Helen Rochford-Brennan talks about living with dementia on The Tommy Tiernan Show

Marine Uldry, European Disability Forum Human Rights Officer, discusses 2nd review of the EU by the UN Disability Rights Committee

Lorène Gilly, France Alzheimer Public Policy Officer, talks about their campaign during the French elections

Wouter Beke, Flemish Minister of Health, introduces new dementia plan
Contents

3 Welcome

Alzheimer Europe

4 Alzheimer Europe signs Operating Grant agreement with EU disability programme
5 Alzheimer Europe hosts online European Parliament Workshop on “Prioritising dementia in European policies on care, disabilities and equalities”
6 Alzheimer Europe hosts Alzheimer’s Association Academy session focusing on “giving a voice to people with dementia”
7 VirtualBrainCloud project uses AI-based brain simulations to improve the classification of Alzheimer’s disease
8 EPAD – Global efforts and cooperation to advance research in Alzheimer’s disease and prevent dementia
9 Neuronet Coordination and Support Action releases Decision Tool for engagement with Regulatory and Health Technology Assessment bodies
10 World Joint Artificial Intelligence Network Challenge awards prototype and product aimed at supporting people with dementia

Policy Watch

14 Minister for Health introduces new Flemish dementia plan
16 France Alzheimer highlights lack of focus on dementia in French elections
19 The Alzheimer Society of Ireland leads parliamentary briefing session on dementia and brain health
21 Civil Society Organisations come together to advocate for patient involvement in brain health policy
23 Second evaluation of the European Union by the UN Disability Rights Committee commences
25 World Health Organization embeds involvement of people with dementia in Knowledge Exchange platform

Dementia in Society

27 Alzheimer associations are working hard to support those affected by the war in Ukraine
30 Putting a face to commitment – Alzheimer Society of Ireland CEO Pat McLoughlin steps down
32 Helen Rochford-Brennan discusses dementia with Tommy Tiernan on Irish television
34 Behind the headlines: Large-scale genetic study identifies novel risk factors for Alzheimer’s disease
36 Multi domain interventions for risk reduction and prevention of dementia and Alzheimer’s disease, an exciting journey from the FINGER trial to World-Wide FINGERS
Welcome

I am delighted to introduce the 39th edition of our Dementia in Europe magazine. This edition is full of interesting articles on the latest developments in the field of dementia, with much excellent work taking place at a national and European level.

We open the Alzheimer Europe section by looking at the Operating Grant Alzheimer Europe has received under the EU’s Citizens, Equalities, Rights and Values programme, which sets the direction of our work for the years ahead. We then revisit the European Parliament Workshop held in March, which examined how social and disability policies at an EU-level impact upon the lives of people with dementia, their families and carers.

In the area of research, we focus on three of the European projects in which we are currently involved. Petra Ritter from VirtualBrainCloud explains the progress made in the project as it seeks to create a “digital brain” to help in the development of treatments for Alzheimer’s disease. The following article celebrates the announcement that genomic data from the European Prevention of Alzheimer’s Disease (EPAD) project, will be included in the Alzheimer’s Disease Data Initiative (ADDI) platform to provide the global neuroscience research community with even greater access to the data. The article also includes comments from Craig Ritchie, EPAD Project Coordinator, and Tetsuyuki Maruyama, Executive Director of ADDI. Next, we look at about the newly launched Neuronet Decision Tool, which will help projects and other stakeholders identify suitable processes and procedures for interacting with regulators, Health Technology Assessment bodies and payers. We round off this section hearing about how Alzheimer Europe and three members of the European Working Group of People with Dementia (EWGPWD) have been involved in the World Joint Artificial Intelligence Network (JAIN) Challenge, which aims to form an international learning community to develop e-health products and services.

In our final section, Dementia in Society, we open with an article looking at what the governments and Alzheimer associations in my country (Czech Republic) and in Poland are doing to support people affected and displaced by the ongoing invasion of Ukraine, particularly those affected by dementia.

In the next article, Pat McLoughlin, former CEO of The Alzheimer Society of Ireland reflects on his time at the organisation, from which he recently retired – we wish him a happy and well-deserved retirement! Staying in Ireland, we look at the appearance of Helen Rochford-Brennan on The Tommy Tiernan Show. Helen, a member of the EWGPWD, highlighted issues around diagnosis, advocacy, funding and homecare. In our next article, we hear from Professor Jean-Charles Lambert and Dr Céline Bellenguez about their fascinating research identifying novel risk loci for Alzheimer’s disease, and about their development of a new genetic risk score for Alzheimer’s disease. The last article showcases the importance of nutrition for better brain health and risk-reduction.

Finally, I am pleased to be able to present a special supplement, in which we celebrate 10 years of the inspirational work of the EWGPWD. We feature interviews from the present Chair and previous Chairs of the group, who share what being part of the group has meant to them and why the work of the group is so vital. I also share my thoughts, alongside the group ensuring the voices of people with dementia are heard at a European level!

I hope you find inspiration in this edition of the magazine and wish you all a safe and pleasant summer!
Alzheimer Europe signs Operating Grant agreement with EU disability programme

Alzheimer Europe has signed a Grant Agreement with the European Commission as part of the Citizens, Equality, Rights and Values (CERV) programme which will support the core operations of the organisation for 2022.

On 8 February 2022, Alzheimer Europe signed a Grant Agreement with the European Commission under the Citizens, Equality, Rights and Values (CERV) programme, which will allow the organisation to continue its work making dementia a policy priority in Europe. Alzheimer Europe is grateful to the European Commission for recognising that dementia is the leading cause for disability and dependency in older adults in Europe and for providing vital financial support for the organisation’s 2022 activities.

The signing of the agreement marks a slight shift in the future focus of Alzheimer Europe’s policy work since the organisation had previously received operating grant funding from the European Union’s (EU) health programme. Building on its previous work promoting a rights-based approach and advocating for the rights of people with dementia and their carers, Alzheimer Europe will now be in a position to place an even greater focus on the citizenship and equal participation of people with dementia in society. Specifically, the Operating Grant will help Alzheimer Europe in its aim to promote the rights, dignity and autonomy of people living with dementia, particularly in relation to the European Convention on Human Rights (ECHR) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Alzheimer Europe will undertake a number of different strands of work throughout 2022, including:

1. Promoting and defending the rights of people with dementia as full EU citizens, giving them a voice in EU and national policies by involving the European Working Group of People with Dementia in all operating grant activities and meetings, as well as publishing a guide on dementia-inclusive language
2. Promoting the compliance of national dementia policies and strategies in the field of employment and social protection, in line with the UNCRPD and the European Strategy on the Rights of Persons with Disabilities (ESRPD), by mapping and analysing national policies, identifying good practices and publishing these in the Dementia in Europe Yearbook 2022
3. Improving the capacity of national member organisations to contribute to national and EU disability policies by organising capacity building webinars and workshops
4. Ensuring that dementia is recognised as a leading cause of disability and dependency by actively contributing to EU policy making and supporting the implementation of the ESRPD and European Semester process
5. Raising awareness of the ESRPD by effectively communicating EU policies and operating grant results and achievements to its members and the general public.

Alzheimer Europe will promote an intersectional approach, recognising that people with dementia are impacted by various sources of discrimination (such as age, sex, gender identity, sexual orientation, ethnicity and social class), building on recommendations and guidelines it has previously developed.

Jean Georges, Executive Director, Alzheimer Europe

“The signing of the Grant Agreement with the European Commission is an important step in securing funding for Alzheimer Europe’s work in the coming years. Dementia and related cognitive impairments are not always recognised as disabilities, despite the significant impact they have on the day-to-day lives of individuals, their families and carers. Thanks to this vital support by the European Commission, we will be able to continue our work focused on citizenship and rights and identify measures which will improve the lives of people with dementia, their families and carers.”

Acknowledgement

Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Commission. Neither the European Union nor the granting authority can be held responsible for them.
Alzheimer Europe hosts online European Parliament Workshop on “Prioritising dementia in European policies on care, disabilities and equalities”

Alzheimer Europe hosted an online European Parliament Workshop, examining how the European Union was developing policies across a range of areas which will benefit people with dementia, their families and carers.

On 22 March 2022, Alzheimer Europe hosted an online European Parliament Workshop, on “Prioritising dementia in European policies on care, disabilities and equalities”, chaired by Sirpa Pietikäinen, MEP (Finland), Chairperson of the European Alzheimer’s Alliance (EAA). The event was attended by EU policymakers, representatives from national Alzheimer’s associations and national health ministries and industry partners.

Ms Pietikäinen set the scene for the Workshop, noting the place of dementia across policies on care, disabilities and equalities. She explained that currently, the Employment and Social Affairs, and Women’s Rights and Gender Equality committees in the European Parliament were exploring the issues around the European Care Strategy. Furthermore, she highlighted that dementia is a cognitive disability and as such, has the same entitlement to care and support, as well as the right to make decisions about their lives.

Astrid Dentler, Member of Cabinet of Vice-President Dubravka Šuica, European Commission, set out the priorities and objectives of the forthcoming European Care Strategy, highlighting that the strategy would look at care throughout the life course. This will result in two recommendations to Council, one focused on the revision of the Barcelona Targets and one on long-term care. In particular, the strategy will seek to address long-standing systemic issues associated with care including accessibility, affordability and quality of care services. The strategy is expected to launch in the third quarter of 2022.

Inmaculada Placencia Porrero, Senior Expert – Social affairs, DG Employment, Social Affairs and Inclusion European Commission, then outlined the EU’s European Strategy on the Rights of Persons with Disabilities 2021–2030 (ESRPD). The ESRPD takes a broad approach looking to address challenges faced by people with disabilities in relation to rights, services, supports and socio-economic issues, amongst others.

Specific areas for action identified within the seven flagship initiatives and eight priority areas of the ESRPD include deinstitutionalisation, accessibility (both physical and digital), access to services and support for people with disabilities to live independently.

Alejandro Moledo, Head of Policy, European Disability Forum (EDF), provided an overview of the current review of the EU’s compliance on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), including EDF’s contribution to the process. He explained that the second review of the EU’s implementation of the UNCRPD had commenced in March 2022 (the first having taken place in 2015). It was explained that EDF had produced and submitted an alternative report, highlighting a range of issues, including challenges in the legal harmonisation and enforcement of the UNCRPD and EU legislation, the lack of structured or documented process for engagement of people with disabilities, and the lack of a dedicated unit across all institutions with responsibility for UNCRPD adherence. The process of review is expected to conclude in 2024.

Alzheimer Europe Chairperson, Iva Holmeyerová, launched the Dementia in Europe Yearbook 2021, which examines dementia inclusive initiatives and communities, revisiting the topic in light of work by the EU, World Health Organization (WHO) and World Dementia Council, and examined examples of policies and resources developed across Europe.

Tilly Metz, MEP (Luxembourg), member of the EAA, closed the session thanking speakers and attendees. She reflected on some of the key challenges raised during the meeting, as well as highlighting stigma, isolation and discrimination, as key challenges facing people with disabilities, which had been often exacerbated during the COVID-19 pandemic. She stressed that the EU’s work in these areas needed to focus on equal access to treatment and services, as well as greater support for people acting as informal caregivers.

The presentations from the day can be viewed here: https://www.youtube.com/playlist?list=PLQ-PhOHIiWQUgsiJW-ZOdYEWLKKXIPslYg
Alzheimer Europe hosts Alzheimer’s Association Academy session focusing on “giving a voice to people with dementia”

On 26 April 2022, Alzheimer Europe held an online session of its popular Alzheimer’s Association Academy series. This session looked at how different Alzheimer’s associations are ensuring the voices of people living with dementia are listened to, with particular emphasis on how this was maintained during the COVID-19 pandemic.

The Alzheimer’s Association Academy brings together Alzheimer Europe’s member organisations, the European Working Group of People with Dementia (EWGPWD), sponsors and researchers. The topic for the session of 26 April, chaired by Dianne Gove (Director for Projects at Alzheimer Europe) was “giving a voice to people with dementia”. Chris Roberts, Chair of the EWGPWD, gave some introductory remarks about the importance of giving people with dementia a voice, and calling on organisations to create safe spaces for them to express their views, concerns and beliefs.

Anne-Rita Øksengård, from Nasjonalforeningen (Norway), discussed her organisation’s experiences of interacting with and engaging people with dementia and their relatives during the pandemic. She explained how the organisation adapted by holding meetings online and providing support via digital tools and telephone. She outlined the results of a 2021 report, which highlighted the negative consequences of daycare centre closures and nursing home visiting restrictions. She also highlighted shortcomings in systems developed by municipal authorities to manage infection control, and a lack of adequately-trained staff. Lessons learned included the need for pathways and guides to support authorities and facilities to maintain person-centred care.

