Alzheimer Europe

Newsletter
OCTOBER 2024

HIGHLIGHTS

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WELCOME

I want to start off by offering my condolences to our colleagues at Federazione Alzheimer Italia after the recent passing of Gabriella Salvini Porro, founder and long-term President of Federazione Alzheimer Italia and former Board member of Alzheimer Europe.

In much happier news, I am delighted to say that the 34th Alzheimer Europe Conference (#34AEC), which took place in Geneva from 8 to 10 October, was a huge success. I would like to thank our co-hosts, Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève without whom the event would not have been possible. I also want to warmly congratulate the members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG), who successfully organised and presented the first plenary of the event. There were several special symposia on the agenda, two of which were organised by Alzheimer Europe: "Preparing for new AD treatments" was chaired by Director for Research Angela Bradshaw and supported by Gold sponsorship from Lilly, whilst "Dementia researchers of the future" was organised by the Alzheimer Europe Foundation and the INTERDEM Academy, thanks to the support of the silver sponsorship of Biogen.

Aside from #34AEC, much else happened in Geneva, including meetings organised by the European Group of Governmental Experts on Dementia, the European Alzheimer's Disease Consortium, the EWGPWD, the EDCWG, and the INTERDEM network, which held its Annual Meeting. We also launched our latest Dementia in Europe magazine, together with a special supplement about clinical trials on dementia. If you enjoyed Geneva, I invite you to mark the dates of our the 35th Alzheimer Europe Conference, which will take place in Bologna (Italy) from 6 to 8 October 2025.

Prior to our Annual Conference, I attended an international conference on dementia in Budapest (Hungary), which brought together policymakers, healthcare and social care professionals and at which I took part in a roundtable discussion emphasising the importance of engaging with policymakers. On the subject of engaging with policymakers, I am pleased to welcome András Kulja MEP (Hungary) as a new member of the European Alzheimer's Alliance (EAA) and thanking Romana Jerković MEP (Croatia) and Dainius Žalimas MEP (Lithuania) for accepting our invitation to act as Co-Chairs of the Alliance. As at the end of October, the EAA has 76 members from 21 EU Member States and the majority of political groups in the European Parliament.

In closing, I also draw your attention to our response to the negative European Medicines Agency decision on lecanemab, in which we highlight concerns with health equity and autonomy and call for robust risk management that balances access to treatment with rigorous safety oversight.

I trust you will enjoy reading our newsletter!

Jean Georges, Executive Director

IN MEMORIAM

14 OCTOBER:

In Memoriam Gabriella Salvini Porro

We were deeply saddened to hear of the passing of our dear friend and colleague Gabriella Salvini Porro, founder and long-term President of Federazione Alzheimer Italia and former Board member of Alzheimer Europe, who passed away on 14 October. Gabriella will be remembered for her lifelong dedication to people with dementia and their carers and families in Italy and Europe.

A few years after the death of her mother, who had Alzheimer's dementia, Gabriella decided to put all her energies into establishing Alzheimer Milano, which she did in 1991. Later, with the conviction that collaboration across Italy was key in addressing dementia, in mid-1993, she worked towards the creation of Federazione Alzheimer Italia, the national federation, which currently brings together more than fifty local associations and 60 Dementia Inclusive Communities.

She was also a convinced European and joined the Alzheimer Europe Board in 1994 where she represented Italy until 2006.

From 1996 to 2002, she served as the organisation’s Honorary Treasurer and from 2002 to 2004 as Vice-Chairperson. Amongst her many contributions to our organisation, she organised the 1995 Annual Meeting of Alzheimer Europe in Milan and as the responsible for the organisation’s first newsletter, she was also the creator of the Alzheimer Europe logo, which is still in use today with some minor modifications.

We will remember her as a passionate advocate for people with dementia and their carers, tirelessly raising awareness, developing the Italian Federation, and working to see dementia recognised as a priority by Italian policy makers. We offer our heartfelt condolences to the family of Gabriella, as well as our colleagues of Federazione Alzheimer Italia.

SPOTLIGHT ON 34AEC

7-8 OCTOBER:

European Group of Governmental Experts on Dementia meets in Geneva prior to #34AEC

The European Group of Governmental Experts on Dementia held an in-person meeting on 7 and 8 October in Geneva, Switzerland, in advance of the 34th Alzheimer Europe Conference (#34AEC). 19 European countries were represented at the meeting, in addition to representatives from the World Health Organization (WHO), WHO Europe, from the European Commission’s DG Research & Innovation (DG RTD), the Organisation for Economic Cooperation and Development (OECD) and from Alzheimer Europe. Over the course of the two-day meeting, the group heard about national dementia strategies and policies, as well as European and international policy developments.

At the national level, representatives from ministries from Belgium (Flanders), Czechia, Estonia, Greece, Germany, Iceland, Ireland, Malta, Poland, Sweden and United Kingdom (Scotland) provided updates to the group on recent developments in their respective countries. Alzheimer Europe led discussions on the use of anti-amyloid treatments and recent developments at a European level, as well as presenting on putting risk-reduction research into practice. The WHO provided an update on work at an international and European region level, including on the future of the Global Action Plan on Dementia. The European Commission presented on the place of dementia and brain health in the EU’s research programmes, whilst the OECD presented on their work which has relevance for dementia. The European Group of Governmental Experts on Dementia was formed in 2018 by Alzheimer Europe, the Dutch Ministry of Health, Welfare and Sport, the Italian Ministry of Health and the Scottish Government and is facilitated by Alzheimer Europe.

7-8 OCTOBER:

European Alzheimer's Disease Consortium hosts autumn meeting in Geneva

The autumn meeting of the European Alzheimer's Disease Consortium (EADC) commenced with introductory remarks from Frank Jessen and Sebastiaan Engelborghs, Chair and co-Chair of the EADC. The EADC is a network of clinical centres of excellence in dementia research and treatment, comprising memory clinics and institutions from 20 countries across Europe.

Key presentations on day one included lectures from Federica Ribaldi (Hopitaux Universitaires de Genève/HUG) on cognitive health initiatives in Geneva, and Claire Chevalier (HUG) on the development of a probiotics platform for Alzheimer’s Disease. Industry experts presented cutting-edge findings on plasma biomarkers and from clinical trials, followed by a special lecture from Sebastian Palmqvist (Lund University) highlighting the value of plasma biomarkers in primary care. The day concluded with a symposium on ageing and senescence, featuring discussions on geroscience and neuroimaging.

On 8 October, the focus shifted to young researcher presentations and new initiatives, with discussions on future plans for meetings and collaborations. The meeting concluded with the award of the first individual EADC membership to Bengt Winblad, Professor of Neurogeriatrics at the Department of Neurobiology, Care Sciences and Society at the Karolinska Institutet. Bengt has had a long and hugely productive research career in the Alzheimer's disease field, and chaired the EADC between 2001 and 2019, expanding its membership to over 60 centres of research excellence.

7-8 OCTOBER:

INTERDEM network celebrates 25th Anniversary at Annual Meeting in Geneva prior to Alzheimer Europe Conference

INTERDEM is a network of researchers interested in psychosocial interventions, made up of more than 600 researchers and academics with different professional disciplines, spread across 20 countries (18 of which are in Europe). The INTERDEM network celebrated its 25th anniversary at its Annual Meeting at the CICG conference centre in Geneva on 7 and 8 October 2024, prior to the 34th Alzheimer Europe Conference (#34AEC).

On 7 October, the meeting kicked off with a welcome from INTERDEM Chairperson Marjolein de Vugt, to all researchers present. Then there was an introduction to new members by Rabih Chattat, a session chaired by Myrra Vernooij-Dassen titled “Research road map”, and a keynote presentation about the WHO’s global response to dementia, delivered by Katrin Seeher in a session chaired by Martin Orrell. Other sessions on this first day included an update of the JPND Working Group INTEREST and a business meeting to discuss new initiatives.

On the second day, 8 October, attendees were split into different “taskforce” groups, to discuss topics including Young Onset Dementia, Intersectionality, Inequalities, and Social Health. A final plenary session was chaired by Esme Moniz-Cook on taskforce progress. Lastly, Frans Verhey chaired a session on the INTERDEM Academy that included a presentation of the publication winner Jacoba Huizinga together with Gerda van Tongerloo who reflected on her role in research as a person with dementia.

Alzheimer Europe is proud to be a key partner of INTERDEM and was represented at the Annual Meeting by Dianne Gove, Director for Ethics and Public Involvement, Ana Diaz, Public Involvement Lead, and Lukas Duffner, Project Officer.

https://interdem.org/

8 OCTOBER:

European Working Group of People with Dementia and European Dementia Carers Working Group host pre-conference meetings and then take centre stage at 34AEC

On the morning of 8 October, prior to the 34th Alzheimer Europe Conference (34AEC) in Geneva, the European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG) held their first face-to-face meetings during the current term of office.

At the meeting of the EWGPWD, members addressed the topic of independent living and housing which is the focus of the 2024 Alzheimer Europe Yearbook. This was followed by a networking event which was attended by conference delegates with dementia and their supporters.

Members of the EDCWG were informed about a brain health campaign for young adults (people in their early twenties) which has been developed in the context of two European projects (ADIS and Pattern-Cog) and discussed how this work, which was initially developed in the Spanish context, could be implemented in other countries. Members also addressed the topic of independent living and housing from the perspective of informal carers.

In the afternoon, the conference was officially opened and the first plenary session was a joint session organised by the members of both working groups, titled "Two voices, one story – navigating dementia together" (you can find out more in our conference article below). Alzheimer Europe congratulates the speakers on their fantastic presentations and congratulates both working groups for their vital work and for organising this plenary session. Alzheimer Europe would also like to thank all members of the EWGPWD and the EDCWG for their very active contributions throughout the whole of 34AEC, including presenting, chairing and participating in other conference sessions, as well as disseminating information about the working groups.

8-10 OCTOBER:

Alzheimer Europe holds its 34th Annual Conference #34AEC in Geneva

The 34th Alzheimer Europe Conference (#34AEC) “New horizons – Innovating for dementia” took place at the Centre International de Conférences Genève (CICG), between 8 and 10 October 2024, attracting 963 delegates from 42 European countries. On the agenda were over 400 presenters (150 presenters for oral presentations, another 100 quick oral presentations and 240 poster presentations), sharing their research, knowledge and experience in an atmosphere of true collaboration and solidarity.

Stefanie Becker, Director of Alzheimer Switzerland and Board Member of Alzheimer Europe, and Jean Georges, Executive Director of Alzheimer Europe, addressed delegates at the Opening Ceremony on the afternoon of 8 October.

Stefanie Becker began by saying “For decades, we’ve been waiting for a breakthrough in dementia treatment, and now, as these innovations emerge, they bring not only hope but also new challenges that people with dementia and their families are already facing”. She also noted that innovation is not just about breakthroughs in treatment, but rather it is also about “shifting social attitudes and embracing new technologies to create a truly dementia-inclusive society.” Innovation, therefore, also means finding better ways to support people in their daily lives, she affirmed. “Patient and carers’ organisations, like Alzheimer Switzerland, are at the forefront and will continue to advocate for everyone, ensuring that no one is left behind”, she said, emphasising that this is especially the case for those who may not meet the criteria for new treatments. Finally, she highlighted the importance of creating a society where the voices of people with dementia and their caregivers are heard, valued, and acted upon. “This is the foundation of a truly dementia-inclusive society”, she said.

Jean Georges extended a special welcome to the 37 people with dementia among the delegates, as well as to the 50 carers/supporters in attendance. He thanked Alzheimer Europe’s sponsors, including Gold sponsor Lilly, Silver sponsors Biogen, Novo Nordisk, Otsuka, and Terumo, and Bronze sponsors, BioArctic, Bristol Myers Squibb, MSD, Prothena and Roche, and expressed Alzheimer Europe’s gratitude to the CICG for hosting the event, as well as to the Geneva Convention Bureau, the République et

Canton de Genève, and the Switzerland Convention & Incentive Bureau, for their support. Last, but certainly not least, he thanked colleagues at Alzheimer Switzerland and Alzheimer Geneva, for co-hosting the event.

Following these opening words, delegates were addressed by Salome von Greyerz, who welcomed delegates on behalf of the Swiss Federal Office for Public Health, noting that this year's conference not only opens up new horizons, but also creates links that are vital for health care professionals, researchers and policy makers and, most importantly, for people with dementia and their caregivers.

A welcome video from Lukas Engelberger, Member of the Executive Council of the Canton of Basel-Stadt, and President of the Swiss Conference of the Cantonal Ministers of Public Health was screened next. You can view the video, here: https://youtu.be/GQ9IrzjPIp0. Pierre Maudet, State Councillor of the Republic and Canton of Geneva, then stepped up to the lectern, to warmly welcome delegates to Geneva.

The Opening Ceremony was rounded off by Marjolein de Vugt, who addressed delegates in her capacity as Chairperson of the INTERDEM (Early detection and timely INTERvention in DEMentia) network. She emphasised the power of small steps and 'golden moments' in dementia. "Dealing with dementia can feel like an insurmountable challenge", she said, "but breaking it down into small, manageable steps leads to significant improvements in quality of life. These small, everyday victories often bring about 'golden moments' of connection and meaning, which are vital in dementia care." She also stressed the importance of collaboration across psychosocial and biomedical approaches, due to the complexity of dementia, which requires diverse solutions. "Psychosocial innovations, risk reduction strategies, and medical advancements are all important. These approaches should complement each other, offering multiple paths toward a better future", she stated. In closing, Marjolein de Vugt pointed to INTERDEM's role in driving innovation, asserting that "as we celebrate 25 years of the INTERDEM network, it's clear that collaboration is key in psychosocial innovations. By focusing on interventions that enhance resilience, cognitive and social health, and quality of life. INTERDEM embodies the spirit of innovation needed to improve the lives of people living with dementia."

The first Plenary of the conference was a joint session organised by the members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG). This was chaired by Jean Georges. The two working groups had decided to focus on the interrelated topics of living with dementia, relationships and independence.

The different presentations provided a balanced overview of what life with dementia can be like, taking into account the very different experiences that people with dementia and carers across Europe may have. People who look at dementia from the outside may hold the view that living life to the full ends on diagnosis but the reality for many people is far removed from this perception. This plenary session set out to illustrate that many who live with dementia, and their carers, have a fierce and positive determination to enjoy themselves and play an active role in their communities. They seek not pity but support. They want empathy rather than sympathy. They require kindness and encouragement not dismissal or rejection.

Paddy Crosbie from Ireland, for example, remembered hearing the words 'It's young onset Alzheimer's' and how he did not know how he'd cope, but he was also told to keep his husband doing what he could for as long as he could and this carried him through.

Trevor Salomon, a fellow carer from the UK, suggested, "It's easy to see what people living with dementia can no longer do" and encouraged people with dementia and carers/supporters to focus on what is possible, and encourage them to do it. He provided an example of an employer who went to considerable lengths to adapt to the Trevor's wife's needs.

Liv Thorsen from Norway who cares for her husband described their philosophy to living with dementia, emphasising the power of thought and how the way that people think about Alzheimer's disease affects their daily lives and to some extent their experience of dementia.

Shelagh Robinson, a person with dementia from the UK, took a close look at relationships that people with dementia have with others and the nature and quality of those relationships (i.e. whether they are abling or disabling, respectful, smothering or inclusive). She emphasised the importance of being kind to oneself and others, and in the context of spirituality, ended on a positive note with a quote from Julian of Norwich, "All shall be well, and all shall be well, and all manner of things shall be well".

Lieselotte (Lilo) Klotz from German shared her first thoughts on hearing her diagnosis, namely, "This can't be, not me", explaining that it was not part of her life plan and how she had not been able to accept for the first few years the many changes and losses she was experiencing. She ended, however, with the statement, "an ordinary day is the greatest blessing".

At the end of the session, there was a short video presentation entitled "I may have Alzheimer's disease, but it doesn't have me", which was recently developed by the European Federation of Pharmaceutical Industries and Associations (EFPIA) and Alzheimer Europe. In this video, Chris Roberts, member and former Chairperson of the EWGPWD, talks about the importance of hope and of the timely detection of Alzheimer's disease, adding that he is not defined by the disease. Watch the video, here: https://youtu.be/1cW92mf5J0o. Each of the five speakers with lived experience at this first plenary session received rapturous applause from the audience, as did the video.

