

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



I am delighted to say that the 33rd Alzheimer Europe Conference (33AEC), which took place in Helsinki from 16 to 18 October, was a huge success and we are really pleased with the great feedback we have had from so many

people, who found the event to be engaging, welcoming, interesting, diverse and inclusive. I would like to thank our co-hosts, Muistiliitto – The Alzheimer Society of Finland. I also want to warmly congratulate the members of the European Working Group of People with Dementia (EWGPWD), who successfully organised, moderated and presented the first plenary session and my particular thanks and congratulations to the speakers and Chair for this excellent session. I would also like to thank the members of the European Dementia Carers Working Group, for their active contributions throughout the whole of 33AEC, including presenting, chairing and participating in other conference sessions, as well as disseminating information about the group.

Aside from 33AEC, much else happened in Helsinki around the conference days, including our Annual General Meeting (AGM), the announcement of this year’s winners of the Anti-Stigma Award and the launch of our latest Dementia in Europe magazine, together with a special supplement about the EU-FINGERS project.

Both publications were launched just prior to 33AEC and given to all delegates at the event, At our AGM, the “Helsinki Manifesto” was adopted. The Helsinki Manifesto sets out the current position of dementia in Europe as well as calling for actions in four main areas: health, research, disability and social rights, and informal carers. The document, along with a public call for action and our 2024 European Parliament election campaign (Dementia Pledge 2024), will be officially launched at our next European Parliament lunch debate in Brussels, taking place on 5 December 2023.

The first place Anti-Stigma Award went to Touchstone’s BME (Black and Minority Ethnic) Dementia Service, while second place went to Brighton and Hove LGBT Switchboard’s initiative “Rainbow Neighbours” and the third place was awarded to Hogeschool Windesheim for its campaign “Assess your assumptions”.

From 24 to 27 October, the Clinical Trials in Alzheimer’s Disease (CTAD) conference was held in Boston, USA. CTAD is a meeting focused entirely on Alzheimer’s Disease Therapeutic Trials with key leaders in Alzheimer’s disease research from industry and academia getting together and forming partnerships with the objective of speeding the development of effective treatments to fight the disease. You can find some of the main news to emerge from this year’s CTAD, in our special “CTAD Watch” news section.

I hope you enjoy our newsletter!

Jean Georges
Executive Director

ALZHEIMER EUROPE

15-18 October: European Working Group of People with Dementia hosts pre-conference meeting and then takes centre stage at 33rd Alzheimer Europe Conference in Helsinki



On Sunday 15 and Monday 16 October, the European Working Group of People with Dementia (EWGPWD) met in Helsinki, prior to the opening of the 33rd Alzheimer Europe Conference (33AEC). On 15 October, members of the group conducted a final practice session for their plenary session, titled "Turning Personal Experiences into Political Advocacy and Public Involvement in Dementia Research," which took place on 16 October. They also provided input on the recommendations for the 2023 Alzheimer Europe Yearbook presented by Owen Miller (Alzheimer Europe). The Yearbook is focused on legal capacity and supported decision-making. The following day, prior to the opening of the conference, Angela Bradshaw joined the group to discuss Alzheimer Europe's position paper on anti-amyloid treatments. EWGPWD members worked on creating an easy-to-understand version of this document. Subsequently, Ana Diaz (Alzheimer Europe) moderated a discussion regarding inclusive travel for people with dementia, and members worked on developing some recommendations targeted at people with dementia.

On 16 October, the first plenary session of 33AEC showcased the work conducted by the EWGPWD in relation to Public Involvement in dementia research and advocacy. The speakers drew on their personal experiences, both at national and European level. This was the first plenary session of its kind, organised, chaired and presented entirely by people living with dementia and Alzheimer Europe was extremely proud to be able to include this special and important plenary in its 2023 conference programme. The work of the EWGPWD and the collective voice of its members are vital to the organisation's work and this long-standing collaboration continues to flourish. The plenary session was chaired by Chris Roberts (Wales, United Kingdom), Chairperson of the EWGPWD, and the four speakers were Kevin Quaid (Ireland), Vice-Chair of the EWGPWD, Pia Knudsen (Denmark), Věra Ryšavá (Czech Republic) and Nigel Hullah (Wales, United Kingdom).