Keith Oliver and James Erskine represented the Three Nations Dementia Working Group (3NDWG), which involves people from Wales, England and Northern Ireland. Keith Oliver is a member of the 3NDWG Steering Group while James Erskine is employed by the Alzheimer’s Society to support the 3NDWG, which was co-founded by Keith Oliver, Chris Roberts and Hilary Doxford. They spoke about the activities of the group during the pandemic, which met online regularly, hosting webinars and informal coffee chats for people with dementia, carers/supporters and family members. Over 45 fortnightly webinars have been hosted since the start of the pandemic, addressing a broad range of topics including faith, diagnosis, creative activities, learning disabilities and gardening. James Erskine explained his role as a supporter for the administrative and technical aspects of 3NDWG’s activities, and emphasised the value of obtaining and acting on feedback from the broader community of people with dementia and carers/supporters.

Olivier Constant and Laura Weyns spoke about the Flemish Working Group of People with Dementia. Olivier Constant outlined the vision for the group, which is to “forget dementia, remember the person”, highlighting the important contributions people with dementia make to policy, research and care. The group’s 2019 manifesto, “hand in hand”, is a charter for people with dementia calling for greater inclusion, involvement, opportunities and respect. Over the last two years, the group has continued to meet online and share their stories despite the challenges caused by the pandemic. Laura Weyns outlined recent work on physical and social activity and the development of a second manifesto, “step by step”. She gave details of e-learning programmes and dementia assistance cards and told delegates about the group’s participation in the television programme “Restaurant Misverstand”, where the entire staff has young-onset dementia. This programme is helping increase awareness and understanding. Finally, Olivier Constant explained how the Flemish working group contributed to the new Flanders Dementia Strategy.

Anne de Boer from Alzheimer Nederland spoke about the organisation’s online consultation methods. She described their online panel for people with dementia, carers/supporters, healthcare professionals and volunteers, who contribute to surveys and other activities. She explained how this online panel allows Alzheimer Nederland to support dementia research and provides a platform for people affected by dementia to express their views. She also emphasised the importance of respecting confidentiality and ensuring the platform is intuitive and easy to use.

Acknowledgement

Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Commission. Neither the European Union nor the granting authority can be held responsible for them. Alzheimer Europe gratefully acknowledges the support of its gold and silver sponsors and of the corporate sponsors of the Alzheimer’s Association Academy.
VirtualBrainCloud project uses AI-based brain simulations to improve the classification of Alzheimer’s disease

A new study from the Horizon 2020-funded VirtualBrainCloud project has shown that brain simulations can improve the classification of patients at different stages of Alzheimer’s disease. We speak to Professor Petra Ritter, Coordinator of the VirtualBrainCloud project, to find out more.

Artificial Intelligence (AI) is everywhere. From entertainment websites to navigation tools and e-commerce applications, AI algorithms power services that we encounter and use in our daily lives. AI also holds great potential for improving healthcare, with advocates saying it could reduce the strain on limited resources and free up time for clinicians.

AI is at the heart of the Horizon 2020-funded project, VirtualBrainCloud, which is using AI algorithms and clinical data to construct personalised, highly detailed brain simulations of individuals with Alzheimer’s disease and other neurodegenerative disorders. VirtualBrainCloud researchers have just published a new AI study in the Alzheimer’s and Dementia: Translational Research and Clinical Interventions journal. This study shows that AI-based brain simulations could also improve the diagnosis of Alzheimer’s disease, accurately classifying people at different stages of disease.

To find out more, we spoke to Prof. Petra Ritter, coordinator of the VirtualBrainCloud project. Petra is the Johanna Quandt Professor for Brain Simulation at the Berlin Institute of Health at Charité Universitätsmedizin (Germany), and leads a research team that is focused on developing brain simulation technologies for personalised medicine.

The VirtualBrainCloud approach can increase the sensitivity and specificity of clinical analyses, and might one day enhance patient stratification and diagnosis.

In our new research paper, we applied this approach to data from the Alzheimer’s disease Neuroimaging Initiative (ADNI) study, including brain scan data from 10 participants with AD, 8 participants with mild cognitive impairment (MCI) and 15 healthy peers. By integrating features from these brain scans into our brain simulation framework, we were able to improve the classification of participants into different stages of disease. This shows how the VirtualBrainCloud approach can increase the sensitivity and specificity of clinical analyses, and might one day enhance patient stratification and diagnosis.

What is patient stratification, and why is it important to improve our mechanistic understanding of AD and dementia?

Patient stratification involves the grouping of patients into subgroups of individuals that share similar health, disease, or other
Understanding the mechanisms of disease in a specific patient means that we can find better target points for interventions. For AD and dementia this is a big unmet need, as there is a constellation of mechanisms that contribute to the development of these complex diseases. This constellation will differ between individuals – and therefore, the best target point for therapy, intervention or prevention will also differ.

The work we and others are doing in research projects such as VirtualBrainCloud is bringing us a step closer towards being able to stratify patients, individually, according to their specific disease mechanisms.

What are the next steps for your research, and what implications could it have for clinical trials and healthcare?

The recent study proved that our approach is feasible, but only used data from a small number of participants. We would now like to validate our approach on larger and more diverse datasets. We need high-quality, well annotated and complex datasets to construct our brain simulations – however they can be challenging to obtain.

If accessing these datasets would be possible in the future, at a larger scale, then our analysis algorithms could be applied much more widely. This would help us to identify early biomarkers that could signal a risk of AD or dementia, and using our models we could see what the contributing mechanisms are, in an individualised way. As well as being useful for healthcare systems, this could be important information for clinical trials on presymptomatic or very early AD, or for trials that are studying drugs which are currently used for other conditions.

By improving the stratification of patients, researchers will be able to recruit the populations who are most likely to benefit from trials of novel and repurposed drugs.

Data sharing can increase the impact and value of research, and is a fundamental part of your work in VirtualBrainCloud. What challenges have you faced in sharing and reusing data?

Effective data sharing relies on trust, knowledge and competence. However there is a knowledge and competence gap when it comes to privacy regulations and the GDPR, and how these can be navigated to allow data to be shared. There are also motivational factors that could be challenging to deal with. A mindset of ownership over data can impede data sharing, and different stakeholders may have their own plans and use priorities for data that take precedence over sharing.

However, there is a solution for this problem: by involving stakeholders in constructive dialogue, and by building competence and knowledge, we can create win-win solutions that benefit all parties and, ultimately, benefit patients and citizens. Policymakers and funders also have an important role to play. Traditional research metrics, such as publications and grant funding, do not adequately incentivise collaboration. By developing and promoting metrics that incentivise collaboration and data sharing, policymakers and funders can help push the field in a direction where researchers will actively work together to find joint solutions, and where they are rewarded for their efforts to share and reuse data.

How does VirtualBrainCloud promote collaboration and data sharing, and how has this benefited your research?

Collaboration is at the heart of VirtualBrainCloud. We have bi-weekly meetings where our technologies are developed together with users, lawyers, data protection specialists and data providers; everyone is welcome and provides input. We have also actively reached out to sister projects and initiatives such as EBRAINS, the Human Brain Project and AI-Mind, developing external collaborations as well as building a solid internal network.

As a result, VirtualBrainCloud has achieved a GDPR compliant, auditable platform that facilitates collaboration between researchers. Researchers in different institutions can use the VirtualBrainCloud platform to access valuable datasets in a protected, secure environment, which also provides compute resources that they need to generate results.

Researchers in different institutions can use the VirtualBrainCloud platform to access valuable datasets in a protected, secure environment.”

Another key achievement of VirtualBrainCloud has come through collaboration with the teams of Martin Hofmann-Apitius and Holger Fröhlich at Fraunhofer SCAI (Germany). These groups developed AI algorithms for automated literature searches, which have generated complex inventories of disease mechanisms based on decades of peer-reviewed scientific research. Building on these tools, we have linked AD pathways and cascades from the published literature to specific locations in the brain, using our simulations. This adds biological accuracy and disease specificity to our models, an enormous and innovative step forwards for the field. As a consortium, we have built the first complex, individualised models of the brain, which will take us closer to more personalised, stratified approaches to AD diagnosis, treatment and prevention.

You can read the published study, here: http://dx.doi.org/10.1002/trc2.12303

Acknowledgement

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 826421.
EPAD – Global efforts and cooperation to advance research in Alzheimer’s disease and prevent dementia

The European Prevention of Alzheimer’s Dementia (EPAD) consortium, in partnership with the Alzheimer’s Disease Data Initiative (ADDI) is delighted to announce that EPAD genomic data has been incorporated into the AD Workbench to provide the global neuroscience research community with even greater access to the data.

The European Prevention of Alzheimer’s Dementia (EPAD) consortium, in partnership with the Alzheimer’s Disease Data Initiative (ADDI) is delighted to announce that EPAD genomic data has been incorporated into the AD Workbench to provide the global neuroscience research community with even greater access to the data.

The European Prevention of Alzheimer’s Dementia (EPAD) consortium was an inter-disciplinary research programme spanning public and private sector organisations across Europe, running until 30 September 2020. EPAD was funded for five and a half years by the Innovative Medicines Initiative (now succeeded by the Innovative Health Initiative) in conjunction with 39 partner organisations. Its aim was to improve the understanding of the early stages of Alzheimer’s disease (AD) and deliver new preventative treatments.

The EPAD Longitudinal Cohort Study

One of the EPAD project’s key achievements was the Longitudinal Cohort Study (LCS). It screened over 2,000 participants across 30 European study centres and collected a wide range of cognitive, clinical, neuroimaging and biomarker data to help further understanding of the early stages of AD. The LCS stopped screening participants in February 2020, reaching a total of 2,096 participants.

Making EPAD data, images and samples accessible

Throughout the study, the LCS collected incredibly rich data, images and samples from research participants. To make this information widely and easily accessible, EPAD has partnered with the Alzheimer’s Disease Data Initiative (ADDI), a non-profit organisation dedicated to fostering greater access to data and enabling researchers worldwide to accelerate the development of new and more effective treatments and cures for AD and related dementias.

Over the last several months, EPAD has been working to provide academic and commercial institutions with access to EPAD data, images and samples for further research in AD. To date, more than 160 researchers received access to EPAD data and 55 to EPAD images and over 3,100 samples have been shared with two commercial collaborators, with more requests underway. In the coming months, EPAD will embark on awareness campaigns to expand interest in the available data, images and samples.

EPAD data and images on ADDI

The LCS EPAD dataset is accessible on the AD Workbench, ADDI’s secure, cloud-based platform that researchers around the world can access at no cost. Researchers simply create an AD Workbench account, request access to the data or images, and once approved by the EPAD team, can then access them on the AD Workbench.

The EPAD dataset includes cognitive (RBANS, MMSE, CDR), clinical (medical history, medications), biomarker (APOE, [CSF] Aβ42, tau) and neuroimaging and lifestyle risk factor (sleep, diet, traumatic life events) information. Recently, the data were enriched with EPAD genomic data. In the future, the dataset will be enhanced with additional data from further analysis of EPAD samples and other programmes at the Edinburgh Dementia Prevention Center.

Bringing the EPAD data and the EPAD researcher community together through ADDI ensures the longevity and value of the EPAD project. This is an important step in the long-term goal of continuing to share the EPAD LCS data and ensuring that it is a
valuable resource for the AD research community. More information about the AD Workbench can be found here: https://www.alzheimersdata.org/ad-workbench

**EPAD samples**

Samples may also be accessed through the EPAD Bioresource. This large BioBank has over 118,000 blood, CSF, saliva and urine samples that were collected in a unique longitudinal study that spanned four years.

The EPAD Bioresource team aims to ensure that every sample collected from participants and stored at the Roslin Institute within the University of Edinburgh (UK) can contribute in the most appropriate way to AD prevention research. A bespoke database and information management system is used to provide traceability and sample validation at every stage in the process.

