English, French and Spanish.

My publisher in Paris has described it as "a poignant ode to the fragility of life"; that in London, "a tribute to compassion", and that in New York, "a story sublimated by song". The book describes the impact of the disease, not only on my wife but on all those who accompanied her closely or from afar, and tries to provide a "survival kit" for the carers of people with a fatal disease, by discussing the physical and metaphysical issues involved, and explaining how I tackled the problems that every helper has to face.

During the last three years of my wife's life I still managed to go to the recording studio one afternoon a week (it was the only break I had, being a carer is a 24/7/365 job), to sing the songs and tell my tale. I was fortunate enough to meet a writer who was looking for a composer, and a few months later found myself entangled in two love affairs: one, tragic (that of my wife), and the other, magic, with the writer, who gave me the encouragement I needed to finish the book and the songs. She became "Maria" in "The Escorts". With her help, the songs formed the soundtrack for the book, and when I had finished writing it, I added the lyrics and a short explanation about whom or what had inspired them.

The songs have been released as an album entitled "For You", available here: <https://malcolmduff.bandcamp.com/album/for-you>

Each song is published with the lyrics and an excerpt from the book, which is perhaps best summed up by the bridge in the title track of the album:

"There's so much to learn about this lonely world, As we ride from mountain high down to the sea. Once upon a time I loved a girl, and for a starry while, she loved me."

Only a fortnight after my wife died, knowing the house and how lonely I was, the secretary in the village hall called and asked if I could take in a family of Ukrainian refugees, a young mother, her two children, two cats and a dog. They had survived a month of Russian bombs and had trekked by bus, by car and on foot across the whole of Europe, seeking the safety they finally found in France – much as my wife's parents had done to escape other fascists almost a century before. I took them in, if only for the dog that I thought might serve as an escort for my old Labrador, who was as sad as I when my wife passed away. They have stayed here ever since, for they turned out to be good, nice, intelligent people; like my wife, their hallmark is courage and character, and they all love music, including the dog and cats (who sleep on my piano, the dogs under it).

But since the war began, my translation work has decreased from three documents a day, to three a week, and now three a month, and my pension is insufficient to make ends meet, let alone feed my guests. Their story is the same as that of a million refugees, world without end. If my tale is any different, it is because I have told it in song. No matter. As a carer, I now know the importance of music in soothing a heavy heart, and that if life has many fine things to offer, love is the greatest of gifts, for one simple reason: in the end, it is all we need.

"The Escorts" has now been published and is available, here, in French: <https://www.editions-pantheon.fr/catalogue/les-escortes/> and here, in English in paperback, hardcover and Kindle format, with its soundtrack:

https://www.amazon.com/Escorts-Malcolm-Duff/dp/B0C9KJ8HF8/ref=tmm_pap_swatch_0?_encoding=UTF8&qid=&sr=

JOB OPPORTUNITIES

30 June: University of Bradford Centre for Applied Dementia Studies seeks two permanent posts at Lecturer or Assistant Professor level to support their work in healthy ageing and dementia



The Centre for Applied Dementia Studies, within the University of Bradford, is seeking two permanent posts at Lecturer or Assistant Professor level (depending on experience) to support their work in healthy ageing and dementia.

The successful candidates will work across all areas of the

Centre being supported to deliver internationally and nationally recognised post-graduate education, training and consultancy as well as implementation and dissemination of ground-breaking research.

Applications are invited from those who have expertise across health and care including, for example, policy, psychology, economics, sociology.

More details here:

<https://jobs.bradford.ac.uk/vacancy.aspx?ref=HR0148907>

<https://jobs.bradford.ac.uk/vacancy.aspx?ref=HR0148198>

The closing date for applications is **7 July 2023**.

Help us give a voice to people with dementia

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NEW PUBLICATIONS AND RESOURCES

18 June: The Alzheimer Society of Ireland's Dementia Carers Campaign Network launches podcast

In Carers Week 2023 (11-18 June), The Alzheimer Society of Ireland (The ASI) launched the DemTalks podcast; Series One, The Dementia Carers



Campaign Network. The Dementia Carers Campaign Network (DCCN), supported by The ASI, is an advocacy group of people who have experience caring for a loved one with dementia. The podcast is proudly sponsored by Hidden Hearing.

This first series of the DemTalks, Our Stories, Our Voices podcast is dedicated to amplifying carer voices and stories and destigmatising the experience of caring. The podcast features diverse stories and aims to create a platform where carers and experts can share their unique experiences, perspectives, and ideas.

The ASI Advocacy, Engagement and Participation Officer and Host of DemTalks, Our Stories, Our Voices, Judy Williams said: "We are incredibly excited to create a space where individuals from different walks of life can come together to share their experience of caring. We believe that everyone's story is important and that by listening to, and learning from, one another, we can build bridges of empathy and understanding."

DemTalks, Our Stories, Our Voices is available for streaming on all major podcast platforms. The ASI hopes that other carers who listen to the podcast will feel less alone. Listeners can expect to hear stories that will inspire, inform, and encourage dialogue on a wide range of topics, including carer identity, home care, and caring in the LGBTQ+ community. Available wherever you get your podcasts - listen here: <https://pod.link/1692512858>

Follow #DemTalks on The ASI's social media platforms, for regular updates and engaging content.



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AE CALENDAR 2023

Date	Meeting	AE representative
3 July	EWGPWD plenary session preparation	Dianne and Ana
3 July	Meeting with Essity	Jean
3 July	EPND workshop on benchmarking	Angela
4 July	Alzheimer’s Association Academy: Providing services and support for people with young onset dementia	AE members and staff
5 July	European Commission/WHO partnership for long term care	Owen
6 July	GSK Health Advisory Board	Jean
6 July	ADIS General Assembly meeting	Jean, Soraya and Chris
7 July	Meeting with the Ataxia Global Initiative for EPND	Angela
10 July	Alzheimer Europe Anti-Stigma Award Jury	Jury members
16-20 July	Alzheimer’s Association International Conference (Amsterdam, Netherlands)	Jean, Cindy, Ana, Angela
17 July	EPND update meeting (Amsterdam, Netherlands)	Angela and Ana
19 July	Alzheimer Centre Amsterdam Advisory Board (Amsterdam, Netherlands)	Jean
7-8 August	Study visit for 33 AEC (Helsinki, Finland)	Gwladys, Cristina and Jean

CONFERENCES 2023

Date	Meeting	Place
1-4 July	9 th EAN Congress - Budapest 2023: Neurology Beyond the Big Data, www.ean.org	Budapest, Hungary
15-19 October	WCN 2023 - The XXVI World Congress of Neurology, https://wcn-neurology.com/	Montreal, Canada
16-18 October	33 rd Alzheimer Europe Conference, “New opportunities in dementia care, policy and research”, www.alzheimer-europe.org/conference Helsinki, Finland	Helsinki, Finland
25 October	Liverpool Dementia & Ageing Research Forum, https://www.alzheimer-europe.org/node/237018	Liverpool, UK



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33rd Alzheimer Europe Conference

New opportunities in dementia
care, policy and research

Helsinki, Finland

16 - 18 October 2023 #33AEC

www.alzheimer-europe.org/conferences