To close day one of the conference, a Welcome Reception was held in the foyer of the CICG conference centre, from 18.30 to 20.00. The folk trio CORSIN entertained conference delegates, with René, the yodelling singer and spoon player, Gérald on the accordion and vocals, and Sylvain on the alphorn, saxophones, musical saw, and bell.

On 9 October, the day began with the second plenary of the conference which was on “Making dementia a priority” and was moderated by Charles Scerri (Malta). Margit Jochum Christin was the first speaker. Responsible for the specialist area “dementia” and co-responsible for the Coordination Centre of the National Dementia Platform at the Federal Office of Public Health, Switzerland, she gave a talk on dementia in Swiss health care policy. Katrin Seeher from the World Health Organization (WHO) Brain Health Unit then discussed key achievements of the WHO’s Global Action Plan on Dementia. The third speaker was Alex Gobey, Director of the Dementia Care Directorate in Malta, whose presentation focused on the National Dementia Strategy for the Maltese Islands 2024 – 2031, titled ‘Reaching New Heights’. The fourth and final speaker at this session was Giovanni Frisoni, Clinical neurologist, full professor of Clinical Neurosciences at the University of Geneva, Switzerland, and director of the Memory Center at Geneva University Hospital, with a presentation about the Swiss Brain Health Plan.

In the afternoon, the third plenary covered topics related to innovation in dementia care. The session was moderated by Marjolein de Vugt (Netherlands), and the first speaker, Tobias Nef, delivered a presentation titled “Digital Biomarkers to support dementia patients and their caregivers”. He is a Full Professor of Gerontechnology and Rehabilitation at the ARTORG Research Center for Biomedical Engineering and the Department of Neurology at the University of Bern, Switzerland. The next speaker was Esther Loseto-Gerritzen from the Institute of Mental Health at the University of Nottingham, United Kingdom, who discussed online peer support for people with Young Onset Dementia. Then, a talk by Aisling Flynn, Lecturer in Occupational Therapy, Bournemouth University, United Kingdom, centred on virtual reality as a means of promoting the social connectedness of people living with dementia and their supporters. The fourth and final speaker was Lizzy Boots from the Alzheimer Center Limburg/Maastricht University, Netherlands, with her presentation, “From research and development to implementation - the Evaluation in Life Cycle of Information Technology (ELICIT) framework”.

Plenary four opened the conference programme on the third and final day, and comprised four presentations revolving around the theme of intersectionality. It was chaired by Maria do Rosário Zincke dos Reis (Portugal). She opened the session, introducing first a short video, before the presentations. The video summarised the journey of dementia researcher Golnaz Atefi, who, during World Alzheimer’s Month (September) this year, skated 1,026 km, setting the Guinness World Record for the farthest distance ever skated by a female, as part of the awareness-raising "Rolling for Dementia" campaign. Golnaz's mission was to engage with professionals and community members across Europe, finishing at the Alzheimer Europe Conference, to highlight the critical need for inclusivity in dementia care and research. Alzheimer Europe was pleased to support this amazing campaign. The video can be viewed, here: https://youtu.be/nJcHHTlJz4Y

After this short video, the first speaker was welcomed to the stage. Antonella Santuccione Chadha, Founder of the Women’s Brain Foundation, Vice President of Euresearch, and former regulator and pharma executive, spoke about the importance of gender in dementia research. The second speaker at this plenary session was T. Rune Nielsen, Associate Professor, PhD, Danish Dementia Research Centre, Copenhagen University Hospital & Department of Psychology, University of Copenhagen, Denmark. His talk was on reaching out to and including minority ethnic groups in dementia research. Next to take the floor was John Angel Bond, a dedicated PhD researcher in dementia studies at the University of Stirling, Scotland, United Kingdom and a committed member of the LGBTQ+ Dementia Advisory Group. He introduced his presentation "Queering Up Dementia Care: The Next Steps" and stressed that this was very much a joint effort together with Mike Parish from the LGBTQ+ Dementia Advisory Group. The final speaker was Eimear McGlinchey, Assistant Professor in Intellectual Disability, Trinity College Dublin, Ireland and Faculty at the Global Brain Health Institute. She discussed the link between Down syndrome and Alzheimer’s disease.

The fifth plenary session at the conference was on the topic of “Brain health and prevention” and was moderated by Giovanni Frisoni (Switzerland). Kicking off the session, the first speaker was Daniela S. Jopp, Professor of Psychology, whose work at the Institute of Psychology and LIVES Center of Competence on Life-span, University of Lausanne, focuses on adult development and ageing. Her presentation was called “Healthy ageing – is it possible to escape dementia?”. Next was Jean-Charles Lambert, PhD, Inserm Research Director, Head of the team "Search for molecular determinants of Alzheimer's disease and related disorders" at the Université de Lille, Institut Pasteur de Lille, France. His talk centred on the question “When does dementia become inescapable?” and explored the role of genetics. Ira Haraldsen, MD, PhD, from the Department of Neurology at Oslo University Hospital, Norway spoke next, sharing results from the AI-Mind project, of which she is the coordinator. Finally, Bogdan Draganski, Professor at the Neurozentrum – Inselspital, University of Bern, Switzerland, discussed new preventative approaches for vascular dementia.

The closing ceremony of the conference included comments from Maria do Rosário Zincke dos Reis, in her capacity as our Chairperson. She took the opportunity to thank all of the delegates and speakers “for making these three days such a fantastic time by sharing experiences and knowledge from different perspectives as people with dementia, carers, researchers, healthcare and social professionals. Different perspectives but with a common goal: To improve the quality of life of people with dementia and carers.” She also thanked all of our corporate sponsors, the Alzheimer Europe team for all the hard work in making the conference happen, and of course our co-hosts Alzheimer Switzerland. Hans Stöckli, President of Alzheimer Switzerland expressed gratitude for the support provided by Swiss partners and especially the CICG conference centre for providing us with free rental and audio-visual support. He also gave a big thanks to the Swiss institutional speakers who spoke at the opening ceremony on Tuesday and finally, thanked the translators and all the local staff for their help and support. Mario Possenti, Secretary General of Federazione Alzheimer Italia, then took to the stage to invite delegates to the 35th Alzheimer Europe Conference, “Connecting science and communities: The future of dementia care”, taking place in Bologna, Italy, from **6-8 October 2025**. Save the dates!

8-10 OCTOBER:

34AEC programme counts seven special symposia including two organised by Alzheimer Europe with support from corporate sponsors Lilly and Biogen

The programme of the 34th Alzheimer Europe Conference included seven special symposia, two of which were organised by Alzheimer Europe:

SS1 "Preparing for new AD treatments"

At Special Symposium 1, “Preparing for new AD treatments”, organised by Alzheimer Europe, chaired by Director for Research Angela Bradshaw and supported by the gold sponsorship from Lilly, four speakers shared the stage. First up was Jan Runar Eliassen (Norway), a member of the EWGPWD, who shared his personal perspective as a person with early-onset Alzheimer’s dementia. He was diagnosed at the age of 45 which was a huge shock for him and his family. “In Norway, we are proud of our health care”, he said, “but care regarding people with dementia has a long way to go”. Jan Runar and his family have had little or no contact or support within their local community since the diagnosis and this is sadly far from a unique story. “When I travel around Norway this is something I hear all over”, he said. Thankfully, he and his wife have established good contact with the Norwegian Health Associations and he was asked to be a member of their working group for people with dementia and, more recently, was nominated to the EWGPWD as well. These groups and contacts, as well as joining Norway’s “Dementia Choir”, a television programme inspired by that of the BBC in the UK, have been a saving grace for Jan Runar and his family. In closing, he stated that his sincere wish for the future of dementia care is that “no one should feel they are alone with this disease”.

Cath Mummery spoke about “Moving from research to clinical practice in the treatment of AD”. Her presentation highlighted that dementia services are currently primarily community based and are insufficiently resourced, while clinical trials environments are highly-regulated, well-resourced and typically manage patients with minimal comorbidities. The arrival of disease-modifying therapies, and the beginning of a treatment era in dementia, “provides a golden opportunity to reshape services, improve access to diagnostics and reframe conceptualisation of dementia”, she said. However, she also emphasised the importance of bridging the gap between the ‘real world’ and clinical trials. She explored some of the questions that arise from this, and what might be done “to start a journey towards access for all to a biological diagnosis and treatments for dementias.”

The next speaker was Julius Popp, head of the Centre for Cognitive Disorders and Alzheimer’s disease at the Hirslanden Hospital Zürich and the head of the research group Biomarkers and Neuropsychiatry at the University of Zürich. He pointed out that “the use of biomarkers is often recommended, but is currently still limited by their relative invasiveness, limited availability, and costs.” He also said that with new drug therapies targeting specific brain pathologies, biomarkers would become mandatory to determine the presence of pathology and to evaluate the therapy effects on this pathology. Finally, he stated that “blood-based biomarkers and other non-invasive markers will become available for clinical practice in the near future. These developments will lead to a much broader utilisation of biomarkers and accelerate the development of tailored prevention and treatment approaches.”

The fourth and final speaker at this symposium was Leonie Visser, PhD, Amsterdam UMC, who began her talk on the paradigm shift in healthcare and professional-patient communication with the assertion that "initiating disease-modifying treatment for AD is a preference-sensitive decision. Shared decision-making is not a new concept, yet it is even more important but also complex, because of the uncertainties regarding the benefits, risk of side effects, and burden of administration and monitoring”. She also noted that, in order to encourage patient engagement and support meaningful conversations about disease-modifying treatment initiation, educational materials and communication tools are needed, and that these should be developed taking a co-creation approach.

SS3 “Dementia Researchers of the future”

The symposium “Dementia researchers of the future” was organised by the Alzheimer Europe Foundation and the INTERDEM Academy, thanks to the support of the silver sponsorship of Biogen. This session afforded a great opportunity to ten early stage researchers, who were selected by our jury to benefit from bursaries to attend and present at the conference. The selection of these ten bursaries was based on the best average scores each received from the jury members.

Iva Holmerová (Czechia) and Fania Dassen (Netherlands) co-chaired this special symposium, and the ten researchers who presented their work were:

- SS3-01 Özlem Çiçek Doğan (Turkey): Understanding the experiences of individuals with dementia and their caregivers after the Turkey-Syria earthquakes: a qualitative study
- SS3-02 Natalia Soldevila-Domenech (Spain): Predictors of the cognitive response to multimodal lifestyle interventions for cognitive decline prevention: pooled analysis of four clinical trials
- SS3-03 Electra Chatzidimitriou (Greece): The predictive value of social cognition assessment over and above neuroimaging for 1-year functional outcomes in behavioral variant frontotemporal dementia
- SS3-04 Raphaella Paradisi (Greece): Modified Cued Recall test for the diagnosis of dementia of the Alzheimer's type in a Greek population of adults with Down syndrome: a validation study
- SS3-05 Matěj Kučera (Czech Republic): The role of risk factors in development of cognitive disorders and cognitive decline in the Czech Republic and the Netherlands: comparative SHARE prospective study
- SS3-06 Eda Atay (Turkey): The effect of cognitive stimulation therapy on apathy, loneliness, anxiety and activities of daily living in elderly individuals diagnosed with Alzheimer's
- SS3-07 Nina Stopar (Slovenia): Risk factors for dementia among patients in memory clinic
- SS3-08 Marina Makri (Greece): An innovative online educational program on Neurodegenerative Genetic Counseling developed in Greece, Germany, Belgium, Spain and Turkey
- SS3-09 Gabriela Początek (Poland): The meanings of the life story of a person living with dementia and their tendency to "wander"-the narrative perspective of Polish caregivers
- SS3-10 Anja Mrhar (Slovenia): The effect of individual characteristics on the level of nutrition related knowledge: exploratory study for older adults across levels of cognitive impairment.

Other special symposia

The five other symposia that took place during the event were:

- SS2 “Enhancing impact: bridging dementia research and practice” was organised by Dutch project DEMPACT.
- SS4 "European platforms advancing dementia detection, diagnosis and care” was supported by Gates Ventures.

- SS6 "Digital devices and psychosocial interventions: challenges and issues" was organised by the Fondation Médéric Alzheimer.
- SS8 "New dementia assistive technologies to transform lives: Presenting the innovators of the Longitude Prize on Dementia" was sponsored by the Longitude Prize on Dementia delivered by Challenge Works in partnership with Alzheimer's Society and Innovate UK.
- SS9 "Support for care giving relatives in continence care" was organised by Essity.

8-10 OCTOBER:

ABOARD project attends Alzheimer Europe Conference in Geneva

The Dutch project ABOARD is working on a future with tailor-made treatments for Alzheimer's disease (AD), which the consortium members are doing by focusing on the stages before dementia, as they believe the key to solutions lies in focusing on diagnosis, prediction, prevention, communication and information provision. They also believe in the importance of working together and have more than 30 partners working on the project, from across a wide spectrum of backgrounds.

Between 8 and 10 October, ABOARD researchers attended the Alzheimer Europe Conference in Geneva. Researchers from all five Dutch Alzheimer centres, from Pharos and, last but not least, from Alzheimer Nederland were present at the conference, where delegates were treated to an opening speech by Marjolein de Vugt and key note presentations from Leonie (N.C.) Visser about communication and from Sebastian Köhler about lifestyle changes and prevention. There were also speakers on blood markers, digital tools, artificial intelligence, inclusive care and research, patient perspectives, improving early recognition and involving participants in research.

It is precisely the voice of patients, family members and citizens at risk that ABOARD finds vital in the research it is carrying out, so the project is very happy to have Jean Georges, Executive Director of Alzheimer Europe, on its Advisory Board, helping to steer the work they are doing in the right direction for the target population. ABOARD is carrying out its work under the banner of the Dutch National Dementia Strategy.

9 OCTOBER:

Prominent project presented at the Alzheimer Europe Conference: Advancing precision medicine in neurodegeneration

On 9 October 2024, Linus Jönsson (Karolinska Institutet), project coordinator of the Innovative Health Initiative (IHI) funded PROMINENT project, presented the project’s objectives and recent work at the Alzheimer Europe Conference in Geneva, Switzerland. PROMINENT aims to support early and precise Alzheimer’s disease (AD) diagnostics, treatment eligibility, and decision-making for both people affected by neurodegeneration as well as clinicians. The presentation was part of a sponsored symposium focussed on European platforms advancing dementia detection, diagnosis and care.

Linus discussed PROMINENT’s integration of advanced predictive models that are being further developed as part of the project and clinical decision-support systems, which guide clinicians in selecting tailored diagnostic pathways based on individual patient profiles. This approach aims to reduce unnecessary testing and increase diagnostic accuracy, potentially making care more personalised and efficient. The system also includes a component for analysing treatment eligibility, helping clinicians determine which patients are most likely to benefit from new disease-modifying treatments, including emerging therapies in AD.

He further underscored the importance of data integration within the platform, which aggregates data from various medical records and imaging repositories to refine diagnostic processes further. By automating data analysis, PROMINENT aims to offer a streamlined experience for healthcare providers, ultimately allowing for more timely interventions. PROMINENT also actively involves patients and caregivers, emphasising their roles in improving data quality and relevance through Public Involvement, that is conducted through Alzheimer Europe’s involvement in the project. The recording of the presentation is available here:

https://youtu.be/Ot-5F00TT1U

9 OCTOBER:

AI-driven dementia prevention: Highlights from the LETHE session at the Alzheimer Europe Conference 2024

On 9 October 2024, the LETHE project was featured in a session at the 34th Alzheimer Europe Conference in Geneva, showcasing advancements in AI and technology for dementia prevention.

Project coordinator Sten Hanke (FH Joanneum) introduced the session, followed by Francesca Mangialasche (Karolinska Institutet), who spoke on risk reduction and prevention. She highlighted research on modifiable risk factors and the need for multi-domain interventions, building on the FINGER model and its global expansion.

Sten Hanke then explained how LETHE uses AI, wearable devices, and apps to provide personalised interventions, monitoring participants' physical activity, sleep, and cognitive function over two years.

Jeroen Bruinsma (Maastricht University) discussed techniques for ensuring participant adherence, detailing goal-setting, self-monitoring, and digital prompts through the app. He shared findings from participant interviews, which revealed challenges in implementing lifestyle changes without structured support.

Elisabeth Stögmann (Medical University of Vienna) provided an update on the study's progress, noting high retention rates and data collection success despite challenges in long-term participant engagement.

Lastly, Ana Diaz (Alzheimer Europe) discussed the importance of Public Involvement, emphasising how input from people with cognitive complaints and their carers shaped the project's design to ensure its relevance. She also provided the attendees with resources about Alzheimer Europe's Public Involvement work, the approach and further information.