Researchers interested in accessing these samples should contact the EPAD Bioresource team to discuss the scope of their research. Following this, they will submit an online request on the AD Workbench, which will be reviewed by the Sample Access Committee. The EPAD team aims to meet individuals’ research needs, and once sample requests are approved, will deliver them directly to researchers. More information about the EPAD Bioresource can be found here: https://ep-ad.org/samples-access/

---

**Craig Ritchie, Project Coordinator, EPAD**

“The large amount of data and samples collected within the EPAD project has been a major scientific effort. EPAD has made this large data source open access, and that is going to serve the scientific community for years to come. EPAD is working in close collaboration with ADDI to make the data findable, accessible, interoperable and reusable, a process known as FAIR principles. The global visibility and ease of access and research which ADDI provides helps us to achieve our objective. There is an incredible excitement about what is going to come out of the high quality and large dataset that we developed through the EPAD Longitudinal Cohort Study. This most recent release with genomic data from the EPAD LCS will provide new knowledge to the global research community and marks another major milestone for EPAD”.

---

**Tetsuyuki Maruyama, Executive Director, ADDI**

“ADDI is genuinely excited about the growth of our partnership with EPAD. The information in EPAD’s datasets, images and samples are an indispensable resource for researchers working to develop new treatments and cures. By making this rich information source available on the AD Workbench, we get closer to our vision of a future where open data and global collaboration powers the end of Alzheimer’s disease and related dementias. We expect the datasets, images and samples from EPAD to spark collaboration, discovery and innovation for researchers around the globe who use the AD Workbench to generate and test brilliant new ideas”.

---

**Acknowledgement**

The EPAD project has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union’s Seventh Framework Programme (FP7/2007–2013) and EFPIA companies’ in kind contribution and an Alzheimer’s Association Grant (SG-21-818099-EPAD).
Neuronet Coordination and Support Action releases Decision Tool for engagement with Regulatory and Health Technology Assessment bodies

The members of the Neuronet (Efficiently Networking European Neurodegeneration Research) programme are pleased to announce the launch of an updated Decision Tool for Regulatory and Health Technology Assessment (HTA) engagement.

Neuronet is a coordination and support action funded by the Innovative Medicines Initiative (IMI), bringing together 21 IMI research projects working on neurodegenerative diseases such as Alzheimer’s, encompassing over EUR 386 million in research funding.

One of Neuronet’s workstreams aims to develop tools and services to support IMI ND projects in areas where unmet needs have been identified, which include the need for further support for interactions with HTA and regulatory agencies.

As part of this work, Neuronet has launched a Decision Tool to help projects and other stakeholders identify suitable processes and procedures for interacting with regulators, HTA bodies, and payers along the research, approval, and reimbursement pathway. It provides a clickable overview of the processes and procedures for HTA and regulatory interactions at different stages of the development pipeline. This will help ensure that the outputs being developed by projects are relevant for regulatory and HTA settings, where applicable.

Representatives of the Neuronet project partner, NICE (UK National Institute for Health and Care Excellence) have performed a general update of the Decision Tool that went live on 5 May. This involved updating the signposting information and text to include any changes to organisations and processes, and providing case studies from projects within the Neuronet portfolio that have been through HTA or regulatory processes and procedures. Additional signposting information on relevant agencies, organisations, tools and projects was also incorporated.

The Decision Tool can be accessed through the Neuronet Knowledge Base, via this link: https://kb.imi-neuronet.org/

The Neuronet Knowledge Base brings together key information about the various projects of the IMI ND portfolio. This comprehensive resource is an integral part of NEURONET’s endeavour to boost collaboration across the research portfolio by assisting in identifying gaps, multiplying the portfolio’s impact, and enhancing its visibility with related initiatives in Europe and worldwide.

As well as providing a summary overview of the IMI neurodegeneration research portfolio through its interactive dashboard, the Neuronet Knowledge Base includes links to over 500 publications and more than 400 project reports, acting as a one-stop shop to explore the diverse projects and outputs of the portfolio.

“The timing of engagement with regulators and which procedures to follow are important considerations to maximise the value of feedback received for research strategies. Neuronet’s interactive tool can help in making such fit-for-purpose decisions.”

Lennert Steukers, Neuronet Project Leader

Acknowledgement

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 821513. The JU receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA and Parkinson’s UK.
World Joint Artificial Intelligence Network Challenge awards prototype and product aimed at supporting people with dementia

The Joint Artificial Intelligence Network (JAIN) hosts the World JAIN Challenge (WJC). Alzheimer Europe and three members of the European Working Group of People with Dementia participated as reviewers in the WJC 2022.

The main purpose of the World JAIN Challenge (WJC) is to form an international learning community that develops e-health products and services for people with memory problems or dementia, informal carers and family, healthcare professionals, healthcare institutions, government and healthcare insurers, which:

- Increase self-reliance and quality of life of people with memory problems or dementia and informal carers
- Extend the time that people with memory problems or dementia can live in one’s own living environment
- Support informal carers, family and healthcare professionals
- Reduce costs within healthcare promoting affordable healthcare, with the same number of Full Time Equivalents serving more clients.

World JAIN Challenge 2022

The WJC 2022 is a public competition for developed or prototyped technical products and services based on artificial intelligence (AI). It concerns products that support the quality of life and self-reliance of people with memory problems or dementia and their informal carers and that will support professionals and informal carers in providing optimal care.

On 23 and 24 March 2022, the WJC was broadcast by the Dutch Embassy in Sweden, live on YouTube. The programme on both days was chaired by Hans Arnold (founder of JAIN) and moderated by Thomas Arnold. On 23 March, the WJC programme started with an introduction by Hans Arnold, followed by a welcome by Bengt van Loosdrecht (Swedish Ambassador), John Dekker (Innovation Attaché at the Embassy of the Kingdom of the Netherlands in Sweden) as well as Hans Scerri (Vice-Chairperson, Alzheimer Europe), an outline of the mission of the WJC by Franka Meiland (Amsterdam UMC) and finally a look at technology solutions for everyday living in dementia care by Arlene Astell (University of Toronto).

After that, the three finalists presented their prototypes in the form of pitches, which were followed by questions from the audience. The three prototypes presented were:

- CeCe: A platform with a wearable tracker (patient) and a companion behaviour noting app (caregiver) aimed at collecting information that can be provided to doctors and care professionals for treatment decisions
- myAVOS: A healthcare platform for cognitive screening, patient monitoring and to provide interventions through a mobile application
- DeepVibes: A phone application aimed at stimulating and recording conversations between family members and people with dementia. It applies AI to monitor disease progression.

Conny Helder, Dutch Minister for long-term care and sport, announced the winners of WJC 2022.
The second day of the competition started with an introduction by Thomas Arnold, followed by presentations. First, Bengt Windblad (Karolinska Institutet) gave a speech on the current developments with regard to treatment strategies for Alzheimer's disease. This was followed by a talk by Wijnand IJsselsteijn (Eindhoven University of Technology) on warm technology: AI and design for people with dementia. Finally, Yeh-Liang Hsu (Yuan Ze University) gave a concluding presentation on their work towards a design approach to Gerontechnology. After that, the three selected product pitchers gave their presentations via Zoom.

The three products presented were:

- ReACT: A phone application that includes module appointment
- InspireD: A phone application to support reminiscence where users can store photographs, audio memories, videos and organise these in albums, so that users can share memories and important events with friends and family
- GenusCare: An always on smart frame device that connects, monitors users and alerts relatives when users are inactive.

Involvement of Alzheimer Europe and the European Working Group of People with Dementia

Both a member of the Alzheimer Europe staff and three members of the European Working Group of People with Dementia (EWGPWD), Margaret McCallion, Idalina Aguilar and Kevin Quaid (Vice-Chairperson of the group), participated as reviewers in WJC 2022. In addition, Marco Blom, Honorary Treasurer, Alzheimer Europe, was part of the JAIN Expert Committee.

The award ceremony

On 6 April, the award ceremony of the WJC took place. The ceremony started with a roundtable discussion involving two experts in the field (Franka Meiland and Wijnand IJsselsteijn), Jos De Groot from the Dutch Ministry of Economic Affairs & Climate Policy, Roland Driece, Director of International Affairs of the Ministry of Health of the Netherlands as well as the finalists, moderated by Thomas Arnold. This was followed by a speech by Conny Helder, Dutch Minister for long-term care and sport, who announced the WJC winners:

- The prototype winner of the WJC 2022 is DeepVibes: https://deepvibes.ai
- The product winner of the WJC 2022 is Genus Care: https://genus.care

The three events can be viewed on the JAIN YouTube channel: https://www.youtube.com/channel/UCTgNRCH86XAlF2v9kYE2W8g

For more information about JAIN, see: https://www.jainprojects.com/world-jain-challenge/

Margaret McCallion, member of the EWGPWD

“As an active member of the Scottish Dementia Working Group as well as an active member in the EWGPWD, it has indeed been a pleasure to be involved as part of the Assessment Committee, to put forward our suggestions of each products for each of the participants in the WJC 2022. Each of the Apps put forward would be worthy winners of the challenge. Perhaps it is just me who found selecting the winner rather daunting (as I thought each of the products would be very useful for anyone living with Dementia – whether in a Care facility or in a home setting). Being a person living with dementia, I found it very helpful to be able to visit the Resource Centre in Glasgow, Scotland, where I took part in pilot groups, therapeutic groups, singing groups and found out about the Scottish Dementia Working Group and then the EWGPWD, which have all been informative, humbling and uplifting. All meetings have been thoroughly enjoyable due in large part to Alzheimer Scotland and the Alzheimer Europe team who enable us all to enjoy meeting up. My thanks to everyone from both organisations for their support.”

Kevin Quaid, Vice-Chairperson, EWGPWD

“Having been involved in the WJC has meant the world to me. I have Lewy body dementia and I am only 58, and to have my voice listened to means everything, it means that the organisers took the time to make sure that people like me and people who have different types of dementia can go on and be more self-reliant and have a better quality of life. Being involved in projects like this improves my future and the future of people who will be diagnosed with dementia in years to come, who will have their lives and the lives of their families made that little bit easier.”
Minister for Health introduces new Flemish dementia plan

In September 2021, the Flemish Government launched its DementiePlan 2021–2025. In this article, Inge Vanfraechem, Coordinator Dementia Plan Flanders, interviewed Flemish Minister for Welfare, Public Health, Family and Poverty Reduction (Belgium), about the plan.

May we start by asking: why did you develop a new plan for the coming years?

Well, since our population is becoming increasingly older, this also includes an increase in the number of people with dementia. Some estimates indicate we might end up with a twofold increase by 2070. Typical for the development of the condition entails the increasing dependence, which of course has its consequences for the social environment and an influence on various life domains. The COVID-situation has shown us the importance of the quality of life, in which the most important factor is autonomy. Therefore, we consider the support by personal caregivers to be so important.

What would you say is your main aim with this plan?

You have a one in five chance of developing dementia. At the moment, dementia cannot be treated or cured and the way the disease progresses differs from one person to another. We want everybody to be able to continue to be part of our society. That is why we are also stimulating the participation in society of people with dementia, and their autonomy when joining a sports club or choir, paying a visit to the museum or going shopping, either alone or with a close relative or buddy. They can still have a good quality of life, if society enables them to do so.

That is why good medical care and support are so important. We want the welfare policy to be inclusive and culture sensitive, while recognising not only the people with dementia but also their informal caregivers.

How did you translate this general aim in concrete actions?

The dementia plan describes specific strategic targets, which we will be focusing on from now on until 2025 in order to be able to plan ahead and offer continuity for the future. Everybody knows the importance of prevention. Prevention almost always begins with scientific knowledge and awareness among the population, followed by an adapted lifestyle. The dementia plan therefore provides actions such as sharing inspirational examples of preventive actions and the development of a new campaign that focuses on awareness of the link between a brain-healthy lifestyle and the reduction of the risk of dementia. For this we work together with the Flanders Centre of Expertise on Dementia, our partner organisation.

Besides prevention, it is also important to give considerable attention to the quality of care for people with dementia. The Flanders Centre of Expertise on Dementia provides a coaching pathway around person-centred care for people with dementia via the ‘Samen MENS’ (HUMAN Together) projects. The aim is to optimise the care even further and, for example, pay attention to small-scale normalised living. Quality of life and resident satisfaction in residential care centres will be other points of focus.

Furthermore, the Government of Flanders wants to promote knowledge enhancement among both current and future care professionals. In Europe, our dementia reference persons are highly regarded. Dementia reference persons have now become well-established in residential care centres. They coach their colleagues, participate in drafting the policy and are the driving force for high-quality dementia care.