Alzheimer Europe congratulates them all on their fantastic presentations and congratulates the entire group for its important work and for organising this plenary session. Alzheimer Europe would also like to thank all EWGPWD members for their very active contributions throughout the whole of 33AEC, including presenting, chairing and participating in other conference sessions, as well as disseminating information about the EWGPWD.

15-18 October: European Dementia Carers Working Group holds meeting in Helsinki and takes an active role at 33rd Alzheimer Europe Conference



On 15 and 16 October 2023, the European Dementia Carers Working Group (EDCWG) held a meeting in Helsinki, Finland. On the first day, the group offered feedback on the Alzheimer Europe Yearbook recommendations on legal capacity and supported decision-making. Clarissa Giebel, leader of the INTERDEM Taskforce "Inequalities in Dementia Care," then joined the meeting to present some of her research and gather input from group members. The EDCWG also made some final preparations for their workshop session titled "When Care Homes Stop Caring", held as part of the 33rd Alzheimer Europe Conference (33AEC).

On the second day of the meeting, Soraya Moradi Bachiller (Alzheimer Europe) shared some of the work conducted as part of the Pattern-Cog project, for which the EDCWG serves as advisory group members. The group members expressed their perspectives on issues related to disclosing dementia risk and raising awareness about brain health. In the final part of the meeting, they provided ideas on how to ensure that meetings and travel arrangements for people with dementia are inclusive.

Alzheimer Europe would like to thank the group's Chairperson Sonata Mačiulskytė (pictured, furthest right) and Vice-Chairperson Trevor Salomon (pictured, third from right), for their impressive work organising the EDCWG workshop session at 33AEC, titled "When Care Homes Stop Caring", and for facilitating the discussion together with other members of the group. The workshop was very well attended and delegates participated very actively, providing useful feedback. Alzheimer

Europe would also like to thank all EDCWG members for their active contributions throughout the whole of 33AEC, including presenting, chairing and participating in other conference sessions, as well as disseminating information about the EDCWG.

16 October: Alzheimer Europe Annual Meeting adopts “Helsinki Manifesto”



Alzheimer Europe organised its Annual General Meeting (AGM) on 16 October 2023, in Helsinki, with representatives of its national member organisations. 33 out of 36 full members were in attendance or were represented. During the AGM, the “Helsinki Manifesto” was adopted. The Helsinki Manifesto sets out the current position of dementia in Europe as well as calling for actions in four main areas: health, research, disability and social rights, and informal carers. The document, along with a public call for action and our 2024 European Parliament election campaign (Dementia Pledge 2024), will be officially launched at our next European Parliament lunch debate in Brussels, taking place on 5 December 2023.

The Alzheimer Europe AGM also celebrated the organisation’s achievements in 2022 and shared its plans for 2024 and its 2022-2023 finances with meeting participants and observers.

Both the Chairperson of the European Working Group of People with Dementia, Chris Roberts (United Kingdom – Wales) and the Chairperson of the European Dementia Carers Working Group, Sonata Mačiulskytė (Lithuania) then addressed the attendees of the meeting and following their speeches, the meeting closed with the AGM unanimously adopting Alzheimer Europe’s 2024 Work Plan and Budget.