The session closed with a lively and engaged questions and answers round. The recording of the session is available here: https://youtu.be/w15OBC4lgj0

10 OCTOBER:

AI-Mind presents results at Alzheimer Europe conference in Geneva

The AI-Mind project made a significant impact during the 34th Alzheimer Europe Conference, held from 8-10 October in Geneva (Switzerland), by unveiling its latest research findings. This milestone marked a key moment for the project, which focused on developing Artificial Intelligence digital tools for screening brain connectivity and dementia risk estimation. These tools aim to support healthcare professionals in their diagnosis and enable them to predict which people with Mild Cognitive Impairment (MCI) are likely to develop dementia. A major highlight was the participation of AI-Mind's project coordinator, Dr Ira Haraldsen, taking the stage as a keynote speaker in the final plenary session on brain health and prevention. She highlighted the innovative potential of artificial intelligence in dementia research, particularly in risk prediction and early diagnosis, signalling promising advancements for the future. Throughout the conference, members of the AI-Mind Consortium showcased their ground-breaking research through several oral presentations.

As the AI-Mind project continues to advance the field of artificial intelligence in dementia prevention, the consortium looks forward to reconvening in Madrid at the end of October for its Project General Assembly Meeting. Additionally, members will continue to disseminate their findings at conferences such as the upcoming 17th Clinical Trials on Alzheimer's Disease (CTAD) to be held on 29 October – 1 November.

https://www.ai-mind.eu/blog/ai-mind-presents-results-at-alzheimer-europe-conference-in-geneva/

14 OCTOBER:

Two new Dementia Researcher video podcasts share some highlights from Alzheimer Europe Conference in Geneva

On 14 October, two new video podcasts were published online, via the Dementia Researcher (UK) YouTube channel and website, each looking at some of the highlights from the Alzheimer Europe Conference in Geneva. The first episode is hosted by Dr Megan Rose Readman, NIHR ARC and Alzheimer's Society Dem Comm Postdoctoral Research Fellow at the University of Liverpool (UK). She talks with three guests: Dr Fiona Carragher from the Alzheimer's Society (UK), Dr Andy Northcott from the Geller Institute of Ageing and Memory, University of West London (UK), and Dr Sébastien Libert from Alzheimer Europe. Each of them reflects on their highlights from the first day of the event in Geneva. Find out more about the podcast and the guests, and watch the video, here:

https://www.dementiaresearcher.nihr.ac.uk/podcast-alzheimer-europe-conference-highlights-2024-part-one/

The second episode is hosted by Dr Megan Polden, Postdoctoral Research Associate at the University of Liverpool and the University of Lancaster (UK). She talks with three guests: Dr Aisling Flynn from Bournemouth University (UK), Dr Emma Law from the Scottish Neuroprogressive and Dementia Network (UK) and Dr Lukas Duffner from Alzheimer Europe. Each of them reflects on their highlights from the second day of the event in Geneva. Find out more about the podcast and the guests, and watch the video, here:

https://www.dementiaresearcher.nihr.ac.uk/podcast-alzheimer-europe-conference-highlights-2024-part-two/

Dementia Research Programme Director Adam Smith joined the conference as a member of the press and is responsible for these excellent podcasts. It was a pleasure to work with him, to make this happen. The audio of both is also available in podcast apps:

- Episode 1: https://pod.fo/e/273507
- Episode 2: https://pod.fo/e/27394c

16 OCTOBER:

"A Congress Full of Hope and Humanity" writes Lieselotte Klotz, Vice-Chairperson of the European Working Group of People with Dementia, about the 34th Alzheimer Europe Conference

There are moments in life that touch us deeply—not only because of their intellectual depth but also because of the people we meet. The 34th Alzheimer Europe Conference, held from October 8 to 10, 2024, in Geneva, was one such event for me. Under the theme "New Horizons – Innovations in Dementia," this conference not only brought forth scientific insights but also created an atmosphere of connection and hope. What stood out most was the open exchange between scientists, professionals, and people with dementia and their caregivers. Rarely have I attended an event that places such great value on listening to the voices of those affected. People with dementia were not just passive listeners but actively participated in presentations and discussions. Their perspectives and experiences were the heart of many presentations.

A key topic of the conference was the progress in dementia research. There was an intense focus on new treatment approaches and possibilities for early detection of the disease. New diagnostic tools, such as biomarkers and modern imaging techniques, raise the hope that people can be diagnosed and treated earlier and more precisely. These developments make us optimistic about the future. Another important subject was the concept of dementia-friendly societies. How can we, as a community, better address the needs of people with dementia? This question permeated many presentations, posters, and discussions. It was about how cities and public spaces can be designed to allow people with dementia to live as independently as possible. The question of inclusion was particularly significant: How do we ensure that people with dementia can actively participate in social life? It became clear that every voice matters and that society can play a crucial role in ensuring that those affected are not excluded.

The familial atmosphere of the conference was impressive. Despite the many participants from across Europe, there was a strong sense of community. It was a diverse group of people dedicated to dementia research and care. People with dementia and their caregivers were just as represented as caregivers, scientists, and researchers. Professionals from healthcare and social sectors, staff from various organizations, politicians, and industry representatives used the conference to exchange ideas and develop innovative approaches to improving the quality of life for people with dementia. During breaks and evening networking events, it was easy to connect, and a warm atmosphere prevailed. This closeness between participants deeply moved me and showed that we all share the common goal of improving the lives of people with dementia. A particularly touching moment for me was when a family member asked a researcher after his presentation what his work meant for the future of those affected. His response went far beyond scientific data: he spoke of his personal motivation to fight the disease and improve lives. It was a moment that revealed the close connection between research and humanity.

Geneva, as the host city, added a special touch to the conference, despite the rain. The city shone in its autumn glory, and although the weather didn’t always cooperate, it did nothing to diminish the wonderful atmosphere. Breaks along the shores of Lake Geneva offered moments of reflection and relaxation, and the city's charm provided an inspiring and welcoming environment that fostered participants' exchange and networking.

In the end, I look back with a deep sense of gratitude - for the many stories that were told and heard, for the researchers who work tirelessly to find new solutions, for the organizers who created this platform, and much more. It was not just a scientific conference, but for me a deeply moving journey full of hope and humanity. The 34th Alzheimer Europe Conference has shown that together we can open new horizons. It was an unforgettable experience that inspired and motivated me to continue advocating for a better future for people with dementia. I am grateful that I was able to be part of this extraordinary event. Now, I am already looking forward to seeing you again at the 35th Alzheimer Europe Conference, “Connecting Science and Communities: The Future of Dementia Care” in Bologna, Italy. MERCI Geneva 2024 & CIAO Bologna 2025!

23 OCTOBER:

The Alzheimer Society of Ireland attends the 34th Alzheimer Europe Conference

The Alzheimer Society of Ireland (The ASI) had an incredible experience at the 34th Alzheimer Europe Conference, themed “New Horizons - Innovating for Dementia” in Geneva. The conference was a great opportunity for learning, strengthening collaboration, and engagement, featuring a variety of sessions that explored the latest advancements in dementia research and care.

Attendees from The ASI, including staff and members of the Dementia Research Advisory Team, were inspired by the wealth of knowledge shared by experts in the field. The ASI delivered six oral presentations during the three-day conference across a range of topics including clinical trials, empowerment, Person Public Involvement (PPI), advocacy, hearing loss, and advocating for change at European level. A particular highlight was Paddy Crosbie, Dementia Carers Campaign Network and European Dementia Carers Working Group member, sharing his experience of caring, during the Opening Ceremony. The ASI found the networking opportunities invaluable, forging connections that will enhance their efforts in advocacy and support.

24 OCTOBER:

Public-private collaborations in dementia research showcased at #34AEC

The recent Alzheimer Europe conference showcased several initiatives that are shaping the future of Alzheimer’s disease (AD) research, with a strong emphasis on collaborative public-private partnerships. These innovative platforms and partnerships underscore the value of collaborative research, bringing new advances in prevention, diagnosis, and treatment to people affected by, or at risk of dementia.

Elisabetta Vaudano, Principal Scientific Manager at the Innovative Health Initiative (IHI), discussed the transformative impact of these partnerships, especially through the work of the Innovative Medicines Initiative (IMI). IMI-funded projects provide a unique framework for uniting research efforts across sectors, amplifying the impact of individual initiatives to benefit people with dementia and society at large. A core principle of these collaborations is a participatory approach, where people with dementia actively contribute as collaborators. This inclusive approach not only enhances the relevance of research outcomes but also ensures that projects align closely with the needs of the dementia community. Elisabetta highlighted the interconnectivity between initiatives, showing how projects are building on advances and leveraging innovations from earlier and ongoing IMI projects.

Claire Chevalier from the University of Geneva presented the European Platform for Neurodegenerative Diseases (EPND), an initiative focused on overcoming barriers to data and sample sharing in biomarker research. EPND addresses the challenges of data silos, regulatory requirements, and accessibility, connecting over 80 research cohorts with data from 250,000 patients across neurodegenerative diseases. By facilitating data discovery, biobanking, and data harmonisation, EPND accelerates research and is paving the way for breakthrough studies on biomarkers in Alzheimer's disease, Parkinson's disease, and related conditions.

Another key initiative presented was the AD-RIDDLE project, by Francesca Mangialasche from Karolinska Institutet in Sweden. AD-RIDDLE focuses on early AD prevention and personalized care pathways, aiming to improve early detection and intervention methods. With support from the IHI, the project is developing a modular platform that integrates both pharmacological and lifestyle interventions across the AD continuum. EPND is the enabling data platform for AD-RIDDLE, supporting data discovery and analysis between partners, with the aim to make datasets available for wider research and innovation. By addressing each step of the AD care pathway—from awareness and risk reduction to diagnosis and treatment—AD-RIDDLE aims to provide scalable, individualised solutions to manage AD in diverse populations across Europe.

Dag Aarsland from Stavanger University in Norway discussed the PREDICTOM platform, which leverages artificial intelligence to screen for AD risk in a home-based setting. The platform digitally collects and analyzes data on biomarkers, including cognition, eye-tracking, and physiological markers like blood and saliva samples. Dag explained how this AI-driven approach enables early identification of at-risk individuals, with follow-up in-clinic assessments to confirm diagnoses. PREDICTOM hopes to integrate its platform into the clinical pathway, making early AD diagnostics more accessible and accurate.

Finally, Linus Jonsson of Karolinska Institutet introduced the PROMINENT project, a digital platform designed to enhance clinical decision-making for AD patients with complex health conditions. Using data from medical records, mobile devices, and imaging, PROMINENT provides evidence-based insights on the most appropriate treatment options for individual patients. The platform also offers patients and caregivers easy-to-understand information on their brain health, supporting informed decision-making and personalised care. By enabling clinicians to better assess treatment effectiveness in real-world settings, PROMINENT has the potential to transform AD management and set a new standard in patient-centered care.

Learn more about the projects:

- EPND: https://epnd.org/
- AD-RIDDLE: https://www.ad-riddle.org/
- PREDICTOM: https://www.predictom.eu/
- PROMINENT: https://www.ihi-prominent.eu/

28 OCTOBER:

Vera Otten cycled 1,400 kilometres from Netherlands to Geneva in 11 days to present her work at the Alzheimer Europe Conference, raising money for Alzheimer Nederland along the way!

For my dear grandfathers and grandmothers.

I've experienced first-hand how dementia can change lives and relationships. No one can stop the disease, but I'm determined to help bring about change through more scientific research. That's why I raised money for Alzheimer Nederland. I cycled 1,400 kilometres in 11 days to the Alzheimer Europe Conference and raised over EUR 5,000.

The most meaningful part of this journey has been the closer bond I now share with my grandparents. In preparing for the trip, I had many heartfelt conversations with them about what it's really like to live with dementia. My grandmother describes it in such a touching way that it deeply moves me. These conversations gave me strength, especially on days when it wouldn't stop raining. My 90-year-old grandmother takes it as a given to care for my grandfather with dementia around the clock, seven days a week. So how could I complain about rain and cold feet?

Although I made this journey alone, I never felt lonely. I met incredibly kind people along the way and had wonderful conversations at the places I stayed. We didn't just talk about cycling, but also about dementia. Everyone knew someone, a brother, mother, or grandfather, living with dementia. Each story was unique and left a lasting impression on me.

I am proud to have raised more than EUR 5,000 for Alzheimer Nederland. I am also proud of having physically and mentally managed to cycle 1,400 kilometres solo. And, of course, I am incredibly proud of my grandparents, who were willing to share their story with the media. So vulnerable, yet beautifully expressed.

This adventure has only strengthened my commitment to supporting people with dementia and their loved ones. Not only did the cycling journey do this, but also the conference and the presentation I had the opportunity to give there. Hearing personal experiences and learning about new research findings showed me that much is being done, and that much more is still needed. I am grateful to be able to contribute to this cause at Alzheimer Nederland.

29 OCTOBER:

Golnaz Atefi's fantastic Rolling for Dementia campaign is highlighted at the Alzheimer Europe Conference

Golnaz Atefi is a dementia researcher affiliated with Maastricht University and University College London. In October 2024, she attended the Alzheimer Europe Conference in a unique way to present her PhD findings She skated over 1,000 km from the north of the Netherlands to the conference in Geneva to raise awareness about dementia. Along the journey, she interviewed many healthcare professionals and community members with the aim of bridging research and community to promote dementia awareness as part of the #RollingforDementia campaign. She wrote the following words about the campaign and about her experience of the journey and attending the conference:

"I believe that any effort toward dementia awareness is valuable and essential, especially given the significant knowledge gaps that exist. However, awareness campaigns are likely to have a greater impact when they focus on building connections and promoting a sense of togetherness, as we are all in this together. The epic journey of skating 1,000 km as part of the Rolling for Dementia campaign has gathered a valuable collection of perspectives, knowledge, memories, and photographs from many healthcare professionals, community members, and stakeholders.

"Part of this effort included raising awareness through educational content across various social media channels. A video created as part of the campaign was released during the Alzheimer Europe conference and featured in the plenary session on October 10. It was one of the highlights of my career to see the video showcasing the connections among all the interviewees and conveying the powerful message of the importance of inclusivity in dementia care and research.

"The overwhelming support the campaign received has led to new connections and interest from professionals and people with lived experience who wish to share their stories for dementia awareness. As a result, the campaign will extend into next year, and I will continue skating. I am enthusiastic about the new knowledge and adventures ahead, and we are considering engaging initiatives such as photo galleries, educational booklets, and more videos. I am grateful to Alzheimer Europe for their support in promoting this campaign, and I look forward to presenting further findings from both my research and the campaign."

Alzheimer Europe congratulates Golnaz and her team on this incredible feat and was delighted to highlight the Rolling for Dementia campaign by screening a video at the start of the fourth plenary session of the event. You can view the video, here: https://youtu.be/nJcHHTlJz4Y

29 OCTOBER:

Enjoyed 34AEC? Check out some of the news, blogs and social media from the event!

We are delighted to share some of the news and media from the 34th Alzheimer Europe Conference (#34AEC), which was held in Geneva from 8 to 10 October, on our website. Please visit: https://www.alzheimer-europe.org/conferences/past-conferences/2024-geneva/news-and-media-34aec

SPONSOR OF THE MONTH

Alzheimer Europe would like to express its gratitude to a new Gold sponsor for its 2025 activities:

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Read more about sponsorship opportunities here:
https://www.alzheimer-europe.org/about-us/governance/finances/2024-sponsorship-opportunities

ALZHEIMER EUROPE

7 OCTOBER:

Alzheimer Europe launches 46th edition of Dementia in Europe magazine at Annual Conference in Geneva

On 7 October 2024, we were pleased to launch the 46th edition of our policy magazine, Dementia in Europe, together with a supplement about clinical trials on dementia. The magazine was published to coincide with the 34th Alzheimer Europe Conference (#34AEC), which took place in Geneva, Switzerland, from 8-10 October. All delegates received a copy of the magazine and supplement in their conference bags.

This is another packed edition of the magazine and we are excited to share many interesting developments at national and European level across policy, research, culture, advocacy, dementia care and lived experience.

We are particularly grateful to the Royal Palace in Belgium for their kind collaboration in providing information and official photographs, including our main cover image, for an article about an important round table event which recently took place at the Palace, presided by His Majesty the King of the Belgians.