Since 70% of people with dementia live at home, we continue to focus in Flanders on support for persons with dementia in their home environment. Working with reference persons in home care, developing a framework for the deployment of dementia reference doctors and further dispersing knowledge about dementia care will contribute to high-quality care for persons with dementia at home.
More is being done to ensure that people with dementia receive the support they need to lead a dignified life and that informal caregivers do not have to face everything alone. This is done, for example, by offering psycho-education, establishing discussion groups and paying attention to interaction and meetings.

In this regard we must all, each from our own experience and perspective, keep collaboration and consultation in mind for the benefit of the person with dementia and their social environment. I already see fine examples of partnerships, such as the partnership between the Flanders Centre of Expertise on Dementia and the various actors in palliative care in Flanders. Advance care planning and end-of-life aspects for dementia remain current topics and we are focusing further on suitable training.

**Is there a central message you want to convey?**

The needs and requirements of persons with dementia and their informal caregivers are the starting point for this policy. Since every person is unique, and therefore their needs are as well, we want to facilitate a varied range of supporting initiatives. People with dementia want, as does everyone, to maintain control over their lives for as long as possible and keep their welfare in their own hands. Autonomy is an important facet in experiencing quality of life. Being able to live a quality life at home is a major target in that autonomy. Remaining at home for a longer time demands flexibility, resilience and knowledge on the part of the informal caregiver. The policy aims to strengthen informal caregivers by offering them support.

There are a whole range of initiatives in Flanders to support informal caregivers. Our aim is to persist with this existing offering and where necessary to adapt and expand it. The main priority is to ensure that informal caregivers and persons with dementia find their way to these initiatives.

Research and daily care practice teach us that the stigma still associated with dementia has a great impact on quite a few other medical and care challenges.

The campaign ‘Forget Dementia, Remember the Person’, has in the past ten years acted as a catalyst in Flanders for building more respectful communication, for breaking down taboos and for the inclusion of people with dementia and the people close to them.

The ambition is not just to aim for a public perception that more closely reflects the daily reality of people with dementia, but especially to lower the threshold to the existing provision of help and support. For this purpose, it is not only vital to update the ‘Forget Dementia, Remember the Person’ campaign but also to strive for the anchoring of the Flemish Working Group of People with Dementia. Hearing the voice of people with dementia is invaluable to our dementia policy.

**Some final words, maybe?**

We want to view people with dementia from the perspective of their talents and account for their possibilities instead of simply concentrating on their limitations, so that they remain fully-fledged human beings. If this approach is to succeed, it is essential that the voice of people with dementia is heard!


---

**Rudy Poedts, Director, Flemish Alzheimer’s League**

“The new dementia plan is a clear signal that Flanders wants to put a strong focus on a good care, attention and support for people with dementia and their caregivers. Of course, we as a patient and caregiver organisation, are very pleased with this fact, especially when we as Alzheimer League Flanders can and may take up an important role in its realisation. Since 70% of the people with dementia are being cared for at home, the role of caregivers next to the professionals will be crucial in the future. They also need to receive the necessary education, support and resources to be able to keep on taking up this heavy task.

As an association, we ensure that the voice of people with dementia and their personal caregivers is not only heard, but also taken into account. This common thread is also foreseen throughout the new dementia plan for Flanders.”
France Alzheimer highlights lack of focus on dementia in French elections

In the run up to the French Presidential and legislative elections, France Alzheimer campaigned around the message “Alzheimer has disappeared from their political will, but not from our lives!”, highlighting the lack of focus on dementia. Public Policy Officer, Lorène Gilly describes the approach of the campaign.

The French policy context

For France Alzheimer and its advocacy mission, 2022 is a crucial year in terms of electoral deadlines and the impact on the French political landscape. Since the expiry of the former French Neurodegenerative Diseases Plan 2014–2019, the Association has worked to strengthen the fight against dementia. Their main objective is to bring awareness on the necessity of collectively responding to the needs of people living with dementia and their caregivers.

The context since then has raised the anger and despair of the families, worried that they have been forgotten by France’s elected representatives, including on the issues of:

- The long-awaited reform of “autonomy” legislation
- The impact of some governmental measures to tackle the COVID-19 pandemic

France Alzheimer also did its best to be heard during the work of construction of a second version (2021–2024) of this road-map, which was developed in a hurry, only a few weeks before the presidential election. Unfortunately, despite the promise of validation by the French Ministry of Health, nothing has changed and we are still hoping for ambitious funding for the first version of the road-map which officially started almost one year ago now.
Developing a policy campaign

Taking all this into account, the association has decided to build a specific campaign ahead of the presidential election in April 2022 and the parliamentary elections in June 2022. The name of this campaign naturally appeared: “Alzheimer has disappeared from their political will, but not from our lives!”. Its dedicated website https://www.alzheimeradisparu.fr carried three main objectives:

- **Raise awareness among the general public and encourage its support by giving the opportunity to vote on our 29 priorities and by allowing to directly issue a call to candidates on Twitter**
- **Challenge the 12 candidates and ask for a meeting to gather their commitments on that field**
- **Underline that dementia is a major public health issue.**

The 29 priorities are the result of a consultation with our network of 101 local branches and have been organised around six major themes: recognition and rights of people living with dementia; prevention and diagnosis; care pathway and life pathway; recognition and support of caregivers; lowering the cost of the disease and research and new horizons. After almost two months of voting on the dedicated website, the trend is quite consistent and the top five priorities the general public elected are:

- Allocate more resources for research on Alzheimer’s disease and related disorders
- Reinforce the intervention of trained and specialised professionals
- Take into account the specific needs of young people living with dementia
- Recognise the cognitive disability of people living with dementia
- Lower the cost of the disease.

Through these results, we get to the heart of the many challenges that people living with dementia and their caregivers must face on a daily basis. It is time to realise that these challenges are in fact imposed on the society as a whole and require an ambitious collective response, bringing lasting changes for millions of people concerned.

These results also helped us shape the meetings we had with the teams of eight of the twelve candidates of the Presidential election before the first round. Most of the time, we met with the Health Advisor of the candidate, the objective being to collect the views and the commitments of each team to make dementia a public health priority.

The priorities identified by the different teams were not always the same, focused on issues such as funding for research, prioritising prevention and diagnosis, or bringing more solutions to caregivers. Only two of the eight candidates represented in these exchanges confirmed their intention to fund a dedicated plan, which is quite appalling to us. You can find the minutes of each meeting on our website: https://www.francealzheimer.org/page-articles/

Reflections and next steps

France Alzheimer had the feeling during the campaign that health issues were not the priority of the public debate and the candidates, all of them, were only reacting to the last worrying scandals in the sector, unable to deliver a vision of the French Health System of tomorrow. We also had the feeling during these meetings that the fight against dementia was understood as part of the issues at stake in terms of autonomy and tackling the ageing issue, but never as a chronic disease that requires specific answers to cover the needs of millions of people concerned.

As we move to the parliamentary phase of the elections, the message is still very clear: we can no longer accept any half-measures to address the fight against dementia, which has to be perceived as a political priority, with dedicated measures and funding. People living with dementia and their families are in urgent need of specific and concrete answers.

France Alzheimer’s 101 local branches are on the front line for this part of the election, as we need to identify and bring awareness to as much deputies as we can. We have to strengthen our advocacy work for the five years to come. Our first demand is the creation of a dedicated working group of parliamentarians in the French National Assembly to institutionalise the need for debate and actions around the fight against Alzheimer’s disease and related disorders. Link for the video: https://www.youtube.com/watch?v=K-L3Xj7bgzc&t=45
POLICY WATCH

LILLY FOR BETTER

At Lilly, we are constantly evolving the way we discover, develop and manufacture medicines to bring new treatments to the people who need them even faster – and to expand access to these medicines for even more people around the world.

lilly.com

PAVING THE WAY FOR BETTER BRAIN HEALTH

Our commitment in Alzheimer’s disease (AD) has the single goal of delivering holistic, preventative, and management solutions that will support patients, their families and caregivers throughout their dementia journey, making a meaningful difference to people’s lives.
The Alzheimer Society of Ireland leads parliamentary briefing session on dementia and brain health

As part of Brain Awareness Week (14–20 March 2022), The Alzheimer Society of Ireland (ASI) led a special briefing in Leinster House at the Irish Parliament in Dublin, focused on the topic of Brain Health and Dementia. ASI Advocacy Manager, Clodagh Whelan, tells us about the session.

On 8 March 2022, in advance of Brain Awareness Week, The All Party Oireachtas Group on Dementia Chairperson, Senator Fiona O’Loughlin, hosted a meeting on Brain Health and Dementia, at which The Alzheimer Society of Ireland (ASI), clinicians, academics, and the Global Brain Health Institute showcased opportunities to increase prevention and significant developments in medical treatments.

The briefing, which was attended by 40 politician representatives, including Members of Parliament (TDs), Senators and Government Ministers, as well as 14 parliamentary staff, heard that up to 40% of dementias are potentially preventable, highlighting the need to resource early intervention, awareness, and new treatments. In addition, the need for sufficient resources to fund these opportunities was highlighted, as there are 64,000 people living with dementia in Ireland, a number which is forecast to more than double in the next 25 years.

ASI Interim CEO, Siobhan O’Connor, opened the session noting that the briefing to elected representatives was one of hope, explaining that it was possible for everyone to look after their brain health, and encouraging people to talk to their doctor as early as possible if any changes in memory become apparent. She further noted that many steps can be taken which will make a real difference, including addressing early risk factors such as hearing loss, high blood pressure, diabetes, smoking and depression, in line with the Lancet Commission report which found that up to 40% of dementias are potentially preventable. It was further highlighted that interventions which can reverse cognitive decline include education, exercise, stimulation and social engagement, with significant new medical treatments emerging which slow down early onset dementia.

Addressing Oireachtas members, Faculty Member of the Global Brain Health Institute anal, Professor Sean Kennelly, explained that dementia is the most significant health condition globally for which there is no definitive treatment. However, he noted that we are now on the cusp of a new era of better interventions to prevent, diagnose, and treat Alzheimer’s disease and other dementias. He further stressed the importance of educating people, so they understand what a ‘brain-healthy’ lifestyle is, and to take action to reduce the risks.

Kevin Quaid, Chairperson of the Irish Dementia Working Group (IDWG) and Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) stressed the importance of educating people that their brain needs to be nourished and looked after, brain health is for everyone not just older people. He further emphasised the importance of social connection for our brain health, noting...
that people can help themselves and others well by reaching out, visiting our neighbours, connecting with friends and spending time with family.

Trinity College Dublin Professor of Intellectual Disability and Ageing, Mary McCarron, highlighted the needs of people with an intellectual disability, for whom the risk of developing dementia is five times higher than their peers in the general population. She explained that dementia symptoms begin at an earlier age for people with an intellectual disability, meaning that the promotion of brain health and the diagnosis of the disease must also begin earlier in life. She further highlighted that almost all persons with Down’s Syndrome have the hallmarks of Alzheimer’s disease by age 40, with an 88% risk of developing the clinical symptoms by age 65. As such, actions to promote brain health in people with intellectual disabilities are needed now and at all ages.

Prof. McCarron shared that the National Intellectual Disability Memory Service had opened up new avenues for people with an intellectual disability to timely assessment, diagnosis and post-diagnostic support. She welcomed the announcement in Budget 2022, by the Minister of State for Mental Health and Older People, Mary Butler, of a further investment of EUR 7.3 million in services such as memory assessment, memory technology resource rooms and the National Intellectual Disability Memory Service.

Siobhan O’Connor concluded the briefing session by welcoming funding as part of the Health Service Executive’s National Service Plan 2022 to facilitate the recruitment of a Project Manager in Brain Health, due to commence with the National Dementia Office in July this year.

Following the briefing there was a debate on brain health and dementia in the Seanad attended by Minister for Mental Health and Older People, Mary Butler. The Seanad heard powerful personal testimonies from politicians on the impact of dementia on their families as well as strong advocacy for service provision. Speaking at the debate, Senator O’Loughlin welcomed the cross-party support for the Seanad discussion on brain health and dementia and called for increased communication to educate the public on how to look after their brain health.
Civil Society Organisations come together to advocate for patient involvement in brain health policy

As discussions commence for the future of brain health policies at a European level, Alzheimer Europe has joined with the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe to issue a Call to Action for patient involvement to be embedded in the planning, development and implementation of policies across Europe.

Alzheimer Europe, the European Federation of Neurological Associations (EFNA) and GAMIAN Europe, have come together to issue a Call to Action for improved patient involvement in brain health in Europe.