16 October: Alzheimer Europe welcomes new colleague and announces new staff structure

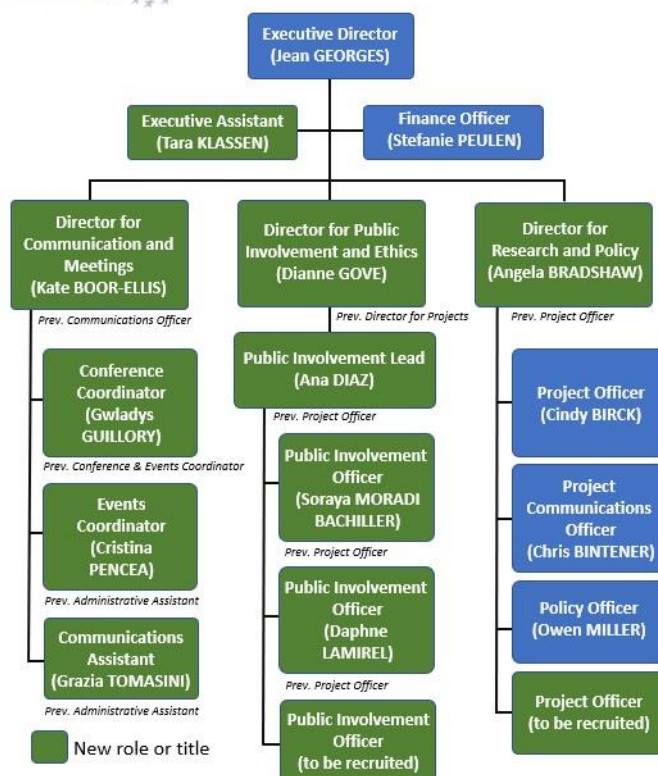
Alzheimer Europe is pleased to welcome a new colleague, Tara Klassen who joined Alzheimer Europe in September 2023. With a background in nursing (BScN), media and accounting, Tara supports Jean Georges, the Executive Director and Stefanie Peulen, the Finance Officer with accounting, as well as supporting the conference and events team. She can be reached at:



tara.klassen@alzheimer-europe.org

<https://www.alzheimer-europe.org/about-us/who-we-are/staff/tara-klassen>

The organisation is also pleased to announce a new structure, following approval by its AGM of 16 October. The new structure can be seen in the organisational chart, hereunder:



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16 October: New Dementia in Europe magazine published to coincide with 33rd Alzheimer Europe Conference



Alzheimer Europe is pleased to present the 43rd edition of its policy magazine, Dementia in Europe, together with a supplement about the EU-FINGERS project. These were published on 16 October 2023, to coincide with the first day of the 33rd Alzheimer Europe Conference (33AEC), in Helsinki. All delegates received a copy of the magazine and supplement in their conference bags.

This is a busy edition of the magazine and we are excited to share a number of interesting developments at an international, European and national level across policy, research and culture.

To mark 33AEC, we have a dedicated section called "Spotlight on Finland", to find out more about the work being done in the

conference host country. You can download the magazine, here:

https://www.alzheimer-europe.org/sites/default/files/2023-10/dementia_in_europe_magazine_issue_43_october_2023.pdf



16-18 October: Alzheimer Europe holds its 33rd Annual Conference #33AEC in Helsinki and online



The 33rd Alzheimer Europe Conference (#33AEC) “New opportunities in dementia care, policy and research” was formally opened on 16 October 2023. The conference took place as a hybrid event, with delegates and presenters able to join either on site at the Messukeskus Helsinki Expo and Convention Centre or online, with the aim of ensuring the event is as accessible, inclusive and interactive as possible. A record number of over 1,100 participants (1,000 of these in person) from 48 countries attended the conference, which took place from 16 to 18 October 2023.

Rosário Zincke dos Reis, Chairperson of Alzheimer Europe, opened the conference. She extended a special welcome to the 56 people with dementia among the delegates, as well as to the 66 carers/supporters in attendance. “I am delighted to note that

we have a record number of participants at this year’s conference, with over 1,100 people joining us today, in person and online”, she said. She also thanked Alzheimer Europe’s sponsors, including Gold sponsors, Lilly and Roche and Bronze sponsors, BioArctic, Eisai, MSD and Prothena. She also stressed the importance of working together, to find and implement better practices when providing care, along the disease pathway, all the while investing in research and fighting to ensure that dementia is recognised as a public health priority, both at European and national level and that specific policies are put in place, accordingly. She also highlighted the importance of the “Helsinki Manifesto”, which was adopted during Alzheimer Europe’s AGM, prior to the conference. [See our article about the AGM, for more information.](#)