To mark #34AEC, we also have a dedicated section called "Spotlight on Switzerland", in which readers can find out more about the work being done in this year's conference host country. Dementia in Europe magazine issue 46 can be downloaded, here:
https://bit.ly/DementiaInEurope46

7 OCTOBER:

Alzheimer Europe publishes a new supplement on Clinical Trials to accompany its latest Dementia in Europe magazine

On 7 October 2024, our new Dementia in Europe policy magazine and our supplement about clinical trials were published to coincide with the 34th Alzheimer Europe Conference.

We are very pleased to welcome the readers of our Dementia in Europe magazine to a special supplement about clinical trials on dementia in Europe. Clinical trials are essential for the development of new ways to prevent, diagnose and treat dementia. As the number of people affected by Alzheimer's disease (AD) continues to rise, we hope you will share our interest and commitment to this important area of research.

In our previous supplement on clinical trials, published in 2019, we highlighted the complexity surrounding access to clinical trials, noting that information was not easily accessible for people wishing to participate in research. To address this, we introduced our Clinical Trials Watch, a user-friendly, web-based resource that consolidates up-to-date information on

Phase II and Phase III clinical trials investigating drugs for the treatment of AD and other forms of dementia in an accessible and easy-to-understand format. This 2024 supplement continues our commitment to highlighting the pivotal role of clinical trials in AD.

The supplement on clinical trials can be downloaded, here: https://bit.ly/AE_ClinicalTrialsSupplement

7 OCTOBER:

The European Working Group of People with Dementia says farewell to Real Larnou and Pia Knudsen

On 7 October, during the 34th Alzheimer Europe Conference in Geneva, Switzerland, Kevin Quaid (Chair of the European Working Group of People with Dementia, EWGPWD) had the difficult task of officially saying farewell on behalf of the EWGPWD to Pia Knudsen (Denmark). Pia has young onset dementia and is passionate about her work as an arts teacher. Her membership in the EWGPWD concluded in June, after having been a member of the group since October 2022. Kevin expressed his heartfelt gratitude to Pia for her significant contribution to the EWGPWD during this time.

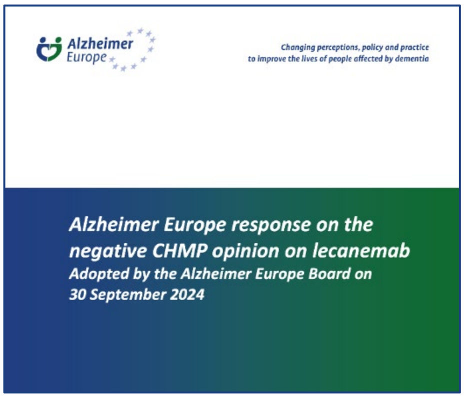
In September 2024, Real Larnou (Belgium) decided, for personal reasons, to step down from the EWGPWD. Prior to his diagnosis of dementia in 2021, Real had worked in the banking industry and as a relationship manager for the agricultural sector. He was nominated by Ligue Nationale Alzheimer Liga to join the EWGPWD in October 2022.

All members of the EWGPWD and the Alzheimer Europe team wish Pia and Real well on their future journeys and hope that their paths cross again. Pia and Real's dedication and hard work have left a lasting impact, and they will always be remembered fondly.

Pictured: (top) Pia Knudsen and Kevin Quaid at this year's Alzheimer Europe Conference in Geneva; (bottom) Real Larnou (second from left) with other EWGPWD members at last year's Alzheimer Europe Conference in Helsinki

14 OCTOBER:

Alzheimer Europe responds to the negative opinion on lecanemab by the European Medicines Agency



Alzheimer Europe

Changing perceptions, policy and practice to improve the lives of people affected by dementia

Alzheimer Europe response on the negative CHMP opinion on lecanemab

Adopted by the Alzheimer Europe Board on 30 September 2024

On 26 July 2024, the Committee for Medicinal Products for Human use (CHMP) of the European Medicines Agency (EMA) issued a negative opinion on the marketing authorisation application of Eisai for lecanemab for the treatment of early Alzheimer's disease. In its opinion, the CHMP identified the risk of amyloid-related imaging abnormalities (also known as ARIA) as a major issue. In particular, the CHMP was concerned by the elevated risk of ARIA in people with two copies of the Apo-Eε4 gene. The CHMP concluded that the benefits of lecanemab in slowing cognitive decline did not outweigh the risks of serious adverse events.

The negative opinion came as a disappointment to the AD community, which had high expectations about the introduction of new treatments in Europe. Alzheimer Europe regrets the negative opinion from the CHMP and hopes that the re-examination will result in a decision that will allow people with early AD in the European Union, Iceland, Liechtenstein and Norway to access treatment options available in other countries, with stringent eligibility criteria and efficient monitoring of side effects to ensure patient safety.

Following on from the CHMP opinion, Alzheimer Europe has engaged in discussions with its member organisations, Working Groups and other members of the dementia community, developing an official response to the opinion outlining key concerns and a call to action. The response, which was shared with Emer Cooke, the Executive Director of EMA, and members of the CHMP on 11 October, identifies six key areas of concern for Alzheimer Europe:

- **Excluding European patients from treatments available in other countries risks exacerbating inequity.** The CHMP opinion is at odds with the decisions by regulatory authorities in the United States, Japan, China, South Korea, Hong Kong, Israel, the United Arab Emirates and the United Kingdom, which means that wealthier patients may seek treatment abroad; creating disparities, and worsening health inequalities.
- **Excluding all patients from anti-amyloid treatments restricts patients' autonomy and reduces choice.** Patients and their families deserve the right

to engage in discussions with their physicians, to make informed decisions about treatment based on their individual circumstances, preferences and values.

- **Risk management approaches, including restriction of eligibility and monitoring, are feasible and available.** Alzheimer Europe welcomes the approach by the CHMP to highlight the safety concerns for anti-amyloid treatments. Regulatory authorities that have approved lecanemab shared these concerns and have therefore incorporated robust risk management measures, ensuring that those who may benefit most are not unduly denied treatment options, whilst protecting individuals who are at greatest risk of ARIA and other side-effects.
- **Despite the safety concerns, anti-amyloid therapies can provide meaningful benefits to patients and carers.** The Clarity AD trial met all its primary and secondary endpoints, with modest reductions in clinical decline on scales such as CDR-SB and ADAS-Cog14. Lecanemab treatment was also associated with a preservation of health-related quality of life on the EQ-5D-5L and QOL-AD scales, measures that are often deemed to be more meaningful for patients and carers.
- **The availability of disease-modifying treatments could support the improvement of clinical pathways for care and treatment.** In the absence of an approved disease-modifying treatment for AD, European healthcare systems may have fewer incentives to adapt and improve, reducing access to a timely diagnosis that will further disadvantage people with AD and other forms of dementia in Europe.
- **A negative regulatory decision risks reducing the attractiveness of Europe as a centre for research and development.** Although Europe remains an important region for clinical trials, a majority of studies are conducted in the US, with 112 active trials compared to fewer than 50 in Europe. A negative decision may impede the momentum of ongoing research, prompting companies to deprioritise Europe as a location for clinical trials.

In its response to the EMA, Alzheimer Europe acknowledges the very real safety risks associated with treatment and indicates that it would welcome a restriction to the indication of lecanemab to exclude those at greatest risk of ARIA, such as individuals carrying two copies of the ApoEε4 gene and those receiving treatment with anticoagulants. Alzheimer Europe also calls on the CHMP to require drug manufacturers to develop risk management plans that include controlled access programmes, balancing access to innovative treatments with rigorous safety oversight. Moreover, Alzheimer Europe calls for the establishment of post-authorisation safety studies and patient registries for long-term collection of real-world evidence on lecanemab and other anti-amyloid drugs, including outcomes that are meaningful for patients and their carers. Download our full response to the CHMP decision, here:

https://www.alzheimer-europe.org/sites/default/files/2024-10/2024-09-30_response_to_negative_chmp_decision_on_lecanemab.pdf

28 OCTOBER:

Mark the dates for our 2025 conference in Bologna!

Mark the dates!

35th Alzheimer Europe Conference

Connecting science and communities: The future of dementia care

Bologna (Italy), 6 - 8 October 2025

We invite you to mark the dates of the 35th Alzheimer Europe Conference, “Connecting science and communities: The future of dementia care”, taking place in Bologna, Italy, from 6 - 8 October 2025. A short video, introducing Bologna as our next host location, was shown. You can view it, here:

https://www.youtube.com/watch?si=Nqv58pGnpy6ivKtT&v=oghB0JVyP7I&feature=youtu.be

AE NETWORKING

30 SEPTEMBER-1 OCTOBER	Dianne and Sarah attended the Predictom GA (Erlangen, Germany)
1-2 OCTOBER	Jean attended the Anniversary Meeting of the Social Cluster Association (Budapest, Hungary)
1-2 OCTOBER	Ange participated in the Prague Gerontological Day of the Czech Alzheimer's Association (Prague, Czechia)
3 OCTOBER	Owen attended a meeting of the European Non-Governmental Organisations hosted by the European Disability Forum
7-8 OCTOBER	Alzheimer Europe organised a meeting of the European Group of Governmental Experts on Dementia (Geneva, Switzerland)
7-8 OCTOBER	Alzheimer Europe hosted a meeting of the European Alzheimer's Disease Consortium (Geneva, Switzerland)
8-10 OCTOBER	Alzheimer Europe organised its 34th Annual Conference "New Horizons – Innovating for Dementia" (Geneva, Switzerland)
8-10 OCTOBER	Jean met with representatives of Biogen, Bristol Myers Squibb, Eisai, Global Brain Health Institute, Lilly, Novo Nordisk and Roche (Geneva, Switzerland)
16 OCTOBER	Sébastien and Lukas attended a high-level policy and networking event organised by the European Patient Forum (Brussels, Belgium)
21 OCTOBER	Cindy and Soraya attended the Pattern-Cog General Assembly meeting
22 OCTOBER	Cindy attended the ACT EU multi-stakeholder platform annual meeting
22 OCTOBER	Lukas attended a consultation regarding non-communicable diseases organised by the WHO Regional Office for Europe
23 OCTOBER	Ana, Sarah and Cindy attended the Multi-Memo & Lethe educational event
23 OCTOBER	Jean and Owen attended a meeting of the EU4Health Civil Society Alliance
23 OCTOBER	Ange joined the online launch of the WHO Preferred Product Characteristics of Blood-Based Biomarkers
23-24 OCTOBER	Dianne attended the Assessing Capacity to Consent Study meeting (Oslo, Norway)
28 OCTOBER	Lukas attended the Inaugural non-State actor event organised by the WHO Regional Office for Europe
28-29 OCTOBER	Dianne and Ange attended the EPND GA (Madrid, Spain)
28-29 OCTOBER	Cindy attended the AI-Mind General Assembly Meeting (Madrid, Spain)
29 OCTOBER	Ange joined a Steering Committee meeting for the AD-RIDDLE project (Madrid, Spain)
29 OCTOBER-1 NOVEMBER	Jean and Ange attended the CTAD (Clinical Trials in Alzheimer's Disease) Conference (Madrid, Spain)

Help us give a voice to people with dementia

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EU PROJECTS

24-25 SEPTEMBER:

TClock4AD doctoral students attend summer school on Public Engagement and dissemination

On 24-25 September, the “Targeting Circadian Clock Dysfunction in Alzheimer’s Disease” (TClock4AD) Doctoral Network held a summer school on Public Engagement and dissemination. The event was hosted by the Mario Negri Institute for Pharmacological Research in Milan, Italy.

TClock4AD is an interdisciplinary, intersectoral and international network composed of 13 beneficiaries and 14 associated partners. Funded by Horizon Europe’s Marie Skłodowska-Curie Doctoral Networks, the consortium focuses on the search of new drugs targeting circadian clock dysfunction in Alzheimer’s disease and aims to train 17 doctoral students from 13 countries (i.e., Bangladesh, China, Croatia, Cyprus, France, Greece, India, Israel, Italy, Pakistan, Portugal, Russia and Spain). The project employs a multidisciplinary approach, focusing on 5 key scientific themes:

1. Developing novel artificial intelligence, proteolysis targeting chimeras and multitarget-based strategies for new circadian clock drug candidates
2. Developing novel drug delivery nanotechnologies, which take into consideration circadian clock timing
3. Investigating innovative in vitro & in vivo, as well as organ-on-chip techniques, for preclinical validation of circadian clock drugs
4. Gaining insights into the molecular mechanisms of the circadian clock in Alzheimer’s disease and associated drug responses in animal models
5. Developing innovative biotech business models and exploitation strategies.

During the summer school, students participated in workshops and training sessions aimed at enhancing their skills in public communication. They learned how to effectively communicate complex scientific topics to the wider public using social and mass media platforms. Additional talks addressed modern communication techniques in the pharmaceutical sector, fundraising communication and scientific journalism. Students also received dementia-friendly recommendations through a talk on the importance of involving people with dementia in research. An insightful presentation on the role of women in science and the importance of gender-inclusive communication free from unconscious bias was also delivered. Cindy Birck, Alzheimer Europe’s Project Officer, was invited to share her insights on the role of Public Engagement and Dissemination in Alzheimer’s disease research. For more information on the TClock4AD Doctoral Network, please visit:

https://site.unibo.it/tclock4ad/en

25 SEPTEMBER:

The Manneken Pis feels the Urge to Act

On 25 September, the "Manneken Pis" (a famous statue and tourist attraction) in Brussels was dressed as a urologist by the European Association of Urology, as part of the Urge to Act campaign, which aims at raising awareness about continence health problems. Continence health problems are very common conditions which affect 55-60 million Europeans. Making tangible changes to European health policy on continence health is vital to improving diagnoses and optimising patient outcomes through increased prevention, better care and access to supportive interventions and treatments.

This same day, the coalition held a reception in Brussels, where a Guidance Document for Policymakers was launched, and the campaign also launched a new infographic at the same time. The organisers at the European Association of Urology had the pleasure of screening a video by Antonella Sberna MEP, Vice-President of the European Parliament and substitute member of the ENVI Committee, which deals with Environment and Public Health topics. MEP Sberna mentioned the importance of expert groups making policymakers aware of public health topics, and the importance of having a multidisciplinary alliance to bring the experience and knowledge needed.

Read more about the event of 25 September: https://uroweb.org/news/the-mannekin-pis-feels-the-urge-to-act

Learn more about An Urge to Act and help spread awareness of continence health: https://uroweb.org/an-urge-to-act.

30 SEPTEMBER:

PREDICTOM Partners meet for Annual Consortium Meeting in Germany

The annual meeting of the PREDICTOM ("Predictive Dementia Diagnostics and Treatment through Customisable Cognitive and Biomarker Screening") project took place in Erlangen (Germany) on 30 September and 1 October 2024. The meeting offered an opportunity for representatives from all 30 partner organisations, including academia, healthcare, industry, and non-profit sectors, to come together to discuss various work packages, address current challenges, and share progress made since the last annual consortium meeting in Stavanger, Norway.

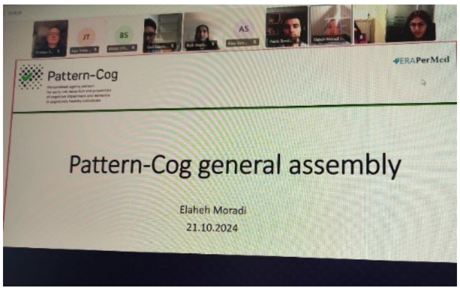
Among the key topics discussed over the two days, several stood out:

- The presentation of the Triple IHI Initiative: Anna-Katherine Brem from King's College London (UK) and Stavanger University Hospital (Norway) introduced this initiative, which aims to create synergies between the IHI-funded research projects: PREDICTOM, AD-RIDDLE, and PROMINENT, helping to avoid duplication of effort. These three projects collectively aim to transform healthcare by leveraging advanced diagnostics, personalised treatments, and comprehensive care strategies to address neurodegenerative diseases like Alzheimer's disease. Dianne Gove from Alzheimer Europe presented the organisation's plans for Public Involvement (PI) activities, which we proudly lead in all three innovative projects. The PREDICTOM consortium meeting was joined online by Francesca Mangialasche, who discussed AD-RIDDLE, and Linus Jönsson, who presented PROMINENT, highlighting how their combined efforts can produce a more significant impact.
- Interactive work package-specific poster workshop: During this session, work package partners sat down together in one room to reflect on project progress, assess deviations from the description of activities, evaluate risks and discuss how to mitigate them, and decide how to efficiently approach upcoming challenges. The workshop activity ended with a poster pitch presentation in the plenary and transitioned into a poster session where everyone could vote for their favourite poster. The poster on the PI contribution to the project, designed with artistic flair by Sarah Campill (pictured), was the clear winner of the competition. The Lygature team's creative idea certainly help kickstart many important conversations.