Specifically, the aforementioned organisations believe that to safeguard the future of brain health for patients, it is imperative that all stakeholders ensure that the priorities, needs and expertise of those living with brain disorders set the policy agenda at an EU and national level. Together, these organisations have called on all stakeholders to be accountable for patient involvement and shared decision-making across all policies related to brain health.

The Call to Action was launched on 12 May 2022, at an online event co-hosted by the three organisations entitled “Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients” which was attended by a range of stakeholders, including Agius Saliba, MEP (Portugal), European Commission representatives, researchers and industry partners. Speakers at the event highlighted the importance and added value of patient involvement, including professionals and policy-makers working in the field. In addition, patients with lived experience spoke during the meeting, including member of the European Working Group of People with Dementia (EWGPWD) and Vice-Chair of the Irish Dementia Working Group (IDWG), Helen Rochford-Brennan, who spoke about the value of including people with lived experience in the planning of both research programmes and projects.

The following article provides an overview of some of the key points of the Call to Action, which seeks to highlight the importance of patient in brain health in relation to eight areas:

1. Promote a human rights based approach in all policies and research affecting people living with brain health conditions
2. Prioritise patient needs in research agenda setting
3. Review funding proposals for research
4. Access, review and report on access to diagnosis, therapeutic intervention and care pathways
5. Support access to and design of clinical trials, and the design and use of patient reported outcome measures
6. Support approval processes for therapeutic interventions
7. Contribute, with industry, to patient-centric design in research, development and commercialisation
8. Optimise data sharing for patients and society.

Why have our organisations issued this Call to Action now?

In the next few years, many EU-level flagship brain-related projects will come to an end, however, there is an evident need to continue the focus on brain health, particularly in the domains of health and research. Discussions are already underway for a European Brain Health Partnership, in an effort to align existing projects and ensure their findings inform future collaborations.

This is to be welcomed however the voice of the patient is often missing from these discussions. Furthermore, discussions are dominated by a focus on basic science, data sharing and clinical trials. These are undeniably important – the progress in these fields in recent years has significantly improved our understanding of brain health and the underlying mechanisms which cause different disorders.

However, insufficient attention is given to the day to day impact on people living with brain conditions, with less focus on how best to support people to continue to live as well as possible or develop models of care and support, both of which would have an
immediate benefit for the quality of life of individuals (and their carers). For policies on brain health to have the greatest benefit for the people living with such conditions, there must be a coordinated and collaborative approach, which involves patients, decision makers, researchers, clinicians and civil society.

The current policy context provides a perfect opportunity to transform not only our understanding of brain health, but to develop new ways to improve the quality of life of individuals living with the conditions, as well as creating structures which give them meaningful involvement in setting the brain health agenda in Europe.

People with lived experience of a condition are uniquely placed to provide insights into what matters most to them and what would most improve their quality of life. These considerations should be the starting point for decision makers across all fields, in developing policies, designing health services or planning research.

As such, the patient voice is vital in setting public the agenda for policy and research. When done properly, it ensures that the outcomes are meaningful and impactful for people living with the condition. For example, in the research sector, EU-funded research, especially projects funded through programmes such as the Innovative Medicines Initiatives (IMI) and, we expect, the Innovative Health Initiative (IHI), has increasingly involved patients in research, as shown by the involvement of patient organisations by various EU projects.

**What are the key asks of the Call to Action?**

EU and national policy makers, regulators, funders and researchers must recognise the value of patient involvement in the development, governance and monitoring of brain health programmes and projects, to ensure their focus remains relevant for people with lived experience.

Our organisations and our members have demonstrated over many years our commitment to ensuring that the patient voice is heard in policy-making processes in health, social affairs and research, often playing leading roles in EU funded projects. We remain committed to ensuring that the voices of patients are heard and wish to see a stronger commitment from decision-makers, funders and researchers to embed the patient voice in priority setting in the brain health agenda.

Therefore, our organisations call for the following:

- Patients should be formally represented in setting the agenda of the European Brain Health Partnership, with a clear and recognised role for patient organisations in its governance and monitoring structures
- Research funders should place a greater emphasis on the role of and need for the patient voice in applications and the extent to which patients have been/are being involved in the development of the project proposal(s)
- The forthcoming European Brain Health Partnership must have a focus across the spectrum of research fields, reflecting a “care today, cure tomorrow” approach which will more likely benefit people living with brain health disorders today
- All stakeholders in the field of brain health, whether researchers, regulators, public health bodies, decision-makers etc. should ensure that resources and materials when involving people are accessible and in formats which meet the needs of patients.

The video of the Brain Health webinar can be viewed here: [https://www.youtube.com/watch?v=9sdkxPaYeeE](https://www.youtube.com/watch?v=9sdkxPaYeeE)
Second evaluation of the European Union by the UN Disability Rights Committee commences

In March 2022, the United Nations Committee on the Rights of Persons with Disabilities started the second evaluation of the protection of disability rights by the European Union: an important moment for the disability movement in Europe. Marine Uldry, Human Rights Officer with the European Disability Forum, talks us through the process and their response.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty adopted in 2006 that reaffirms that all persons with disabilities must enjoy all human rights and fundamental freedoms. It covers rights related to all areas of life such as equality, accessibility, education, independent living, health, employment, social protection and freedom from violence.

In 2010, the European Union (EU) became a Party to this important Convention. It is the first regional organisation to have done so. As a Party to the Convention, the EU has the obligation to respect, promote and protect all the rights under the Convention or persons with disabilities in all their diversity. People with Alzheimer and older persons with disabilities are part of the diversity of persons with disabilities.

Since 2010, the EU has already been evaluated once by the UN Committee. This resulted in the adoption of recommendations, in a document called “Concluding observations” adopted in 2015. This year, the Committee starts the second evaluation of the EU that will look at measures adopted by the EU to apply the 2015 recommendations and other issues that may have arisen since. The objective is to make the Convention a reality for all persons with disabilities living in the Union. The second evaluation is organised in two parts, starting with the adoption of a list of questions to which the EU will have to answer, and that will be followed with a dialogue between the EU and the UN Committee leading to the adoption of new recommendations in the next years.

Organisations of persons with disabilities play an important role in the evaluation process by providing the United Nations with information on the rights of persons with disabilities on the ground and at EU level. As European umbrella organisation of persons with disabilities, the European Disability Forum has been very active, together with member organisations, to inform the UN expert about the challenges faced by persons with disabilities in Europe, and issues of the EU in applying the CRPD as policy-makers but also as public administration.

Our alternative reports give information to the CRPD Committee about how the EU implements the Convention. Our first alternative report was prepared for the first review of the EU in 2015. It gave the view of 100 million Europeans with disabilities on the enjoyment of their political, civil, economic, social and cultural rights in the EU. The report was the result of collective work with EDF’s members, civil society organisations and other stakeholders. Giving a clear view of the situation of persons with disabilities all over Europe would not have been possible without their contribution and expertise.

In February 2022, working once again closely with our members, including Alzheimer Europe, we submitted our alternative report for the second evaluation of the EU, with a suggested list of questions that the Committee could ask to the EU. In addition, we participated in a joint briefing document on equality and intersectionality endorsed by over 10 European organisations and an alternative report on international cooperation with the International Disability and Development Consortium IDDC. As member of the EU Monitoring Framework on the CRPD, EDF also made a submission for the joint document sent by the Framework.

Our 2022 alternative report covers all articles of the Convention and identified 17 main concerns in the executive summary. Thanks to the support of Alzheimer Europe and other of our members, the report also...
includes specific attention to persons with cognitive disabilities. Three specific issues have been identified. The first one, concerns the little to no attention to disability as a result of cognitive or neurological conditions, such as dementia and Alzheimer – including of the most recent policies adopted by the EU such as the Strategy on the rights of persons with disabilities. The second issue relates to the lack of report and research on the situation of people with cognitive disabilities such as dementia: for example, although the EU Agency of fundamental rights conducted several research relating to the rights of persons with disabilities, they do not include people with Dementia. Finally, the report also highlights the neglect faced by persons with Alzheimer and dementia during COVID-19 and humanitarian emergencies.

Other important issues included in the alternative report are important to persons with Alzheimer’s, such as discrimination, denial of legal capacity, violence including in institutions and care homes, the use of EU fund and the lack of independent living. Our report highlights that some Member States have used Structural Funds to maintain and promote institutional care, rather than developing community-based alternatives in line with the CRPD and investing in opportunities for personal assistance. This results in the continuation of human rights violations in institutions within the European Union. The EU also fails to collect data on people living in institutions. Persons with disabilities, in particular children and women with disabilities, older persons with disabilities and persons with disabilities living in closed settings, are still at higher risk of violence and abuse than other people.

Overall, even if some progresses have been made, there are still many issues faced by people with disabilities in Europe. Targeted actions for older people, people with Alzheimer and many others are still lacking. The EU evaluation offers us with the opportunity to raise those failures and to influence the future of disability rights in Europe. Acting as a strong and united voice in the next steps of the process will thus remain important.

The list of issues prior to reporting on the EU can be found at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2fQPR%2f2-3&Lang=en

https://www.edf-feph.org/un-crpd/@MyEDF
https://www.facebook.com/EuropeanDisabilityForumEDF
World Health Organization embeds involvement of people with dementia in Knowledge Exchange platform

Since launching the Global Dementia Observatory Knowledge Exchange Platform in May 2021, the World Health Organization has embedded involvement of people with dementia in the peer review process. In this article, Laura García Diaz explains the approach.

The World Health Organization’s (WHO) Global Dementia Observatory Knowledge Exchange (GDO KE) Platform (https://www.globaldementia.org/en), launched in May 2021, supports the implementation of the global dementia action plan and aims to enhance countries’ responses to dementia by providing a space for stakeholders to share resources (e.g. policies, guidelines and examples of good practice) available at no cost. Resources submitted to the Platform undergo a comprehensive review process including focus groups of people with lived experience of dementia, a panel of peer reviewers and the WHO Secretariat. In doing so, the process ensures that resources uploaded onto the platform meet quality and good practice criteria, to provide greatest potential value for those using the platform.

Inclusion and engagement of people with lived experience of dementia in the peer-review process

In a dementia inclusive society, the human rights of people living with dementia are protected so that they can enjoy respect, freedom, dignity, equality, accessibility and quality of life. The United Nations Convention on the Rights of Persons with Disabilities ensures, among other things, that persons with disabilities, including people living with dementia, have the right to participate in political and cultural life. Similarly, the charters of rights for people with dementia developed in Scotland and Ireland emphasise that people living with dementia have the right to participate in developing and implementing policies that affect their lives. The WHO is fully committed to promoting the rights of people living with dementia. We recognise that people with lived experience of dementia have important insights and valuable knowledge. To ensure that the resources included in the Platform are meaningful and relevant, people with lived experience of dementia are involved as irreplaceable partners in the peer-review process.

Eight people with lived experience of dementia are actively involved in the review process through the GDO KE Focus Groups. Current focus group members come from Canada, Germany, Ireland, New Zealand, Singapore and the United Kingdom. They provide feedback on whether a given resource would likely make a difference to the lives of people with dementia and their carers if implemented in a country. They also provide
feedback on ways to improve the reviewed resources, to increase their accessibility and applicability to people with lived experience of dementia. Their feedback is shared with resource submitters, and it is publicly available on the Platform.

Over the course of a year, WHO co-developed the way of working together with Focus Group members so that the process – to the extent possible – responds to, and addresses, the unique needs of each member. The Focus Groups meet virtually to review the submitted resources and collectively discuss their feedback and recommendations.

Jim Mann, a Focus Group member from Canada, reflected: “Participating in the Focus Groups also provides an opportunity for members to learn about global initiatives and how other members are advocating for change in their respective countries. This shared information provides members with ideas and resources for use in their own country, further advancing advocacy efforts at the national and global levels.”

The WHO Secretariat supports the work of the Focus Groups by scheduling meetings, taking notes, and incorporating members’ feedback into summary paragraphs for each resource that is approved. Our work with the Focus Groups has taught us that for change to happen, a strong commitment and collaboration between people living with dementia and stakeholders is needed.

How to get involved

Resources in all languages can be submitted to the Platform. To support the review process, we need more language diversity among Focus Groups and peer-reviewers. If you are interested in joining one of the GDO KE Focus Groups, please email whodementiagroup@who.int

The peer-review panel currently has 79 peer-reviewers who are experts in the field of dementia, including academics, clinicians, policy makers and carers from 34 countries, covering all WHO regions. If you are interested in joining the peer-review panel, please complete this registration form: https://extranet.who.int/dataformv3/456467?lang=en

How to submit a resource

67 good practice examples from 16 countries, covering all seven action areas of the global dementia action plan, are currently featured on the Platform. WHO is calling for additional resource submissions for the Platform. We are looking for a wide range of resources from diverse contexts, geographies, languages and cultures. We encourage all stakeholders to share resources by completing this submission form: https://extranet.who.int/dataformv3/895286?lang=en

---

**TauRx** has a mission to discover, develop and commercialise new products for the diagnosis, treatment and cure of neurodegenerative diseases caused through protein aggregation.