Within the consortium, Alzheimer Europe leads the work package named "Involve" which concerns the facilitation of PI and Ethics activities. Dianne Gove (Director for Public Involvement and Ethics) and Sarah Campill (Public Involvement Officer) joined the annual meeting on behalf of Alzheimer Europe.

21 OCTOBER:

Pattern-Cog project convenes a virtual General Assembly meeting



Pattern-Cog general assembly

Elaheh Moradi

21.10.2024

On 21 October, the Pattern-Cog project hosted its yearly General Assembly meeting, bringing together representatives from six partner organisations to discuss progress and updates on the collaborative initiative. The overarching goal of this project is to improve dementia prevention strategies by developing support tools for the detection of earliest signs of impeding cognitive decline which would allow early and personalised multidomain interventions.

The meeting commenced with a warm welcome from Jussi Tohka, the Coordinator of the Pattern-Cog project. Each leading partner presented updates on their respective work packages, highlighting key activities, progress and future work. Alzheimer Europe (AE) is actively involved in several work packages of the Pattern-Cog project, focusing on communication and dissemination as well as Public Involvement. The meeting was attended by AE Project Officer Cindy Birck and Public Involvement Officer Soraya Moradi-Bachiller. During the meeting, Cindy presented the recent and ongoing communication work, while Soraya provided insights into recent discussions with the Pattern-Cog Advisory Board, which is composed of members of the European Dementia Carers Working Group. As the meeting concluded, Jussi expressed gratitude to all attendees for their active engagement and fruitful discussions.

To learn more about the Pattern-Cog project, visit the project website:

https://pattern-cog.eu/

22 OCTOBER:

LETHE project launches webinar series with a first edition on digital solutions to reducing the risk factors causing dementia

On 22 October, partners of the LETHE project are proud to announce the launch of a webinar series open to the public.

To kick off the series, the first webinar is titled "Digital Solutions to Reducing the Risk Factors Causing Dementia - The Lethe Approach" and will be held on the 15 November from 10.30-11.30 am CET. It will introduce the project activities and focus on how the project uses digital solutions, such as the Lethe App, to reduce the risk factors that cause dementia. We will also discuss how we capture patient data, use the Clinical Trial Monitoring System (CTMS) and how the consortium is using the EGI Fedcloud for the Lethe infrastructure. There will be a panel discussion and a chance for the audience members to ask their own questions to our speakers. Don't miss out, come and join! Register for the Webinar:

https://docs.google.com/forms/d/e/1FAIpQLScx3eFzSw13HTBjGdsTlTWj11Cjp5ao8KaMIPf7Bv6zQ9ACDw/viewform

Title: Digital Solutions to Reducing the Risk Factors Causing Dementia - The Lethe Approach

Date and time: 15 November 2024, 10.30-11.30 CET

Agenda:

1. Interventions:
    - The Lethe Approach - Jon Switters, The Lisbon Council
    - Capturing Patient Data Through Apps - Vassilis Loukas, FORTH
    - The Lethe App, CTMS and Risk Profile - Hannes Hilberger, FH Joanneum
    - Using EGI Fedcloud for the Lethe Infrastructure - Ignacio Lamata Martínez, EGI.
2. Panel Discussion
3. Questions from the Audience.

23 OCTOBER:

Members of Multi-MeMo and LETHE Advisory Boards participate in an informative event

On 23 October, members of the LETHE and Multi-MeMo Advisory Boards (AB) participated in a joint informative event focused on dementia medications. The online session was organised by Alzheimer Europe (AE) and provided an opportunity for AB members to deepen their understanding of current developments in this important area.

We extend our thanks to Prof. Alina Solomon from the University of Eastern Finland, for her engaging presentation. She covered the latest therapies in development, including lecanemab and donanemab, two anti-amyloid therapies currently under regulatory review in Europe for early Alzheimer's disease.

The presentation was followed by an interactive Q&A session, allowing members to engage in a lively discussion about the topics raised. AE Public Involvement Lead Ana Diaz, Public Involvement Officer Sarah Campill and Project Officer Cindy Birck, participated in the meeting.

The LETHE project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement no 101017405.

https://www.lethe-project.eu/

25 OCTOBER:

Contributing to Alzheimer's research through the REBALANCE project: join our survey and interviews

The REBALANCE project is investigating an innovative approach called focused ultrasound (FUS) for Alzheimer's disease. This research explores how FUS could help clear proteins like beta-amyloid, which are associated with Alzheimer's, potentially reducing the disease's impact and improving quality of life for those affected. Currently in preclinical stages, the project aims to better understand the effects of FUS.

Ethical considerations are central to REBALANCE, ensuring careful evaluation of the transition from preclinical findings to early-phase human studies. To ensure inclusion of all stakeholders' views on ethical aspects and needs, the project also conducts focus groups and interviews with basic scientists, clinicians, and people living with dementia and their supporters.

Seeking input from people with dementia and their carers

An important focus of the REBALANCE project is gathering insights from those directly affected by Alzheimer's disease or other types of dementia. We are conducting online interviews with people living with dementia and their carers to better understand their experiences and perspectives on needs, expectations and concerns about available and potentially new treatments of the disease.

These insights will contribute to developing an ethical decision-making tool for researchers and, in close collaboration with Alzheimer Europe, carefully crafted, balanced information on ongoing research studies for people living with dementia and the general public, ensuring that all communications avoid exaggerated or unfounded health claims.

What to Expect from the Interviews:

Topics: Diagnosis, daily life with dementia, healthcare interactions, available support, perspectives on research participation, attitudes, expectations and hopes of innovative therapies
Format: Online (via Zoom or similar platform)
Duration: 40-60 minutes (flexible, with breaks if needed)
Confidentiality: All interviews will be anonymised.

If you are interested in participating, please contact Anna Žabicka from the University of Latvia at: anna.zabicka@lu.lv

Survey for Physicians: your views on innovative Alzheimer's treatments

As part of the REBALANCE project, a survey has been launched for physicians. It seeks to understand physicians' perspectives, including risk perceptions on new treatment approaches and how these might influence their practice. If you are a physician who cares for patients with dementia and would like to participate, please follow this link: https://tinyurl.com/ADtreatment . The survey is anonymous and will take approximately 10 min. Your views will help the project to better understand the expectations and concerns surrounding emerging treatments for Alzheimer's disease.

The REBALANCE project is funded under the 2022 JPND Call for "Understanding the Mechanisms for Non-Pharmacological Interventions". The project is supported through the following national funding organisations: Academy of Finland, Finland; Brain Canada Foundation; Luxembourg National Research Fund; The Netherlands Organization for Health Research; French National Research Agency and the Latvian Council of Science. The project will be carried out during 1 April 2023–31 December 2026.

You can find more information about the REBALANCE project here: https://uefconnect.uef.fi/en/group/rebalance/

EU project acknowledgements

A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon 2020, Horizon Europe, the Innovative Medicines Initiative 2 (IMI2) Joint Undertaking (JU), or the Innovative Health Initiative (IHI) JU. Projects funded through the IMI2 or IHI JU receive support from EU Research & Innovation programmes, as well as industry federations and other contributing partners. Please visit the project website(s) listed below for specific details on the organisations, federations and funders providing support for individual projects.
The projects in this newsletter are:

AD-RIDDLE – grant agreement 101132933 (https://ad-riddle.org/)
AI-Mind - grant agreement 964220 (https://www.ai-mind.eu/)
EPND - grant agreement 101034344 (https://epnd.org/)
LETHE - grant agreement 101017405 (https://www.lethe-project.eu/)
PREDICTOM - grant agreement 101132356 (https://www.predictom.eu/)
Prominent - grant agreement 101112145 (https://www.ihi-prominent.eu/)

The **Multi-MeMo** project is supported by the Luxembourg National Research Fund (INTER/JPND22/17107181/Multi-MeMo) under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu

The **PatternCog** project was supported by the Luxembourg National Research Fund (INTER/PerMed21/15748787/Pattern-Cog), under the frame of ERA PerMed (https://pattern-cog.eu/)

MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE

Currently, the total number of MEPs in the European Alzheimer's Alliance (EAA) stands at **76**, representing **21** Member States of the European Union and seven out of eight political groups in the European Parliament. Alzheimer Europe is grateful to the Co-Chairs of the EAA: Nina Carberry MEP (Ireland, EPP), Tilly Metz MEP (Luxembourg, Greens/EFA), Romana Jerković MEP (Croatia, S&D), Hilde Vautmans MEP (Belgium, Renew Europe) and Dainius Žalimas (Renew, Lithuania) for their leadership and for hosting the organisation's European Parliament lunch debates on dementia. Alzheimer Europe would also like to thank the following MEPs for their support of the EAA:
Belgium: Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria**: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D). **Croatia**: Biljana Borzan (S&D); Romana Jerković (S&D); Tonino Picula (S&D). **Cyprus**: Costas Mavrides (S&D). **Czechia**: Tomáš Zdechovský (EPP). **Denmark**: Kira Marie Peter-Hansen (Greens/EFA); (Christel Schaldemose (S&D). **Estonia**: Urmas Paet (Renew Europe). **Finland**: Merja Kyllönen (GUE/NGL). **France**: François-Xavier Bellamy (EPP); Mélissa Camara (Greens/EFA); Laurent Castillo (EPP); David Cormand (Greens/EFA); Marie Dauchy (PFE); Christophe Gomart (EPP); Catherine Griset (PFE); Céline Imart (EPP); Isabelle Le Callennec (EPP); Nadine

Morano (EPP); Philippe Olivier (PFE); Mounir Satouri (Greens/EFA); Majdouline Sbai (Greens/EFA); Marie Toussaint (Greens/EFA). **Germany**: Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Manuela Ripa (Greens/EFA); Terry Reintke (Greens/EFA). **Greece**: Elissavet Vozemberg-Vrionidi (EPP). **Hungary**: Tamás Deutsch (PFE); Enikő Győri (PFE); Kinga Gál (PFE); György Hölvényi (EPP), András Kulja MEP (EPP). **Ireland**: Barry Andrews (Renew Europe); Lynn Boylan (GUE/NGL); Nina Carberry (EPP); Luke 'Ming' Flanagan (NI); Billy Kelleher (Renew Europe); Aodhán Ó Ríordáin; Maria Walsh (EPP). **Italy**: Brando Benifei (S&D); Caterine Chinnici (EPP); Carlo Fidanza (ECR); Aldo Patriciello (PFE). **Lithuania**: Petras Auštrevičius (Renew); Vilija Blinkevičiūtė (S&D); Dainius Žalimas (Renew). **Luxembourg**: Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Isabel Wiseler-Lima (EPP). **Poland**: Elżbieta Katarzyna Łukacijewska (EPP); Anna Zalewska (ECR). **Portugal**: Marta Temido (S&D); Catarina Martins (GUE/NGL). **Slovenia**: Matjaž Nemec (S&D); Irena Joveva (Renew Europe); Vladimir Prebilič (Greens/EFA); Marjan Šarec (Renew); Milan Zver (EPP). **Spain**: Rosa Estaräs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ana Miranda Paz (Greens/EFA). **Sweden**: Pär Holmgren (Greens-EFA); Jonas Sjöstedt (S&D).

EUROPEAN ALZHEIMER’S ALLIANCE

28 OCTOBER:

New Co-Chairs and MEPs join European Alzheimer’s Alliance

Alzheimer Europe is delighted to announce that three Members of the European Parliament (MEPs) have joined the European Alzheimer’s Alliance (EAA). The EAA is a non-exclusive, multinational and cross-party group, with two key objectives:

- Send out the political message that concerted action is needed in the field of prevention, diagnosis and treatment of Alzheimer’s disease, as well as research and social policies.
- Promote actions to give dementia priority at European and national level.

We are delighted to welcome:

- Romana Jerković MEP (S&D, Croatia) as a Co-Chair of the EAA (pictured, left)
- András Kulja MEP (EPP, Hungary) as a member of the EAA (pictured, middle)
- Dainius Žalimas MEP (Renew, Lithuania) as a Co-Chair of the EAA (pictured, right).

We very much look forward to working with them to prioritise dementia as a policy priority at a European level.

A full list of Co-Chairs and members of the EAA is available at: https://www.alzheimer-europe.org/policy/european-alzheimers-alliance/members

EU DEVELOPMENTS

14 OCTOBER:

Council of the EU adopts European disability card directives

On 14 October, the Council of the European Union has adopted two new directives, one establishing the European Disability Card and the other broadening the European parking card for persons with disabilities to all EU countries.

The Cards aim to ensure equal access to special conditions or preferential treatment for persons with disabilities during short stays throughout the EU, for example, reduced or zero entry fees, priority access, assistance and reserved parking spaces. The directive extends these provisions to non-EU citizens who legally reside in EU countries, meaning they will also be able to use these cards during short-term stays in other member states.

National authorities will be responsible for issuing physical and digital European disability cards in an accessible format. The cards will be recognised throughout the EU as proof of disability or entitlement to specific services based on a disability. The European parking cards for persons with disabilities will be produced in physical format, with member states having the option to also issue them in digital format.

The directives will be signed by both the Council and the European Parliament and will enter into force following publication in the EU’s Official Journal. Member states will have two and a half years to adapt their national legislation and three and a half years to apply the measures.

Further details on the Cards are available at: https://www.consilium.europa.eu/en/press/press-releases/2024/10/14/european-disability-card-and-european-parking-card-for-persons-with-disabilities-council-adopts-new-directives/

16 OCTOBER:

European Patients' Forum hosts high-level policy event "Towards a Patient-Centred EU Mandate: Health Policy with and for Patients"

The event was organised by the European Patients' Forum (EPF) and provided a platform for a series of talks from Members of the European Parliament (MEPs), representatives from the European Federation of Pharmaceutical Industries and Associations (EFPIA), the European Medicines Agency (EMA), stakeholders, and non-governmental organisations (NGOs). Discussions centred around the critical issue of patient-centred policy, public involvement, and research within the European Union.

During the event, Alzheimer Europe staff members Lukas Duffner, Project Officer and Sebastien Libert, Public Involvement Officer met with four MEPs attending: Adam Jarubas (Poland), András Kulja (Hungary), Ondřej Dostál (Czechia) and Vytenis Andriukaitis (Lithuania). They advocated for dementia to be prioritised in the MEPs' mandates, communicating about the recently developed Helsinki Manifesto by Alzheimer Europe, and offering guidance to MEPs who were interested to join the European Alzheimer Alliance.

Sebastien and Lukas also talked to the Chair of the Latvian Network of Patient Organisations Baiba Ziemele, and inquired about national developments regarding the formation of a national Alzheimer's association. Additionally, they connected with colleagues from EPF to exchange ideas, discuss common challenges, and explore potential collaborations.

Overall, the EPF's high-level policy event provided valuable insights into the current landscape of patient-centred health organisations and policy and allowed Alzheimer Europe to advocate for the specific needs of people living with dementia. Engagement with MEPs and colleagues from EPF will contribute to Alzheimer Europe's efforts to advance the recognition of dementia as an important priority for EU research, policy, health and social care programmes.

Alzheimer Europe is grateful to EPF for the invitation to this well-organised and interesting event and for valuable insights and networking opportunities.

17 OCTOBER:

European Public Health Alliance publishes report on policy-making for health in the EU as part of Better Regulation for Better Health project

Between art and science:
Policy-making for health in the EU

The European Public Health Alliance (EPHA) has published a report on policy-making for health in the EU, in collaboration with the University of Edinburgh, as part of the Better Regulation for Better Health project (BRBH), funded by UK Research & Innovation (UKRI).

The health-relevant policy adopted by the European Union (EU) is shaped by a complex policy-making system that seeks to balance the diverse interests, values, and needs of a broad range of societal groups. This system resembles a development between science and art, processing both scientific evidence and political narrative. Recognising that health and politics are inextricably linked, one of EPHA's strategic objectives is to improve the policy-making system and increase civil society involvement in it - by advocating for change and building capacity within the public health community. The report therefore contributes to this objective by introducing the key framework that structures the EU policy-making system – Better Regulation – and its relevance to health civil society advocacy activities and engagement.

The Better Regulation agenda is the EU's 'good governance' programme, shaping the process by which laws should be adopted and the common ends that they should serve. It is the framework that requires that, for instance, impact assessments be conducted for all new initiatives with significant expected impacts, options for simplification to be explored in all evaluations of existing policy, and all new administrative burdens to be offset by reduced burdens elsewhere. It is also a political agenda – a commitment to reducing 'red tape', simplifying legislation, controlling the 'stock and flow' of EU law, and reducing the EU's perceived image as a creator of bureaucracy and burden. As such, it shapes the political and technical space within which health policy is conceived, developed and adopted.

With a view to increasing awareness of and engagement with Better Regulation and the politics of the EU policy-making system among the public health community, the aim of this report is to provide a first point of reference for those seeking to understand how EU health policy-making structures work, what role the Better Regulation agenda has in shaping them, how they are relevant to health advocacy and objectives, and what tangible engagement with Better Regulation the public health community might seek.

The report has defined key recommendations for improved engagement of civil society with the Better Regulation programme, including the fact that it should be part of civil society's advocacy activities, and for civil society to engage with elements such as the Regulatory Scrutiny Board. Civil society should also re-claim the terminology of the agenda, and define what is understood as better, i.e., push for the narrative that better regulation should mean regulation that delivers improved health outcomes. Overall, civil society should also call for more transparency, and continue their work on improving civic space, to support their participation in policymaking.

The full report is available here: https://epha.org/between-art-and-science-policy-making-for-health-in-the-eu/
The project will continue with the publication of a toolkit to support civil society in engaging with the Better Regulation agenda.
Contacts:
Clémentine Richer Delforge clementine.richer-delforge@epha.org
Dr Eleanor Brooks Eleanor.Brooks@ed.ac.uk

POLICY WATCH

1-2 OCTOBER:

"Common Speaking Experts" international conference on dementia in Budapest brings together policymakers, healthcare and social care professionals to meet and exchange ideas

The Social Cluster Association organised an international conference on dementia in Budapest from 1-2 October 2024, under the title "Common Speaking Experts". The first afternoon featured an expert meeting, providing an opportunity for invited national and international speakers, including healthcare and social care professionals, and policymakers, to meet and exchange ideas. Conferences often allow little time for discussion among presenters due to the focus on the audience. Here, however, participants had the opportunity to learn from each other and share experiences from different countries' dementia strategies, including both their achievements and challenges.

Among the international guests were Katarzyna Wieczorowska-Tobis and Slavomir Tobis from Poland, René Thyrian from Germany, Iva Holmerová (former Chairperson of Alzheimer Europe) from Czechia, Jean Georges, Executive Director of Alzheimer Europe, Charles Scerri (former Vice-Chairperson of Alzheimer Europe) from Malta. Pavlos Theodorakis, representing the World Health Organization (WHO) and Norbert Zilka from the Slovak Alzheimer Society joined the discussions online.

On the second day, the conference continued in a hybrid format; one-third of the 380 registered participants attended in person, while the rest joined online. Following opening remarks from State Secretaries Zsófia Koncz (Family Affairs) and Attila Fülöp (Social Care Policy) the keynote speaker Prof. Balázs Gulyás, neurobiologist and president of the Research Network, gave a keynote address on the background and reasons for preserving cognitive vitality.

In a roundtable discussion, Jean Georges (pictured, with the microphone), spoke of the importance of engaging with policymakers, while Iva Holmerová (pictured, to the right of Jean Georges) shared insights from Czechia, emphasising the importance of resource allocation and the challenges of human resources. Deputy State Secretary Attila Beneda, responsible for family policy, explained why dementia care is significant for Hungarian family policy. Ágnes Egervári (pictured, to the right of Iva Holmerová) representing the Social Cluster Association, highlighted the importance of supporting caregiving families, increasing public knowledge on dementia, and valuing caregivers. The discussion also covered research and training, as well as the recognition of dementia as a disability.

The plenary lectures and sessions addressed topics including research, treatment options for dementia, prevention methods, and non-pharmacological therapies, as well as the new opportunities offered by digitalisation and Artificial Intelligence (AI).

While Hungary does not yet have an official dementia strategy, significant progress has been made in recent years. Neither the healthcare system nor the social care system alone can address the challenges of dementia, as the majority of caregiving responsibilities fall to families; around 94% of the approximately 250,000 people with dementia live at home. The Social Cluster Association is encouraged by the fact that family policy in Hungary recognises the importance of supporting individuals living with dementia and their caregivers. This conference represents an important milestone in moving these efforts forward.

1-3 OCTOBER:

Lausanne XI Workshop focuses on opportunities for action and collaboration

ADDING URGENCY TO ACTION
LAUSANNE XI
1 - 3 October 2024
Opportunities for Action & Collaboration

From 1 to 3 October 2024, Alzheimer's experts gathered at the Lausanne XI Workshop in Lausanne, Switzerland. Participants engaged in collaborative discussions aimed to identify obstacles, establish actionable solutions, measure progress, and commit to accountability in tackling the most urgent issues faced by Alzheimer's disease today. The event showcased innovative ideas, diverse perspectives, and deep expertise, all focused on advancing the fight against Alzheimer's disease.

Lausanne X was organised under the auspices of the Organisation for Economic Co-Operation and Development (OECD) and supported by The Global CEO Initiative on Alzheimer's Disease (CEOi), Alzheimer's Disease International, and The World Economic Forum. The workshop is a world stage for solutions-oriented dialogue on Alzheimer's-related efforts and is a platform for Alzheimer's stakeholders to report on progress, hold each other accountable, align on opportunities for collaboration, and drive change.

Read the full conference report, here:
https://mcusercontent.com/60520355e3a9761add0b9d1d9/files/2fb20ae9-3cb0-14a7-4e0b-8d46a37da9c0/Lausanne_XI_Summary.pdf

16 OCTOBER:

G7 launches Solfagnano Charter on disability inclusion

On 16 October, G7 members, under the Italian Presidency, adopted the Solfagnano Charter, a first-of-its-kind document setting out priorities in relation to disability inclusion, as well as commitments for countries in attendance at the meeting.

The document is inspired by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and contains eight priorities under which more specific actions and policies are discussed to improve the inclusion and empowerment of people with dementia. The priority areas are:

- Inclusion as a priority issue in the political agenda of all countries
- Access and accessibility
- Autonomous and independent life
- Enhancement of talents and work inclusion
- Promotion of new technologies
- Sports, recreational and cultural dimensions of life
- Dignity of life and appropriate community-based services
- Prevention and management of emergency preparedness and post-emergency management situations, including climate crises, armed conflicts and humanitarian crises.

The full charter is available at: https://www.g7disabilityinclusion.it/en/the-charter-of-solfagnano/

SCIENCE WATCH

30 SEPTEMBER:

"It's just getting the word out there" – Self-disclosure by people with young-onset dementia

In September 2024, Gianna Kohl, Wei Qi Koh, Katrina Scior, and Georgina Charlesworth's published a paper exploring how people with young-onset dementia disclose their diagnosis to others and how this self-disclosure evolves over time. They chose an exploratory qualitative approach for their study and used semi-structured interviews with nine participants, analysed through a narrative approach. The participants were between 55 and 69 years old (female = 5; male = 4) and at the time of the study they were diagnosed for one to ten years. Their types of young-onset dementia included Alzheimer's disease, frontotemporal dementia, posterior cortical atrophy, and vascular dementia.

Even though each participant had a unique narrative, there were some similarities between them, the cross-case themes that emerged from the analysis were:

1. "It is just an illness like any other"
2. Changes over time, and
3. Impact of disclosure on interpersonal relationships and support.

Key findings of the paper included the general trend of acceptance of the diagnosis. The participants disclosed it openly, though reactions varied. They talked about how stigmatising responses often led to social withdrawal, while positive reactions encouraged them to further disclose information about their diagnosis. Peer support groups and advocacy activities were crucial in supporting self-disclosure. The researchers concluded that creating dementia-friendly communities and integrating empowerment interventions and peer support into post-diagnostic care to aid self-disclosure and improve the quality of life for individuals with young-onset dementia are essential.

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0310983

1 OCTOBER:

A new study suggests that time of day matters when sampling plasma biomarkers to monitor Alzheimer's disease progression or to evaluate the outcome of a treatment

Plasma biomarkers, such as Aβ40, Aβ42 and phosphorylated tau, offer a promising tool for diagnosing Alzheimer's disease (AD), recruitment for clinical trials and monitoring the disease progression and treatment outcome in people living with the disease. However, whether these plasma biomarker levels change with the time of the day is still unknown.

In a new study published in the journal of Translational Psychiatry (Nature), a team of researchers led by Dr Derk-Jan Dijk from the Surrey Sleep Research Centre, University of Surrey (UK), investigated whether timing could affect plasma biomarker levels and, therefore, AD diagnosis and monitoring of disease progression.

This research involved 38 participants of which eight were people living with mild AD, six were partners, carers or supporters of people with AD and 24 were cognitively healthy adults. All the participants were aged between 50 and 85 years old. Cognitively healthy participants were recruited via the Surrey Clinical Research Facility Database. Participants with mild AD were approached via Surrey and Borders Partnership NHS Foundation Trust memory services. After a screening visit to assess eligibility, participants attended a clinical facility and took part in two studies. In the first study, participants had two blood samples drawn, one sample collected in the evening and another in the morning. In the second study, blood samples were drawn at three-hour intervals starting nine hours before habitual bedtime and continuing 15 hours after habitual bedtime.

Researchers found that, in the second study, there was a significant effect of the time of the day when blood samples were collected for all biomarkers analysed. In general, the lowest values were observed in the morning. In the case of p-tau217, the lowest values were observed in the morning after wake-up time, whereas the highest levels were reported in the afternoon and evening. For Aβ40, Aβ42 and NFL, peak levels were observed during the nocturnal sleep period whereas lowest levels occurred in the morning hours (upon waking for Aβ40 and Aβ42, and in mid-morning for NFL). A significant effect of the group of participants was observed for p-tau217 with the highest levels observed in participants with mild AD.

Although this study shows that levels of commonly used plasma biomarkers in dementia research vary with the time of the day when samples are collected and despite the presence of factors such as light/dark cycle, sleep/wake state and meals, larger sample sizes are needed to determine the shape of this variation, the difference across biomarkers and the factors responsible for this variation. Until then, researchers recommend that the reference limits for biomarkers used in dementia research are established in samples collected while fasting and in the morning.

https://www.nature.com/articles/s41398-024-03084-7

3 OCTOBER:

Higher exposure to air pollution associated with more brain atrophy, Dutch study suggests

Exposure to air pollutants has been identified as a potential target for risk reduction at the policy level, as outlined in the recently updated report from the Lancet Commission on Dementia Prevention, Intervention, and Care. In recent years, the body of research on environmental risk factors for dementia, such as exposure to air and noise pollution, has expanded, urging policymakers to prioritise public health initiatives to reduce these exposures and to implement stricter environmental regulations.

A newly published epidemiological study, led by doctoral student Jens Soeterboek from Maastricht University (Netherlands), investigated the relationship between ambient air pollution and cognitive functioning as well as brain volume. The researchers used data from more than 4,000 participants of the Maastricht study, an observational study of residents in the

South of the Netherlands, and matched it to postcode-level air pollution exposure data. Specifically, they assessed exposure to particulate matter smaller than 2.5 μm and 10 μm (e.g., as emitted by traffic, livestock stables, industry, and wood burning), nitrogen dioxide (e.g., mostly emitted by traffic and industry), and soot (e.g., as emitted by wood burning, industry and traffic). Cognitive functioning was evaluated using neuropsychological tests of memory, executive function, and attention. They also underwent structural MRI scans.

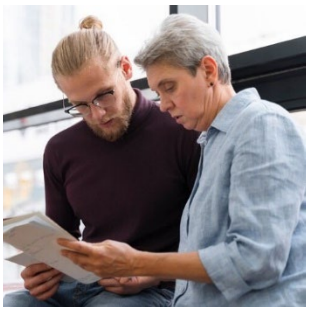
The study found no association between the level of exposure to these pollutants and cognitive function. However, participants exposed to higher levels of particulate matter smaller than 2.5 μm showed a higher degree of brain atrophy on average. “These particularly small particles can enter the bloodstream, affecting the circulatory system and potentially causing systemic inflammation, which can impact brain integrity," Jens Soeterboek explains. The associations were independent of age, sex, lifestyle, socioeconomic status, and the degree of urbanisation - the population density in a given area.

"Our findings suggest that exposure to small particulate matter within mid to high ranges, within our specific sample, may be associated with brain morphology," he explains. While some studies have linked elevated levels of neuroinflammation and proteins associated with Alzheimer’s disease to air pollution exposure, further investigation into potential underlying mechanisms is needed.

The study was published open access in the journal Environment International and can be read here: https://www.sciencedirect.com/science/article/pii/S0160412024006342?via%3Dihub

8 OCTOBER:

Sage Therapeutics announces discontinuation of dalzanemdor for AD, following LIGHTWAVE study results



On 8 October, Sage Therapeutics, a biopharmaceutical company focused on delivering brain health therapies, announced top-line results from its Phase II LIGHTWAVE study evaluating dalzanemdor in Alzheimer’s disease (AD). The 12-week, randomised, double-blind, placebo-controlled trial included 174 participants from US and Puerto Rico, aged 50-80, with mild cognitive impairment (MCI) or mild dementia due to AD.

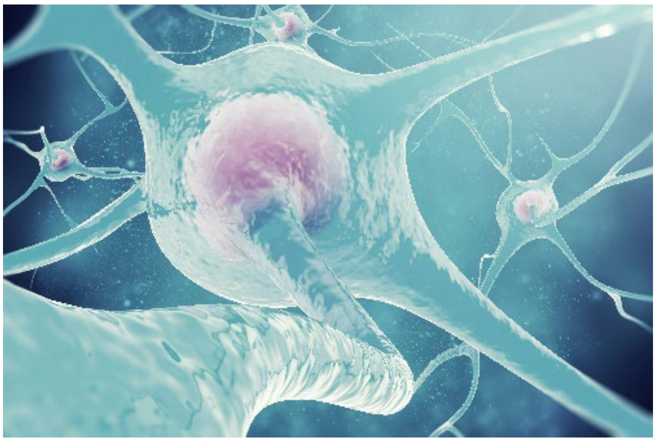
The primary aim of the study was to assess changes in cognitive function using the Wechsler Adult Intelligence Scale Fourth Edition (WAIS-IV) Coding Test. Top-line results showed that dalzanemdor failed to demonstrate statistically significant improvement in cognitive function compared to placebo after 12 weeks. The majority of treatment emergent adverse events were mild to moderate in severity. Additionally, no meaningful differences were observed in exploratory endpoints including the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) and the Montreal Cognitive Assessment (MoCA) total scores.

As a result of these findings, Sage Therapeutics does not plan further clinical development of dalzanemdor in AD. The company continues to investigate the drug in other indications, including Huntington’s disease, with top-line results from the Phase II DIMENSION study expected later this year.

https://investor.sagerx.com/news-releases/news-release-details/sage-therapeutics-announces-topline-results-phase-2-lightwave

10 OCTOBER:

NULISAseq platform assessed for multi-analyte biomarker detection in Alzheimer’s disease



On 10 October, a paper titled “Multi-analyte proteomic analysis identifies blood-based neuroinflammation, cerebrovascular and synaptic biomarkers in preclinical Alzheimer’s disease” was published in Molecular Neurodegeneration. The study, led by researchers from the University of Pittsburgh, highlights the use of the NULISAseq CNS disease panel, a novel proteomic method capable of simultaneously measuring 116 analytes related to neurodegenerative diseases, including core Alzheimer's disease (AD) biomarkers like tau and amyloid-beta, as well as non-core markers for processes such as neuroinflammation and cerebrovascular dysfunction. The research, involving 113 participants from southwestern Pennsylvania, identified blood-based biomarkers that could support earlier detection and monitoring of AD. The platform shows potential for broader use in research, aiding in the study of preclinical stages of the disease. The article is open access and can be read here: https://molecularneurodegeneration.biomedcentral.com/articles/10.1186/s13024-024-00753-5

16 OCTOBER:

Australia’s Therapeutic Goods Administration (TGA) rejects lecanemab for early AD

On 16 October, the Therapeutic Goods Administration (TGA) of Australia issued a public statement about the decision not to register lecanemab for the treatment of people with early Alzheimer’s disease (mild cognitive impairment and mild dementia due to Alzheimer's disease). While lecanemab has been approved in the US, Japan, China, South Korea, Hong Kong, Israel and Great Britain, the European Medicines Agency (EMA) issued a negative opinion on the marketing authorisation application for lecanemab in late July.