Tau pathology is widely recognised as a principal driver of clinical dementia in Alzheimer’s disease and TauRx’s Tau Aggregation Inhibitors (TAIs) target the formation or aggregation of tau ‘tangles’ in the brain.

GT Diagnostics, a joint venture between Genting Bhd and TauRx, aims to transform the diagnostic pathway by launching cost effective and accurate assessment tools for dementia.

Learn more about our research and progress at [www.taurx.com](http://www.taurx.com).
Alzheimer associations are working hard to support those affected by the war in Ukraine

Our Chairperson Iva Holmerová, who is also founder of the Czech Alzheimer Society, Martina Mátlová, Director of the Czech Alzheimer Society, and Zbigniew Tomczak, Chairperson of the Polish Alzheimer’s Association, share their thoughts on the ongoing invasion of Ukraine and what is being done by their countries and their associations to support people affected and displaced by the conflict, particularly those affected by dementia.

Iva Holmerová, Chairperson, Alzheimer Europe

We have been watching the war live for many days. A war in Europe that threatens to be the biggest since the Second World War, threatening not only the entire continent but also the civilised world. A peaceful European country has been invaded by an aggressor. By an aggressor that has never given up its expansionist tendencies for many decades and which, systematically and unfortunately largely undetected, has been building up its intelligence networks in all European countries and across the Atlantic, significantly influencing major political events, elections and otherwise doing all sorts of damage in order to consolidate its power and connect its malicious networks.

How damaging this is was perhaps not something we wanted to believe until the first invasion of Ukraine in 2014, the murders on UK soil or the attack on ammunition depots in my country (Czech Republic). This undoubted international influence, together with a sense of unlimited power in their own realm, but also complete isolation from ordinary people in democratic nations, undoubtedly accentuated by fear during a pandemic, has led a psychopathic individual, gradually consolidating his power and dreaming of unlimited world domination, to make the insane decision to launch this unprecedented aggression.

I live in a country that experienced aggression in 1968, when the Soviet occupation isolated us from the countries of democratic Europe for the next decades. Even when Russian tanks were shuffling along our borders, we also did not believe that occupation was possible. It happened, and afterwards we lived in an environment of fear, oppression of freedoms and opinions, restriction of all activities, not only political ones, but also cultural and simple civic ones. The totalitarian power supervised everything that was taught in schools, what people could and could not say, and what and who could appear in the media.

Even thirty years after the fall of the Iron Curtain in Europe, these devastating effects of decades of totalitarian rule are still evident throughout the former Soviet bloc. I am always aware of this when I present the new version of the European Dementia Monitor (see: https://www.alzheimer-europe.org/reports-publication/2020-alzheimer-europe-report-european-dementia-monitor-2020-comparing-and).

The Central and Eastern countries have integrated into Europe in many respects, especially politically and economically, but there are areas where traces of the division of Europe are still evident. These include, among others, the success of scientists and their participation in European collaborative research, and also the care of people living with dementia. The traces of the Iron Curtain are still evident in the provision of care for people with dementia, but that is no cause for regret. On the contrary: I would like to thank our member organisations in these countries for doing everything they can to improve the care of people with dementia and the quality of life of people living with dementia and their families.
Most of the refugees from Ukraine are heading to these countries, and there has been a huge wave of solidarity and of all-out efforts to help. This is far from enough, however, as it is necessary to stop the aggression, to hold the guilty to account and to support Ukraine in military operations, but also in its reconstruction, including important civic activities and the support society gives its people, including people with dementia and carers.

Here, at our Centre of Gerontology we have moved all possible services to smaller rooms and thus opened one small sector with five rooms for people fleeing from Ukraine – seven mothers and seven children between the ages of two and 14. This happened immediately in the first wave of emigration, because mostly mothers and children were leaving their country. Only a bit later did the exodus of older people begin. Our colleague, Lucie Hájková, is trying to focus on and support people with dementia and many of our colleagues have also housed people from Ukraine in their own homes. We remain flexible, within our limited possibilities.

I would like to thank Alzheimer Europe’s national member associations for the support they are already providing to the people of Ukraine and I continue to hold firm to the belief that, in these difficult times, something very valuable can lay the foundations for future cooperation and belonging.

Martina Mátlová, Director, Czech Alzheimer Society

According to the latest data from the Ministry of the Interior of the Czech Republic (at the time of writing, 19 April 2022), more than 300,000 Ukrainians have found shelter from the war in the Czech Republic. 292,000 of them have already been granted a “tolerance visa”, which entitles them to, among other things, health care covered by public health insurance, free social services if necessary, employment or social assistance in the form of financial contributions (humanitarian benefits).

The Ministry figures show that people over 65 years of age account for 3.5% of all registered refugees, and more than 10,000 of them in absolute numbers. On the basis of these figures and the experience of, for example, my colleague Lucie Hájková, who works as a volunteer at the municipal assistance centre, we assume that there are not many people with dementia who have fled the war in Ukraine to the Czech Republic, for the time being. Nevertheless, like many other organisations that help different groups with specific needs, we have prepared ourselves to help people from Ukraine living with dementia.

In cooperation with the Ukrainian Alzheimer’s Society, we are also looking for new colleagues directly among the people who seek shelter from the war with us. After all, helping and supporting people living with dementia in their mother tongue is crucial. At the same time, the experience that new colleagues gain with us can potentially contribute to the development of services in Ukraine.

We all believe that this war will soon be over and people will be able to return home. But we do not think that the return of refugees to their homeland will be the end of it, and we are ready to help rebuild a devastated Ukraine, in the aftermath of this terrible war. The Czech Alzheimer Society has published leaflets in Czech, English and Ukrainian, about medical help for people with dementia who have fled from Ukraine.

You can find the leaflets, here: https://www.alzheimer-europe.org/sites/default/files/2022-03/Czech%20cards%20for%20Ukraine.pdf

“...a... Česká alzheimerovská společnost

mode. Similarly, we can also provide consultations.

In cooperation with the Ukrainian Alzheimer’s Society, we are also looking for new colleagues directly among the people who seek shelter from the war with us. After all, helping and supporting people living with dementia in their mother tongue is crucial. At the same time, the experience that new colleagues gain with us can potentially contribute to the development of services in Ukraine.

We all believe that this war will soon be over and people will be able to return home. But we do not think that the return of refugees to their homeland will be the end of it, and we are ready to help rebuild a devastated Ukraine, in the aftermath of this terrible war. The Czech Alzheimer Society has published leaflets in Czech, English and Ukrainian, about medical help for people with dementia who have fled from Ukraine.

You can find the leaflets, here: https://www.alzheimer-europe.org/sites/default/files/2022-03/Czech%20cards%20for%20Ukraine.pdf

“...In cooperation with the Ukrainian Alzheimer’s Society, we are also looking for new colleagues directly among the people who seek shelter from the war with us. After all, helping and supporting people living with dementia in their mother tongue is crucial.”

Martina Mátlová
Poland has long been linked with Ukraine in a special way: ethnically, nationally, historically and as neighbours. Until the war, about 1.5 million citizens of Ukraine worked and lived in Poland. A large proportion of women were employed as carers for the elderly, including those with dementia. There were also many social visits to Poland including from the families of caregivers, most often children.

Over 2.84 million people from Ukraine have come to Poland since the invasion began; mainly mothers with children but also with their parents. There are over 600,000 refugees in Warsaw alone. NGOs, the Polish Government and local governments offer full housing, medical, social and school assistance for children. Ukrainians receive a special ID number (PESEL), on the basis of which they can receive financial support and access to free health care, just like Polish citizens. This also allows refugees to obtain vital psychological help and support. Additional Polish language lessons are organised in schools, there is free transport in Warsaw for Ukrainian citizens and to facilitate communication in many parts of the city and on websites, information is provided in Ukrainian. Local self-governing authorities provide hotels, sports halls, or other facilities suitable for temporary accommodation.

NGOs meet frequently to exchange experiences, work together to help the people of Ukraine and we cooperate with the Patients’ Rights Ombudsman and with local governments. It should be emphasised that most of the support for people from Ukraine is based on the activities of volunteers, without whom this support would be impossible.”

Zbigniew Tomczak

Due to the location of our Association, close to the main railway station where people from Ukraine arrive, caregivers of people with dementia often come to us to ask for help and information, which we provide, as much as we can. Our Association initiated contact with the Ukrainian Alzheimer’s Society in Kiev, and is and will continue to help all those coming to Poland. I am in constant contact with a dozen or so friends from Ukraine to help if necessary. Both I and many of our members are trying to participate in the wide-ranging aid operation, including by housing refugees from Ukraine.

NGOs meet frequently to exchange experiences, work together to help the people of Ukraine and we cooperate with the Patients’ Rights Ombudsman and with local governments. It should be emphasised that most of the support for people from Ukraine is based on the activities of volunteers, without whom this support would be impossible. We believe that the proud Ukrainian people will effectively put a dam on the totalitarian Russian system, which also threatens other European countries.

Resources and support

To support people with dementia and carers, during the ongoing war in Ukraine, Alzheimer Europe has put together a range of online resources with information and guidance: https://www.alzheimer-europe.org/resources/ukraine-resources

Various resources can be found on the Alzheimer Europe website, including this one from the Czech Alzheimer Society.
Putting a face to commitment – Alzheimer Society of Ireland CEO Pat McLoughlin steps down

It was with great regret that The Alzheimer Society of Ireland (ASI) announced, on 5 January 2022, that Pat McLoughlin had decided to step down from his role as CEO. Mr McLoughlin, who is also a Board member of Alzheimer Europe, became CEO in October 2016 and officially retired from his role in March 2022. He reflects on his time in this role.

You joined The ASI as its CEO in 2016. What were your reasons for taking the position and why have you decided to step down?

When I left senior management roles in the public health services, I assisted many organisations in the charity and voluntary sector, as either a mentor, Board director or Chairperson. I became aware that persons with dementia and their carers had no rights to care, services were patchy and were heavily dependent on fundraising and charitable donations and it appeared to me that residential care became the default option because of the lack of equitable access to both home and community supports that other care groups could access.

When the vacancy of CEO was advertised, I was delighted to compete and subsequently take on the role when offered it. Following a very happy time there, I decided to resign to deal with a health issue which was going to take three months to recover from and having spent 44 years in full-time employment it was time to reduce my working week and allow a new CEO to develop a new strategy with the Board and celebrate ASI’s 40 years as an organisation founded by carers.

Can you share some highlights from your five years as CEO? What do you think has been the biggest achievement of the ASI during that period?

I have been fortunate to lead ASI when the key aims of our last strategy were achieved. We decided, following a very inclusive process that we had to build awareness of the reality of dementia in our communities and allow the voices of persons with dementia and carers to be the key in our awareness raising and lobbying.

We were very determined that our lobbying would be evidenced based, robust and sustained. We never wavered from the position of dementia care requiring a dedicated budget each year to make up for historic underfunding. The organisation has achieved these targets and services are being developed based on population needs.

Left to right: Pat McLoughlin, Jacinta Dixon and Paddy Crosbie campaigning at Leinster House

“Out our greatest achievement was our response to the devastating impact of COVID-19. The organisation focused on restructuring our care and support services and bringing new innovations.”

Pat McLoughlin

Probably our greatest achievement was our response to the devastating impact of COVID-19. The organisation focused on restructuring our care and support services and bringing new innovations. It is a credit to our funders, the Health Service Executive, corporate and individual donations, that we were sustained financially.
You have been a Board member of Alzheimer Europe since 2018. How would you describe the benefits of the collaboration between our two organisations?

We are very strong supporters of Alzheimer Europe and are one of the founding members. Its strength comes from its membership and the manner in which Jean Georges and his excellent small team have represented the views of its membership and lobbying of the Members of the European Parliament.

Dementia is a global issue and requires political commitment to support brain health, research and services. The linkages to pharmaceutical developments, lunch time debates, coordination of research activities and the Annual Conference are of tremendous benefit to Ireland as a small country. It has helped our working group develop contacts and participate in research and policy at a European level.