In its opinion, the TGA found that the reduction in disease progression was not deemed significant enough to provide a meaningful clinical benefit or to outweigh the associated safety risks. In particular, the TGA considered the frequent occurrence of amyloid-related imaging abnormalities (ARIA) in people receiving lecanemab. This decision was supported by independent expert advice from the TGA's Advisory Committee on Medicines (ACM).

Eisai, the sponsor of lecanemab, has announced its intention to request a reconsideration of this decision, with the TGA expected to issue a final decision within 60 days of the request.

https://www.tga.gov.au/news/news/tgas-decision-not-register-lecanemab-leqembi

23 OCTOBER:

Anti-amyloid drug, Donanemab, is approved by the UK Medicines and Healthcare products Regulatory Agency

Today, the UK Medicines and Healthcare products Regulatory Agency (MHRA) announced the approval of donanemab for the treatment of the mild cognitive impairment and mild dementia stages of Alzheimer’s disease (AD). This approval, which comes two months after lecanemab was approved by the MHRA, was based on data from the Phase 3 TRAILBLAZER-ALZ2 study, which enrolled 1,736 participants with early AD. As well as amyloid plaques, participants had evidence of tau protein accumulation in their brains and were accordingly stratified into two groups (low-medium or high tau).

TRAILBLAZER-ALZ2 demonstrated a 35% slowing of clinical decline for participants with low to medium levels of tau, equating to a 4.4-month delay in disease progression. In the overall population, there was a 22% slowing of clinical decline, as measured on the iADRS scale for cognitive and functional impairment. Similar to other anti-amyloid drugs, donanemab treatment was associated with the development of amyloid-related imaging abnormalities (ARIA), a potentially severe side effect linked to brain microbleeds and swelling. The incidence of ARIA in TRAILBLAZER-ALZ2 was much higher in participants carrying two copies of the ApoE4 gene (40.6%) compared to participants who weren’t ApoE4 carriers (15.7%).

In its press release, the MHRA explained that donanemab meets acceptable standards of safety, quality and efficacy. The regulator stated that people should receive genetic testing to ascertain their ApoE4 status, and that people carrying two copies of ApoE4 should not receive donanemab. The MHRA also ruled out treatment of people who are on anticoagulants, as the risks in this group are considered to be greater than the benefits of receiving donanemab. A controlled access programme was mandated, with obligatory enrolment of patients in a central registration system during treatment. A post-authorisation safety study will also be conducted, particularly focusing on the safety and benefit-risk profile of donanemab in routine clinical practice.

While the marketing of donanemab in the UK has been authorised by the MHRA, the widespread use of donanemab on the National Health Service (NHS) was refused, according to draft guidance issued by the National Institute for Health and Care Excellence (NICE). In a press release published today, NICE explained that donanemab does not currently demonstrate value for the NHS, based on present evidence on clinical benefit and cost-effectiveness of the drug. In particular, they cited uncertainties on how much benefit donanemab provides to patients, how long benefits last after stopping treatment, and the costs of administering donanemab on the NHS. A consultation on the draft guidance will close on 20 November, with the Committee expected to provide a final ruling in early 2025.

Alzheimer Europe welcomes the positive decision by the MHRA, which means that two disease-modifying therapies for AD will now be available to patients in the UK. The organisation appreciates the considered approach that the MHRA has taken to manage risks associated with donanemab treatment and hopes that NICE will recommend NHS coverage for donanemab in its final decision, enabling equitable access to these innovative medicines for people with AD in the UK.

Donanemab is currently under review at the European Medicines Agency, with an outcome anticipated during the first quarter of 2025.

Read the MHRA press release:
https://www.gov.uk/government/news/donanemab-licensed-for-early-stages-of-alzheimers-disease-in-adult-patients-who-have-one-or-no-copies-of-apolipoprotein-e4-gene

Read the NICE press release:
https://www.nice.org.uk/news/articles/new-alzheimer-s-treatment-donanemab-does-not-currently-demonstrate-value-for-the-nhs-says-nice

24 OCTOBER:

Applications open for Cohort II of the AD Data Initiative's William H. Gates Sr. Fellowship

The William H. Gates Sr. Fellowship, an initiative from the Alzheimer's Disease (AD) Data Initiative, offers early- and mid-career researchers an opportunity to apply data science approaches to advance research on Alzheimer's disease and dementia. Named in honour of William H. Gates Sr., this fellowship will provide support for projects that leverage generative AI techniques, including multi-modal learning, explainable AI, and privacy-preserving methods.

William H. Gates Sr. Fellows will receive USD 100,000 (EUR 91,700 approx.) in funding over two years, and can also avail of support to develop professional networks, identify mentors, present findings, assist with peer-reviewed publications, and more. Fellows will perform their proposed analysis on the AD Data Initiative's AD Workbench, a cloud-based data discovery and analysis platform equipped with tools, resources, compute power and data storage space.

Applications are open globally, with the AD Data Initiative actively seeking applicants from diverse backgrounds and countries, promoting a collaborative and inclusive approach to solving complex dementia-related challenges. Applications close on December 1, 2024, and those interested are encouraged to visit the AD Data Initiative website for more details on eligibility, application guidelines, and potential research topics. For more information, visit http://bit.ly/GatesSrADFellowship

29 OCTOBER:

New research explores the motivations of family carers involved in Patient and Public Involvement activities to improve palliative dementia care

Patient and Public Involvement (PPI) is a critical component of dementia research and advocacy. By empowering people with dementia and their families, PPI ensures that research, policies, and interventions reflect the perspectives, views, concerns and worries of those who are most affected.

Recent research published by a Canadian research team on 6 September in the journal Research Involvement and Engagement delves into the motivations of family carers who participated in the Strategic Guiding Council (SGC) of the Family Carer Decisions Support study. This international group of family carers was initially recruited to provide insights into improving palliative care for people with advanced dementia.

Through in-depth interviews with ten family carers part of the SGC, the researchers identified three key motivations for these carers to engage in PPI activities. Firstly, the carers valued the opportunity to learn from each other and from healthcare professionals. Secondly, they were driven by a desire to share their experiences and provide support to others. Thirdly, they aimed to use their collective voice to advocate for improved end-of-life care.

Overall, this study underscores the significant impact that PPI can make. By involving family carers in research and decision-making, PPI can help improve the quality of care and support for people with dementia and their families, develop more relevant and effective interventions, and foster a more inclusive and compassionate healthcare system. It can also empower individuals to further advocate for their rights and needs.

The publication can be freely accessed here:
https://doi.org/10.1188/14.ONF.545-54

MEMBERS' NEWS

20 SEPTEMBER:

Alzheimer Scotland organises its Annual Conference in Edinburgh

On 20 September, Alzheimer Scotland welcomed almost 400 delegates to the Edinburgh International Conference Centre (EICC) for its Annual Conference. The theme for the day was "Your choice, Your voice, Your future" and there was a wide range of informative sessions and presenters.

At Alzheimer Scotland, the voice of lived experience is at the heart of everything the organisation does. The conference was opened by Tommy McLean (Scottish Dementia Working Group) and Maureen Huggins (National Dementia Carers Action Network). Each shared their personal experiences - Tommy as a person with dementia and Maureen as a former carer. There was also a ministerial address from Maree Todd MSP, Minister for Social Care, Mental Wellbeing and Sport who joined by video link.

The Opening Session keynote speaker was Scott Mitchell (pictured), Peoples Champion, Dame Barbara Windsor Dementia Mission. In 2022, the UK Government announced a National Dementia Mission that Mr Mitchell had helped campaign for in his late wife's name – "The Dame Barbara Windsor Dementia Mission" (Barbara Windsor, 1937-2020, was a well-known English film and television actress). Mr Mitchell spoke about their life together and about the impact that Alzheimer's disease had on them. He also spoke about his campaigning work and his commitment to the Mission.

Alzheimer Scotland Chief Executive, Henry Simmons also addressed the conference, speaking about the overarching conference theme and discussing each of the individual session themes: "Protecting personhood", "Practice evolutions & innovations", "The future is green", "The future of long term care", and "Dementia research in Scotland".

The full conference report can be read on Alzheimer Scotland's website:
https://www.alzscot.org/news/our-annual-conference-2024
All sessions were recorded and can be viewed, here:
https://www.alzscot.org/news/www.alzscot.org/conference24

1 OCTOBER:

The Alzheimer Society of Ireland welcomes funding in Budget 2025

On 1 October, the Irish Budget for 2025 was announced and The Alzheimer Society of Ireland (The ASI) was pleased to see increased investment in dementia care. The ASI welcomes EUR 2.3 million funding with more budget for day care at home and in the community, ring-fencing of 20% of new home support hours for dementia, additional dementia advisers, and expanded diagnostic services.

Commenting on the announcement, Andy Heffernan, CEO at The ASI said: "The Alzheimer Society of Ireland is very grateful to Minister of State Mary Butler TD for securing the EUR 2.3 million in funding for dementia-specific support in #Budget2025. It will make a huge impact on the lives of people with dementia and family carers across Ireland and we really appreciate the Minister's ongoing support and understanding. The Alzheimer Society of Ireland is committed to working with the Government, the HSE, the All-Party Oireachtas Group on dementia, which is chaired by Senator Fiona O'Loughlin and people affected by dementia to meet the challenges that dementia presents in Irish society and budget 2025 marks another step in this journey."

Given the rising need for dementia supports and services, this extra funding in Budget 2025 will build on the investment in recent years and will help address the challenges faced by people impacted by dementia across the country. As Ireland heads into an anticipated general election in the coming months, The ASI looks forward to highlighting the needs of people impacted by dementia and continuing the work of ensuring dementia remains a political priority in Ireland. Read Mr Heffernan's statement on Budget 2025 in full:

https://alzheimer.ie/creating-change/political-campaigns/equal-dementia-supports-building-on-momentum-in-2025/

Pictured: Members of The ASI's operations team at the launch of The ASI's Pre-Budget Submission

3 OCTOBER:

Greece organised many activities during World Alzheimer's Month

The members of the Panhellenic Federation of Alzheimer's Disease and Related Disorders organised many successful events to celebrate World Alzheimer's Month this year. Throughout Greece, speeches, festivals, memory walks, informational stands, free memory tests and many more awareness activities were hosted by Alzheimer's associations across the country.

Alzheimer Athens held its 3rd Alzheimer's Festival with great success at the Stavros Niarchos Foundation Cultural Center in Athens. This years' motto was "Dementia. We give the right stigma!". Thousands of people visited the festival, memory tests and a series of activities and events were conducted to inform, raise awareness and entertain adults and children alike. The Greek Minister of Health Adonis Georgiadis attended the event, alongside other stakeholders. Professor

Magda Tsolaki, Chair of the Panhellenic Federation of Alzheimer's Disease and Related Disorders was present too and spoke with participants. Alzheimer Athens also carried out informational activities in Peiraias, Neo Irakleio, Thrakomakedones and Arta. The association "Nestor" held an interesting photography exhibition and the integrated Alzheimer's and Related Disease Unit of the "Apostoli" association conducted free memory tests for participants over 60 , at the elderly open care centres of Mandra-Idyllia, Athens, Florina and other towns around Greece.

Alzheimer Hellas organised a successful informative event called "Talk with the experts about dementia", at the Archaeological Museum in Thessaloniki, which focused on prevention factors and useful ways to cope with the disease. A Memory Walk took place, with attendees holding balloons and marching through the main streets of the city, ending at the well-known sculpture "Umbrellas" which was illuminated in honour of World Alzheimer's Day. Alzheimer Hellas also held informational stands in "Balkan Square", for a week in Menemeni square, and in the Youth Volunteering Festival "Connected we stand". Memory tests were also carried out in the city centre together with City College and the YMCA, while speeches were made at the "17th Festival Art4." Several other informative speeches were also conducted in towns close to Thessaloniki, such as Serres, Trilofos, N. Triglia, Ierissos.

Frontizo association organised an informative event in Patra entitled "Dementia-Let's talk openly", and co-organised an intergenerational workshop with creative activities and games that were exciting for both younger and older participants. They also screened a motion picture about the disease.

Alzheimer's Larissa launched an information campaign with the motto "Erase the stigma, stay strong, stay united". Information stands, speeches and public awareness visits peaked with the 6th Memory Walk in Larissa, which took place in a festive and encouraging atmosphere.

REMIND-Alzheimer Chalkida association gave a presentation on the radio station of the Holy Metropolis of Chalkida and participated in the Alzheimer Athens Dementia Festival, as well as an event called "Prevention Paths" in Chalkida, featuring four esteemed doctors who discussed cognitive development, brain and heart health. Various memory and behavioural symptoms were highlighted to prompt individuals, especially those over 55, to seek professional advice to protect their memory and mental health. This years' activities underscored the vital role of community support in addressing Alzheimer's disease.

SOFPSI association carried out a 3-day festival called "Let's make mental health and dementia a priority for all" to celebrate World Alzheimer's Day and World Mental Health Day 2024 in Serres. A true celebration of information, prevention and awareness through a multitude of parallel actions addressed to children, teenagers, adults and elderly people in a continuous *in vivo* interaction.

EPSEP association gave a speech on prevention and primary symptoms entitled "Learning about dementia - the importance of physical and mental health" in Ioannina. an informational stand and media coverage contributed to their campaign.

Alzheimer's Association Panakeia carried out blood-pressure tests and memory tests on World Alzheimer's Day, in the centre of Rhodes to promote the importance of healthy living.

The **Day Care Center of Alzheimer Hellas** in Katerini organised an interesting, informative speech about dementia prevention and on diagnosis and treatment services provided by the structure.

15 OCTOBER:

CEAFA launches the 'Pacto por el Recuerdo' to make an urgent call to adopt real measures in the fight against Alzheimer's disease

On 15 October, the Confederación Española de Alzheimer y otras Demencias (CEAFA) presented the 'Pacto por el Recuerdo'. In this document, CEAFA makes an urgent call to action to the Spanish health and political authorities to adopt immediate measures to make progress in the fight against Alzheimer's disease (AD). In the 'Pacto por el Recuerdo', CEAFA calls for the creation of an official census of people with AD, to facilitate access to early diagnosis, and guarantee equal access to care, pharmacological and non-pharmacological treatments. These demands are presented as essential responses to improve the quality of life of the more than 1.2 million people living with AD in Spain, as well as the 5 million informal carers and supporters who look after them.

At the launch event of the ‘Pacto por el Recuerdo’, Mariló Almagro, President of CEAFA, stressed the importance of society understanding the scale of the problem: "Alzheimer's is everyone's business, those diagnosed, families, those who have the disease without even knowing it and, therefore, society as a whole".

One of the aspects highlighted in the document is the need to move towards an early diagnosis of the disease, overcoming the challenges that make this difficult, i.e. lack of specialised centres and insufficient time and resources for doctors in primary care practices.

Together with an official census and an early diagnosis of the disease, equal access to the best treatments is another key point of the ‘Pacto por el Recuerdo’. People with AD and their families should be provided with equitable and flexible access to pharmacological and non-pharmacological treatments from the very early stages of the disease. Equal access to care and the importance of family carers were also emphasised in the document and during the launch event. Currently, the unpaid work performed by the informal carers and supporters could represent up to 3% of the national Gross Domestic Product. This highlights the importance of recognising and supporting informal carers not only financially, but with services and resources to alleviate the burden they face on a daily basis.

With the right tools, it is possible to improve the quality of life of those affected by AD. However, for this to be possible, CEAFA stresses that it is essential that measures such as those proposed in the ‘Pacto por el Recuerdo’ are implemented.

22 OCTOBER:

Alzheimer Iceland organises Annual Conference and shares news about ongoing awareness campaign and other activities

On 21 September, Alzheimer Iceland held its Annual Conference under the motto “Take matters into your own hands” where over 200 persons met onsite and 200 attended online.

The Association also organises regular educational meetings onsite and streamed online, as well as educational meetings for institutions and companies. and maintains a powerful website and social media presence.

The Association has recently launched an app (translated from a Norwegian model) accessible to everyone and free of charge. It is available in Icelandic for people who want to increase their knowledge of dementia and interact with or care for people with dementia. The app is divided into three parts: observations, word art and good advice. Leaflets for people with dementia and brochures concerning the Association and its service centre called “Seiglan” are also available.