Irish MEPs have been at the forefront, in driving issues forward. As a Board Member of Alzheimer Europe, I have been very impressed by the highly participative nature of our discussions and the solution-focused approach to issues. The participation of the European Working Group of People with Dementia keeps us grounded in the realities of living with dementia.

What are your hopes for the future of the ASI? Do you have a few words of wisdom for your successor?

ASI will need to continue to lobby for dementia-specific homecare as part of the new statutory framework being developed by the Irish Government. I also believe that the value of social care services such as day services, meetings and support groups will need ongoing lobbying, to ensure that a fully comprehensive range of supports both in the home and community are available.

I am delighted with the progress made in developing integrated care pathways and quality diagnostic services linked with our staff in ASI. The roll-out of these initiatives will need resourcing but they are now part of government policy.

I am delighted that ASI has chosen a new CEO and I wish him the very best in the role. Looking back on what worked for me, I would say it was listening carefully to the stories of those impacted by dementia and speaking their truth to power in lobbying.

Looking back on what worked for me, I would say it was listening carefully to the stories of those impacted by dementia

Pat McLoughlin

A few words from The Alzheimer Society of Ireland and its new CEO, Andy Heffernan

The Alzheimer Society of Ireland (ASI) is delighted to announce that Andy Heffernan has been appointed as the new CEO.

Andy Heffernan has recently taken up the role to lead The ASI as the charity continues its work of supporting people with dementia, their family carers, and supporters in Ireland. Andy will bring expertise, experience, and drive to his new role. He has the value set, corporate oversight and compliance experience, and the commitment to person-centred approaches to lead the charity forward.

He holds significant experience at a senior leadership level across several areas and most recently with The Society of St Vincent De Paul, where he served as National Secretary.

He has also previously worked in the disability and mental health sector serving as Chief Executive of St John of God Community Services. Before this, Andy served in the Defence Forces.

The Alzheimer Society of Ireland CEO, Andy Heffernan said: “I’m delighted to have started my role with The Alzheimer Society of Ireland and I feel so privileged to meet with our service users, staff, volunteers, and supporters across Ireland. I am really looking forward to working with everyone in the charity and continuing our work as the leading dementia-specific service provider in Ireland.

The ASI works across Ireland in the heart of local communities providing dementia-specific services and supports and advocating for the rights and needs of all people living with dementia and their carers. Our vision is an Ireland where people on the journey of dementia are valued and supported. I would like to thank the ASI Board of Directors, express my sincere gratitude to Siobhan O’Connor for serving as our interim CEO and to thank former CEO Pat McLoughlin for his service to our charity. I am really looking forward to the journey ahead and working with everyone in Ireland and our counterparts in Europe and beyond.”

Andy Heffernan
Helen Rochford-Brennan discusses dementia with Tommy Tiernan on Irish television

Helen Rochford-Brennan appeared on The Tommy Tiernan Show on national Irish television station RTE, on 29 January 2022. Helen, an international dementia ambassador and a member of the European Working Group of People with Dementia (EWGPWD), spoke in-depth about diagnosis, advocacy, funding and home care.

Helen was 57 when she first got what she said was an “earth-shattering” diagnosis of early-onset Alzheimer’s. “It’s called early-onset and to get a diagnosis is very difficult, I understand. It was hard to identify in the beginning because I was working and a busy woman,” she said, “but when I got the diagnosis, of course, it was earth-shattering. I was in Galway and I was driving back to Tubbercurry and I was trying to think what I was going to say to Sean (husband) and Martin (son). All that kept coming up in my head was that maybe in an undisclosed amount of time I may not remember them, or remember all the memories we shared along the way.”

She continued: “It is difficult to live with it but it is liveable with. You have to have strategies and I think that is what has sustained me, to be honest with you: Working really hard every day and getting out in the fresh air and meeting people. You have to be pretty resilient and in particular, in the last year and a half I have had to be quite resilient because I was isolated at home.”

Helen went on to say that more support is needed for people with dementia in Ireland, especially those living at home who receive very little support, “which has been a big issue in this country when it comes to funding, because we’re not supported to stay at home, because the policy for homecare in Ireland, as it stands, is take a shower and take your medicine. So as long as I am clean and lipstick is on and I take my medicine, that’s grand. That’s not good enough. We need support to live at home as long as we can and to have that choice.”

Home care, she stressed, is not just about personal care, it’s about social activity also. “It is vital that we take a more holistic view” she said.

“Being on the Tommy Tiernan show was a daunting but enjoyable experience overall. There was a lot of preparation. It was a much longer conversation than what appeared on the show; Tommy and I spoke for over ninety minutes, which was then edited for broadcast. There were numerous conversations with the researcher Eoin Sweeney and my support Carmel Geoghegan, before the interview. We had to develop a strategy for how I was going to travel there, where I was going to stay, how I would travel from the hotel to the studios, and I had to make Tommy’s team aware of what I needed, before I arrived. COVID-19 is still very much a concern, so I had to make the team aware of my safety concerns. It was fun to help the team with dementia training, and I’m very grateful that they supported all my needs.”

“Tommy doesn’t know who his guests will be or what they are on the show to discuss. I wasn’t sure how much Tommy knew about the condition or whether he had a family member who lived with the condition. I didn’t know how he’d react when I told him I had a brain disease. Tommy has a wonderful sense of empathy. He has a fantastic production team who have a great understanding of the topic. I was slightly shocked by one of the questions, I wasn’t prepared, but sometimes we have to be ready for the uncomfortable questions.”

One lady wrote to say that her mother was beginning to go out again, after watching my interview. That is my job done, in telling my story, just to help others.”

Helen Rochford-Brennan
"It was essential that I expressed myself correctly; I thought that what I said may have an impact globally. I was overwhelmed by the response on social media. I was very humbled to have the opportunity to advocate for people with the condition, and I appreciate how comfortable Tommy and his team made me during the production. Since the show, I have received the most heartfelt letters, from people I have never met. One lady wrote to say that her mother was beginning to go out again, after watching my interview. That is my job done, in telling my story, just to help others."

The interview is available to view on the RTE Player, here: https://www.rte.ie/player/series/the-tommy-tiernan-show/S10000001918?epguid=IP000067669

Kevin Quaid, Chair of the Irish Dementia Working Group and Vice-Chair of the EWGPWD

“It was with great pride that I watched my good friend on the Tommy Tiernan Show. Helen and I have done so much advocacy work both in Ireland and indeed at this stage, worldwide. I was just filled with pride to hear her speak for those of us who have a voice but more importantly for the people who don’t have a voice because of this difficult disease we call dementia.”

Cormac Cahill, Interim Head of Advocacy & Public Affairs at The Alzheimer Society of Ireland

“We at The Alzheimer Society of Ireland are so proud of Helen for her bravery, honesty, and willingness to share so much of herself and her own journey with dementia in her interview on the Tommy Tiernan Show. Following Helen’s diagnosis with Alzheimer’s, she has been an inspiration to others living with the condition and has helped to put a spotlight on dementia in Ireland, Europe and further afield. For over ten years now, as a global dementia ambassador, Helen has worked tirelessly to help and support other people living with dementia to encourage them to continue to live their lives to the fullest.

In the interview, Helen spoke about how much her own community in Sligo supports her to live her life and about the importance of meeting other people and getting out and about in her community. This is such an important message as communities all over Ireland must support people living with dementia. The response to dementia should be a community one and Helen expressed this so well on the show.

We had an amazing reaction to Helen’s interview with Tommy Tiernan and so many people have been in touch with us to commend her for her honesty and bravery. Helen delivers an inspiring message of hope and despite Helen’s many challenges, which she so eloquently expressed in the interview, her determined nature and human spirit always shine through. Helen is continuing her campaigning journey today and helping to get greater access to home help for people with dementia to give them a greater quality of life. Well done, Helen. We are so proud of you.”
Alzheimer’s disease (AD) is the most common cause of dementia, with an estimated prevalence of 5% in Europe. As such, the search for genes that may contribute to the development of AD has attracted substantial interest, to support efforts towards improving the diagnosis, treatment and prevention of disease. A landmark study of genetic risk factors has recently been published in the Nature Genetics journal, providing a wealth of new evidence on the genetic underpinnings of AD.

The first genetic studies of AD in the early 1990’s involved participants with familial, inherited forms of the disease, who often develop symptoms of dementia in middle age. These landmark studies pinpointed variants in the amyloid precursor protein (APP) gene, linked to the buildup of damaging amyloid plaques in the brain. Subsequent studies found further genetic mutations linked to AD. In genes such as presenilin 1 and presenilin 2, inheritance of disease-causing mutations in these genes almost inevitably leads to early onset AD.

However, early-onset and familial forms of AD only make up a small percentage of all AD cases. Late onset AD, which accounts for 95% of cases, is a complex disease with no consistent pattern of inheritance – although genetic factors are thought to play an important role in disease onset and development.

The first culprit gene to be implicated in late onset AD was apolipoprotein E (also known as APOE), which has three different forms: APOE2, APOE3 and APOE4. A 1993 study, published in the Science journal, showed that over two thirds of late onset AD cases possessed at least one APOE4 allele. APOE remains the strongest genetic risk factor identified to date, with a single copy of APOE4 conferring a three-fold risk of developing AD.

Technical advances in genetic analysis methods catapulted the field forwards in the 2000’s, allowing researchers to rapidly scan hundreds or even thousands of people for genetic markers spread across the whole genome. Termed genome-wide association studies, or GWAS, these high-powered analyses revealed many new genes that were associated with an increased risk of AD, such as clusterin, CD33, BNI, CR1 and PICALM.

The identification of genetic risk also provided researchers with valuable clues as to the biological processes that drive AD. These clues led to discoveries showing that cholesterol metabolism, cell communication and inflammation play an important role in AD. In turn, this has prompting pharmaceutical companies to broaden their efforts to develop diagnostics and treatments for the disease.

Thanks to considerable research efforts, our understanding of the genetic landscape of AD has evolved substantially over the last decades. On 4 April 2022, a large group of international scientists released their findings from the largest genetic study of Alzheimer’s disease to date. Published in the Nature Genetics journal, these findings identify an additional 42 genetic risk factors for Alzheimer’s disease (AD), and provide compelling evidence to support a role for inflammation and the immune system in the development of AD.

The study was led by researchers from the European Alzheimer’s and Dementia Biobank (EADB) consortium, a JPND-funded initiative that has created a GWAS dataset from 20,464 people with AD and 22,244 controls, from 15 different European countries. This dataset was complemented by additional GWAS data from various European consortia working on AD, as well as the UK Biobank, AD Genetics Consortium, FinnGen and CHARGE consortia – totalling over 100,000 people with AD and almost 700,000 cognitively healthy peers, and making this the largest genetic study of its kind.

The genetic landscape of AD is the most common cause of dementia, with an estimated prevalence of 5% in Europe. As such, the search for genes that may contribute to the development of AD has attracted substantial interest, to support efforts towards improving the diagnosis, treatment and prevention of disease. A landmark study of genetic risk factors has recently been published in the Nature Genetics journal, providing a wealth of new evidence on the genetic underpinnings of AD.

The first genetic studies of AD in the early 1990’s involved participants with familial, inherited forms of the disease, who often develop symptoms of dementia in middle age. These landmark studies pinpointed variants in the amyloid precursor protein (APP) gene, linked to the buildup of damaging amyloid plaques in the brain. Subsequent studies found further genetic mutations linked to AD. In genes such as presenilin 1 and presenilin 2, inheritance of disease-causing mutations in these genes almost inevitably leads to early onset AD.

However, early-onset and familial forms of AD only make up a small percentage of all AD cases. Late onset AD, which accounts for 95% of cases, is a complex disease with no consistent pattern of inheritance – although genetic factors are thought to play an important role in disease onset and development.

The first culprit gene to be implicated in late onset AD was apolipoprotein E (also known as APOE), which has three different forms: APOE2, APOE3 and APOE4. A 1993 study, published in the Science journal, showed that over two thirds of late onset AD cases possessed at least one APOE4 allele. APOE remains the strongest genetic risk factor identified to date, with a single copy of APOE4 conferring a three-fold risk of developing AD.

Technical advances in genetic analysis methods catapulted the field forwards in the 2000’s, allowing researchers to rapidly scan hundreds or even thousands of people for genetic markers spread across the whole genome. Termed genome-wide association studies, or GWAS, these high-powered analyses revealed many new genes that were associated with an increased risk of AD, such as clusterin, CD33, BNI, CR1 and PICALM.