In 2023 the Association launched an awareness campaign called “Remember the path…” on social media and all over Iceland. They held a sponsored concert to raise money for the Association and many more engaging events. As a part of the dementia-friendly society in Iceland, Alzheimer Iceland collaborated with municipalities to paint benches in purple in their local communities on busy walking routes. On the purple benches there is a QR code that leads to their website (www.alzheimer.is) and a sentence: “Remember the path…” This initiative raised much attention and many municipalities joined, and the benches are now part of their society. A “benchwalk” was held last spring, people walked from one bench to the Association offices joined by people with dementia and their relatives, many of them dressed in purple.

LIVING WITH DEMENTIA

24 OCTOBER:

Annick Germeys, member of the European Dementia Carers Working Group, shares an extract from an interview she did for the latest magazine of the Flemish Alzheimer Association

My husband Geert, who lives with young-onset dementia, and I are determined to advocate for better help and support for everyone affected by (young-onset) dementia. We do this by focusing on the glass half full, rather than half empty, but the journey after diagnosis remains one of overcoming obstacles and learning to cope with loss. I had the opportunity to passionately and convincingly speak about my commitment to breaking the taboo that still surrounds (young-onset) dementia, the difficult road after diagnosis, and the urgent need for a decisive policy that provides caregivers with the support they deserve, during an interview with Olivier Constant from the Alzheimer Liga Vlaanderen. The interview appeared in this autumn's edition of their magazine. I would like to share a part of it with you:

You witnessed the beginning of the 'Flemish Working Group for Caregivers of People with Dementia,' established in June last year by Alzheimer Liga Vlaanderen. How do you reflect on the first year of the working group?

When I attended the inaugural meeting in June 2023, I didn't have a clear idea of what to expect. That changed quickly as everyone began discussing the needs that arise after a (young-onset) dementia diagnosis. Each member of the group shared the challenges they faced and what could be improved. We brainstormed potential solutions and how things could be better. As people with this experience, we were given the chance to make our voices heard. Alzheimer Liga Vlaanderen translated these needs into a comprehensive file, from which a memorandum and later a basic manifesto were drafted. In the past few months, we've been able to present this to our policymakers. First-hand information, clearly formulated needs, and calls for action made this a fruitful year.

With the manifesto 'We Don't Just Want to Survive, We Want to Live,' you recently made a clear appeal to policymakers. What are the most pressing challenges that, in your opinion, need urgent attention?

When my husband was diagnosed with young-onset dementia, we were told that there is no cure. Medication was prescribed to slow the disease's progression, and we were referred to our general practitioner. That was it. Medically, everything was clear, but the question remained: what now? This turned out to be an experience shared by many members of the working group. As caregivers, we had to immediately take matters into our own hands and arrange everything for our partners from the day of diagnosis. A dynamic care plan and a case manager are indispensable in this situation.
Personally, I found my way through various websites. You read that right: I had to actively search and piece everything together myself. Gathering information, repeatedly proving my husband's illness, and dealing with unnecessary paperwork, all while my partner needed me the most. A person with (young-onset) dementia still has a life, but can no longer live it independently. As a caregiver, you take over what your partner can no longer do. You take control of their life. But in addition to taking over various tasks, you also want to ensure that their cognitive reserves are not depleted. You spend time maintaining social connections, staying active and creative, and engaging in enjoyable activities to fill the days. In short, everything to keep the brain stimulated, while also cherishing the time you still have together.

What motivated you to join the 'European Dementia Carers Working Group' of Alzheimer Europe, and what plans are in place for the near future?

As a member of the 'Flemish Working Group for Caregivers of People with Dementia' and the partner of someone with young-onset dementia, I want to share my experiences and knowledge and collaborate with others internationally to find solutions. At the same time, I want to bring this knowledge back to the Flemish working group. My involvement with this group comes from a sincere desire to help others and advocate for the needs of caregivers like myself. Through my personal experiences and professional background, I believe I can offer a valuable perspective and contribute to identifying the practical barriers and the support we need on a daily basis. Together, I hope we can make a difference in the lives of those affected by dementia and their loved ones.

If you could share one important message with the reader based on all your experiences, what would it be?

Don't put off until tomorrow what may no longer be possible then. Enjoy what is still possible today. Focusing only on what cannot be done will only lead to negativity. Do fun things and make the most of the situation.

To our policymakers: A care tsunami is coming, and the system is already under pressure. Invest in the many caregivers and ensure a solid financial and support framework for those diagnosed with dementia. Prioritize awareness around (young-onset) dementia. Invest in prevention, as a healthy and active lifestyle has a significant positive impact on dementia.

DEMENTIA IN SOCIETY

1-10 OCTOBER:

International Psychogeriatric Association organises third annual Older Adults Mental Health Awareness Week

Today, there are roughly 1 billion people aged 60 or older, a number now projected to exceed 2 billion by 2050. Of these, approximately 20% will have mental health conditions such as dementia, depression, anxiety and substance use, often complicated by physical and psychosocial comorbidities culminating in disability. In addition, recent reports from the WHO show that half of all people are ageist against older persons.

As professionals working with mental health of older adults, International Psychogeriatric Association (IPA) leaders are focused on raising awareness around the impact of ageism on health outcomes and to support the protection of human rights of older persons with mental health conditions. IPA will use their platform to highlight both older persons mental health issues as well as promoting healthy ageing initiatives around the globe through Older Adult Mental Health Awareness Week from 1 October through 10 October 2024.

For 40 years, the IPA has been a leader in supporting the mental health and wellness of older persons globally. IPA's multidisciplinary members across the world provide care, education, and innovation across multiple segments of society enabling older persons to increase their longevity and to remain a vital resource to their families, communities, and economies.

4 OCTOBER:

Irish carer Carmel Geoghegan co-chairs event on assisted dying

This report was written by Carmen Elise Pocknell, a student from University College Cork, with comments from Carmel Geoghegan:

On Wednesday, September 18th, I was fortunate enough to participate in an event co-chaired by the remarkable Carmel Geoghegan from Dementia Ireland and the diligent Janie Lazar from End of Life Ireland. We gathered in the intimate Studio Theatre at the Lexicon Library and Cultural Centre in Dun Laoghaire, by the wonderful seaside in Ireland. The venue perfectly facilitated a deep exploration of the challenging realities many face during difficult life moments.

Canadian, Jule Briese shared her deeply impactful journey she experienced alongside her husband, Wayne Briese, shedding light on the significance of Assisted Death for their family and the influence of legislation on those living with dementia. The grace and serenity with which Jule shared her story felt like a privilege in itself. She also introduced us to the one-act play "Ten Minutes to Midnight," which allowed audience members from diverse backgrounds to grasp the complexities involved in navigating such significant experiences and highlighted the critical importance of communication.

What resonated with me most was the profound exchange of hopes and desires regarding assisted dying. The conversation was infused with remarkable compassion, empathy, and goodwill from both partners, highlighting the beauty of their bond and the importance of such meaningful discussions.

As a neuroscientist focused on reminiscence therapy in my doctoral studies and a contributor to the 'In-Touch' Horizon Europe trial, where we provide sensory activities for individuals with advanced dementia, I often reflect on the essential role of connection. A person-centred approach and environment during these moments are essential. While I recognise the profound structural changes the brain undergoes in late-stage dementia, this in no way diminishes the essence of the individual within. It is the simple, heartfelt interactions that continue to hold transformative power.

However, it is only through direct observation that one truly grasps the importance of honouring each unique individual, understanding their history, and recognising how it shapes their present choices.

Jule and Wayne exemplified this beautifully, embracing a deep bond (see photos). Their love, the tranquillity they provided for one another, and their ability to make decisions together up until the end serve as a powerful reminder to cherish the moments we have.

As a young neuroscientist immersed in the study of dementia, I find it essential to reflect on the myriad dimensions of these experiences. Dementia can touch the lives of individuals at any stage of life, and it is vital that we honour the autonomy to navigate our own paths. Understanding the choices available to us, while also considering the wishes and needs of those we care about, is fundamental. Furthermore, the role of support and structured guidance in this journey cannot be overstated; they can truly make a difference in how we approach these complex situations. For a deeper understanding, I highly recommend reading Jule Briese's book, "Shared Conversations – Glimpses into Alzheimer's."

To conclude, I want to share a resonant quote by Wayne Briese that will remain with me throughout my professional journey:

"Quality time is more important than time; life needs to be meaningful, not just a series of existences."

We must strive to be better at supporting one another, take the time to truly understand each individual's unique journey, and foster connections not just in greetings, but also in farewells.

Thank you, Jule and Wayne, for graciously inviting us into your beautiful world and demonstrating what true love means.

Thank you, Jule, for your strength, kindness, and honesty.

I also extend my gratitude to the organisers for making this event possible and for driving change.

Lastly, thank you to the wonderful audience members who shared their stories, enriching the experience for all. It's vital that we engage in these conversations, and I remain hopeful for the future.

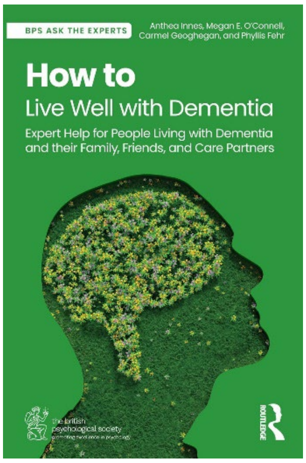
Carmel, as Founder of Dementia Ireland noted that "the reasoning was always about getting all the information out there, no gatekeeping, we are obliged to get the full account to the public and let individuals choose for themselves, It is all about CHOICE."

She also commented that End of Life Ireland are a very open and diverse group of individuals who are opening up the conversation in Ireland and "working hard to get a choice for those who wish to avail of assisting dying. We know many travel abroad to avail of this and at the moment the only other option here is suicide."

PUBLICATIONS AND RESOURCES

8 OCTOBER:

New book "How to Live Well with Dementia" is published



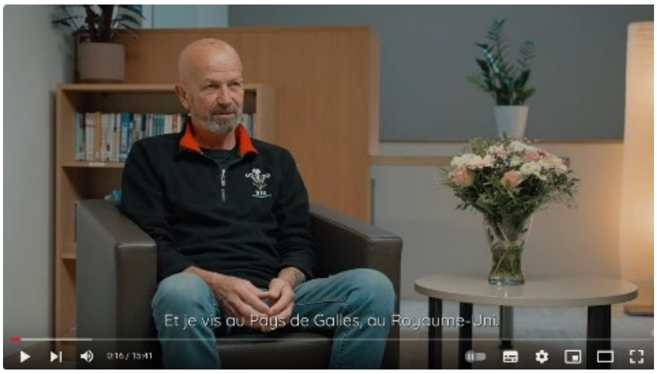
"How to Live Well with Dementia: Expert Help for People Living with Dementia and their Family, Friends, and Care Partners" provides an array of essential guidance about the different aspects of dementia for all whose lives are touched by dementia, including people living with dementia and their support network.

Following an effective Q&A framework, this book offers valuable, easy-to-navigate guidance on the burning questions that those living with a dementia diagnosis and their carer/supporter need to know. Questions addressed include 'How can I adjust to life with the diagnosis?', 'How can I plan for the future?', and 'How can we support our loved ones living with dementia?'. It provides expert explanations about changes in the brain and the various causes and types of dementia, as well as support on how to adjust to living with a diagnosis. It also offers practical information about care planning and advanced directives, maintaining health and social connections, accessing appropriate community care, and supporting medical and hospital care. It concludes with important self-care information for care/support partners.

Written jointly by academic experts and experts through lived experience, this book is indispensable for people living with dementia, care partners, and anyone wanting to understand more about the condition, as well as health and social care professionals and students of health and social care. The four authors of this new book are Anthea Innes, Carmel Geoghegan, Megan E. O'Connell and Phyllis Fehr.

14 OCTOBER:

Luxembourg's Info-Zenter Demenz publishes video interview with Chris Roberts discussing his life with dementia


Et je vis au Pays de Galles, au Royaume-Uni.

On 14 October, the Info-Zenter Demenz - Luxembourg's national information and advice centre for all questions relating to memory disorders and dementia - published a video interview with Chris Roberts online. Chris is the former Chairperson and a current member of the European Working Group of People with Dementia. In the video interview, he discusses his experiences of life with dementia. The video is part of a series called "Mäi Liewen Mat Demenz" ("My Life with Dementia").
The Info-Zenter Demenz is very grateful to Chris Roberts for taking the time to do this interview during his visit to Luxembourg for Alzheimer Europe's Annual Meeting, earlier this year. They particularly thank him for his openness and for combatting many stigmas and misconceptions around dementia. Watch the video, here:
https://www.youtube.com/watch?v=JbrbnKrgALY

25 OCTOBER:

touchNEUROLOGY publishes interview giving insights from Prof. Dr Murat Emre about his career in neurology and about the future of neurodegenerative disorders

In recently-published online interview, touchNEUROLOGY welcomes Prof. Dr Murat Emre. Prof. Emre, who studied medicine at Istanbul University and specialised in neurology in Zurich University Hospital in Zurich, Switzerland. After his training he did fellowships in movement disorders in Queen Square Hospital London and in behavioural neurology in Beth Israel Hospital, Harvard Medical School in Boston. He also worked in clinical research to develop new drugs for Parkinson’s disease and Alzheimer’s disease. Upon his return to Turkey he founded the Movement Disorders and Behavioural Neurology Unit in the Department of Neurology, İstanbul Faculty of Medicine. His main areas of interest are Parkinson’s disease, in particular cognitive aspects/dementia and Alzheimer’s disease.
touchNEUROLOGY asked Prof. Emre about his career motivations, advice for up-and-coming neurologists and his predictions for the future of neurodegenerative disorders. Read his interview, here:
https://touchneurology.com/insight/insights-from-prof-dr-murat-emre-a-career-in-neurology-and-the-future-of-neurodegenerative-disorders/

AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
5 November	Meeting with András Kulja, MEP (Brussels, Belgium)	Jean
8 November	Meeting with Janssen	Jean
12 November	IHI Brokerage Event (Brussels, Belgium)	Ange
13 November	Meeting with EFPIA AD Platform	Jean
13 November	PRIME roundtable at Brain Innovation Days (Brussels, Belgium)	Ange
18 November	European Dementia Carers Working Group (EDCWG) consultation	PI team
19 November	Alzheimer’s Association Academy “Involvement in HTA, pricing and reimbursement procedures”	Jean

20 November	European Medicines Agency Patients' and Consumers' Working Party meeting	Ange
21 November	EFPIA Patient Think Tank	Owen
21-22 November	PROMINENT General Assembly meeting (Barcelona, Spain)	Jean, Chris, Sébastien
24-25 November	Closing meeting of the TIMING project (Copenhagen, Denmark)	Dianne
28 November	EU4Health Civil Society Alliance	Owen
28 November	HMA/EMA Big Data Stakeholder Forum 2024 (Amsterdam, Netherlands)	Ange

CONFERENCES 2024-2025

DATE	MEETING	PLACE
26-27 November 2024	The 18th UK Dementia Congress (UKDC), https://journalofdementiacare.co.uk/events/uk-dementia-congress	Coventry, UK
13-16 February 2025	14th Panhellenic Conference on Alzheimer's Disease and 6th Mediterranean Conference on Neurodegenerative Diseases, https://www.alzheimer-conference.gr/index.php/en/	Thessaloniki, Greece
20-22 March	19th World Congress on Controversies in Neurology (CONy), https://cony2025.comtecmed.com/	Prague, Czechia
1-5 April	International Conference on Alzheimer’s and Parkinson’s Diseases and Related Neurological Disorders (AD/PD™ 2025) https://adpd.kenes.com/partners-related-events/	Vienna, Austria
21-24 June	11th Congress of the European Academy of Neurology, Neurology within society, https://www.ean.org/	Helsinki, Finland
6-8 October	35th Alzheimer Europe Conference, “Connecting science and communities: The future of dementia care”, https://www.alzheimer-europe.org/conferences	Bologna, Italy
4-5 February 2026	2nd International Conference on the Prevention of Alzheimer's Disease (ICOPAD 2026), https://www.hug.ch/en/evenement/2nd-international-conference-prevention-alzheimers-disease-icopad-2026	Geneva, Switzerland

35th Alzheimer Europe Conference

Connecting science and communities: The future of dementia care

Bologna, Italy

6 - 8 October 2025 #35AEC

www.alzheimer-europe.org/conferences

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