The identification of genetic risk also provided researchers with valuable clues as to the biological processes that drive AD. These clues led to discoveries showing that cholesterol metabolism, cell communication and inflammation play an important role in AD. In turn, this has prompting pharmaceutical companies to broaden their efforts to develop diagnostics and treatments for the disease.

Thanks to considerable research efforts, our understanding of the genetic landscape of AD has evolved substantially over the last decades. On 4 April 2022, a large group of international scientists released their findings from the largest genetic study of Alzheimer’s disease to date. Published in the Nature Genetics journal, these findings identify an additional 42 genetic risk factors for Alzheimer’s disease (AD), and provide compelling evidence to support a role for inflammation and the immune system in the development of AD.

The study was led by researchers from the European Alzheimer’s and Dementia Biobank (EADB) consortium, a JPND-funded initiative that has created a GWAS dataset from 20,464 people with AD and 22,244 controls, from 15 different European countries. This dataset was complemented by additional GWAS data from various European consortia working on AD, as well as the UK Biobank, AD Genetics Consortium, FinnGen and CHARGE consortia – totalling over 100,000 people with AD and almost 700,000 cognitively healthy peers, and making this the largest genetic study of its kind.

What is the genetic landscape of AD, and why is it important for us to understand it?

Jean-Charles Lambert: The genetic landscape of AD is made up of genes that are key actors in the development of AD. If we can pinpoint these genetic risk factors, we can also determine the important pathophysiological processes that drive AD – and this can help companies to develop new diagnostic and prognostic tools.

In our study, we used GWAS analyses to expand our understanding of the genetic landscape of AD. By analysing data from such a large number of participants, we were able to identify novel genetic risk factors, and among these we found biological pathways such as the TNFalpha pathway – which can be targeted by drugs that are currently used for other conditions. We were also able to construct a genetic risk score, which could help identify populations that may be at greater risk of AD or dementia progression.
What is GWAS, and what is the advantage of doing large-scale GWAS analyses?

Céline Bellenguez: GWAS are a fundamental tool for genetic epidemiologists. In GWAS, we compare the frequency of gene alleles in people who have a disease, and their healthy peers. When a gene allele or variant is more frequent in people with disease, this indicates that it may be a genetic risk factor for that disease. By using GWAS data from a large number of people, and combining results across studies, we can increase the accuracy and power of our analyses, and find rarer genetic variants.

How did the EADB contribute to your study?

Céline Bellenguez: It is important to have statistical power to do effective GWAS analyses, and this power is directly correlated to the number of cases analysed. In a large-scale collaborative effort, the EADB gathered a huge number of clinical samples from different countries in Europe, generating GWAS data that has been shared with all partners. We were able to analyse the raw datasets and then combine the results of these analyses with results from other cohorts and datasets, which really increased the significance and value of our studies, and allowed us to find new risk variants. There are many challenges with data sharing, such as issues with privacy regulations and the GDPR, but through effective collaboration we were able to overcome these challenges within the EADB.

You developed a new genetic risk score as part of your research. What value could this have for healthcare systems, clinicians and patients?

Jean-Charles Lambert: The genetic risk score has not been developed to assess individual risk. However, it could be useful for clinical research and for trial design, because it could help stratify populations and research participants. For example, it could be used to identify a population with a specific genetic risk profile for AD or dementia, who might then be compared to a different population in a clinical trial. It could also, eventually, provide more certainty in a diagnosis of AD.

What do you see as the next steps for your research?

Jean-Charles Lambert and Céline Bellenguez: The main value of our research lies in highlighting key actors and biological pathways involved in the development of AD. Our results show that the immune system and inflammation may play a particularly important role, for example via the TNFα pathway. We are now investigating these mechanisms in the laboratory, to get a greater understanding of them. We are also extending the sample size for our GWAS analyses, which might reveal further genetic variants and new signals. Our research was mainly focused on populations with European ancestry, and we want to extend this to different ancestries. Finally, we also want to analyse sequencing data, to rare variants that our GWAS analyses might have overlooked.

A final question: what are your aspirations for AD research?

Céline Bellenguez: In our study, we mainly focused on genetics. To really understand and interpret the data, we need to use next-generation sequencing (NGS) methods to look at how genetic variants might impact on mRNA and protein expression, as these are the molecular actors that influence biological processes. It would be fantastic to have those different types of data from the same individuals, at different timepoints during the development of AD, so we can really understand what is happening on a personalised level.

Jean-Charles Lambert: As Céline says, it would be hugely valuable to have an integrated database with genetic and other biological data from participants with AD, over the life course. We also need more funding for research on AD. AD has a huge impact on society, and is a major cause of death and disability worldwide, with growing prevalence – but research investment in AD is still disproportionately low compared to the investment in other diseases. Societies also need to address the stigma associated with dementia, to emphasise the value of research into a disease that affects millions of people across the globe.

You can read the published study, here: https://doi.org/10.1002/trc2.12303
Multi domain interventions for risk reduction and prevention of dementia and Alzheimer’s disease, an exciting journey from the FINGER trial to World-Wide FINGERS

Professor Miia Kivipelto is leading EU-FINGERS project, a JPND-funded consortium, which focuses on solutions for risk reduction of Alzheimer´s disease and dementia through a Precision Prevention approach. Prof. Kivipelto shines a spotlight on the importance of nutrition as a factor in risk-reduction.

It is becoming more and more apparent that an individual’s risk to develop cognitive impairment and dementia is not set in stone, but is modifiable. The most recent estimates indicate that around 40% of dementia is related to modifiable risk factors. Risk reduction and prevention will be pivotal in managing the global dementia epidemic, with The Lancet Commission report of 2020 listing 12 modifiable risk factors; including hypertension, obesity and diabetes, which can be targeted through nutrition and lifestyle changes.

Alongside these more well-established risk factors, there are also more novel risk factors, such as hearing loss and air pollution. In addition, not only depression, but also feelings of loneliness and hopelessness have been suggested to increase the risk of dementia, as well as stress and sleep disturbances. It is important to keep in mind that the evidence level for these different risk factors is varying. For some of these, such as vascular and metabolic risk factors, it is already quite strong, while for others, further research is needed. Many patients, especially older individuals, have impaired oral health that may be linked to dementia through suboptimal diet, inflammation, or infection.

More recently, it has been suggested that COVID infection may increase the risk of cognitive impairment and dementia, a topic which is currently being further investigated.

We also need to keep in mind that the processes in the brain leading to dementia may start to develop 20 to 30 years before a diagnosis is established. In this context it is never too early to start to prevent dementia. By turning risk factors into avenues for action, we can empower individuals to take control of their brain health. Protective factors can, for example, be a healthy, balanced diet, and a generally active lifestyle.

Prevention and risk-reduction strategies

Risk reduction and prevention has been gaining attention globally, as a means to deal with the so-called dementia epidemic. We have been working with the World Health Organization (WHO) regarding the Risk Reduction Guidelines, which were published in 2019. This important document provides an evidence base for the implementation of prevention and risk reduction strategies around the world. Among all of the documented risk factors, nutrition, and subsequent nutritional interventions, are getting increasing focus due to the growing evidence linking poor diet to cognitive impairment and dementia. Evidence supporting this link originated from the FINGER trial: the first large scale randomized controlled trial showing that it is possible to slow cognitive decline among at-risk older individuals through a multidomain, lifestyle-based intervention. The trial included 1260 persons, aged 60 to 77 years. We selected participants based on their dementia risk score, meaning that all participants had at least some modifiable risk factors present. The multidomain intervention, which lasted for two years, consisted of five components or ‘fingers’: nutrition, exercise, cognitive training, social activities, and monitoring of vascular and metabolic risk factors. The five- and seven-year extended follow-ups are currently ready and the eleven-year follow-up is now running. Understanding the long-term effects of this kind of intervention will help us to further improve upon the intervention model and ensure the best possible reduction in dementia risk.

FINGER trial data

Data from the FINGER trial show beneficial effects of this multidomain intervention on general cognition with 25% more improvement in the intervention group compared to the control group. The same pattern was seen for all pre-specified cognitive sub-domains: 83% more improvement for executive function, 150% for processing speed and 40% more improvement for complex memory. The control group showed also a 30% increased risk of cognitive decline in global cognition.

Beyond these clear effects on cognition, there were several other beneficial effects, such as a 30% lower risk of functional decline, improved mobility, as well as better health-related quality of life. Interestingly, there was also a 60% lower risk of other chronic diseases, particularly multimorbidity. In relation to this we have seen a 20% lower risk of hospitalization and health economic benefits. It can be concluded that the same intervention is valuable not only for cognition but also for healthy aging in...
imaging (MRI), positron emission topography (PET), and multiple blood based biomarkers to better understand various mediating pathways behind the intervention.

The FINGER intervention has gained increasing global interest, and in response we established the World-Wide FINGERS (WW-FINGERS) Network in 2017 to support the testing, adapting and optimization of the FINGER model in different cultures across the globe. One key component of WW-FINGERS is the prospective harmonization of study methodology, which will allow us to compare results between countries and interventions. It is also an important goal to share the experiences and data. Currently, there are around 45 countries, across all continents and including several low and middle income countries, which are part of the WW-FINGERS Network. While there have been several COVID-related delays, we have been working tirelessly to try to mitigate these issues in our studies. One solution has led to the creation of the ‘e-FINGERS’ initiative, investigating whether and how we can use new technology to support the implementation of multidomain interventions. The entire FINGER concept itself is evolving as well and we are moving towards an upgraded FINGER 2.0 model, with the aim to develop an even more individualized and optimized FINGER lifestyle model combined with pharmacological and nutrition-based interventions.

**MIND-AD mini trial**

The prototype for such an intervention is already ready – the MIND-AD mini trial, where we adapted the original FINGER intervention for patients with early Alzheimer’s disease and vascular and lifestyle risk factors. The preliminary feasibility results and feedback from the participants have been very positive. In one of the arms of the trial we combined the FINGER model with a medical food containing Fortasyn Connect (Souvenaid) to investigate whether, through such a combination, it is possible to obtain even greater benefits. This is the test of a design for future trials where we aim to combine lifestyle factors with dietary interventions or even with disease-modifying drugs. The reason for selecting Fortasyn Connect for the MIND-AD trial were the positive findings from the LipiDiDiet study. It was interesting to see that after 36 months in the LipiDiDiet study there was a benefit for both global cognition and memory and the differences in cognitive function between the intervention and control groups appeared to increase during the two-year to three-year follow-ups. There were also benefits to brain structure, including hippocampal and total brain volume, as evidenced by the MRI.

A further example of WW-FINGERS utilizing such a ‘hybrid’ design is the MET-FINGER-trial, which will start later this year. This study combines an updated FINGER model with a possible disease-modifying drug – metformin, a widely available diabetes medication (repurposed drug approach). Such combinations outline the direction for the next generation of clinical trials where lifestyle and other interventions can be combined for a more powerful and personalized effect.

The notion that a significant portion of dementia cases can be prevented, or at least delayed, is both empowering to individuals and encouraging to the dementia field of research. There is evidence that a multidomain, lifestyle-based intervention can be both feasible and effective, with such a model now being further developed within the WW-FINGERS Network. The new studies will give important information about diet, nutritional interventions other lifestyle interventions in various settings and cultures. We are also learning more about the multiple mediating pathways involved in dementia risk and development, such as vascular, lipids, inflammation, synaptic plasticity, and interactions between lifestyle and genetic factors. This will help us to move from complexity to precision prevention, where the right interventions are targeted to the right people at the right time.

The COVID-19 pandemic has had a negative impact on several risk factors for brain health, particularly lifestyle factors that were disrupted due to public health restrictions. Thus, focus on prevention and risk reduction is even more important in the current landscape and we should be ambitious with our prevention goals, both at the societal level and as individuals. We also need to ensure that the voice of the patient is heard in relation to both research programs and policy development.
transforming AD to protect what makes people who they are

Driving change to improve the lives of people with Alzheimer’s disease

At Novo Nordisk, we are thousands of passionate colleagues that are advancing research and development in Alzheimer’s disease.

This is a devastating disease that robs a person of their independence and the family of their loved one.

Together, we have an ambition of improving the lives of people impacted by Alzheimer’s disease through meaningful innovation.

The image shown features models and not real patients.
Our members are helping people with dementia and their carers in 33 countries.
32nd Alzheimer Europe Conference
Building bridges
Bucharest, Romania
17 to 19 October 2022

www.alzheimer-europe.org/conferences  #32AEC