Following these opening words, delegates were addressed by Jenni Kulmala, Chairperson of Muistiliitto and Associate Professor of Gerontology, Tampere University, Finland, who noted that 26 years had passed since Alzheimer Europe first held an Annual Conference in Helsinki. While dementia still poses one of the biggest health challenges we face in an ageing society, she said, it is important that we should also take note of the steps forward that we have taken together over the last decades. She emphasised that this conference was a place "where we can take new steps forward. We will have dialogue between dementia researchers, healthcare professionals, policymakers and non-governmental organisations. Ultimately, multi-professional collaboration is the

key to a more dementia-friendly world”, she said and stated that “Finland is paving the way in dementia prevention research, and we also want to be a country where research meets practice”.

Kaisa Juuso, Minister of Social Affairs and Health, Finland, was next up to the lectern, addressing delegates on the topics of early detection of memory problems, research work and respect for people with memory disorders. In order for us to be able to meet the growing demand for services and the rising costs, we need action to promote brain health, prevent memory disorders and detect memory problems as early as possible, she stated. The Minister also commented that the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) had shown that it is possible to prevent memory disorders by managing the risk factors associated with them, when people follow a multidomain lifestyle programme. This can improve cognitive functions in older people, she insisted, and can also prevent memory decline. The FINGER model will be implemented as a preventive measure throughout Finland. She stressed that the most important thing is to ensure we treat older people with respect for their right to self-determination, and that we provide them with services that meet their needs, support their inclusion and make their lives as good as possible.

Marjolein de Vugt, Professor of psychosocial innovations in dementia at the Alzheimer Center Limburg, Maastricht UMC+ addressed delegates in her capacity as Chairperson of INTERDEM (Early detection and timely INTERvention in DEMentia). “Focusing on everyday transformations to improve the lives of people living with dementia has the potential to reshape the landscape of dementia care, influence policy development, and cutting-edge research, emphasising the importance of psychosocial innovations”, she said. She also noted that, as the search for major breakthroughs continues, it is important to recognise the positive impact of psychosocial research and innovations in dementia and stressed that Alzheimer Europe and the INTERDEM network play a crucial role in fostering shared purpose, offering unique platforms for collaboration, learning, and inspiration to reshape the landscape of dementia care, influence policy development, and cutting-edge research.

Sirpa Pietikäinen, Member of the European Parliament (Finland) and Chairperson of the European Alzheimer’s Alliance welcomed everyone warmly to the conference and to Finland. During her speech, she stressed that dementia care needs to be more and more person-centred, integrative and transformative. She also emphasised the need to take technology and its opportunities into account. “These are the new avenues for better care for memory-disabled persons in Europe” she said.

Petri Lampinen was the final speaker at the Opening Ceremony and spoke on behalf of the European Working Group of People with Dementia (EWGPWD). Petri is from Finland and has been a member of the EWGPWD since 2017. Chris Roberts, Chairperson of the EWGPWD translated Petri’s words into English. In his speech, Petri pointed out that we all participate in the conference in many roles, but that what unites us all is our desire to advance dementia issues and the many future solutions related to it. In the coming years, times will be challenging, he said, because of the increasing numbers of people with dementia. It is worthwhile, therefore, to conduct active research and to invest in citizens’ brain health and make people aware of its importance. We also need to educate decision-makers about the importance of these issues in society.

“We who are diagnosed with dementia, want to make a difference with our loved ones in these matters. Because we can raise the issues, to the best of our ability. We can speak up for our rights. We have already been genuinely listened to and our opinions have also been valued. This has felt very good!”

He expressed his gratitude to Alzheimer Europe, its member associations and to dementia organisations the world over, for supporting people living with dementia and he reminded delegates that together, we can change perceptions of living with dementia and reduce the stigma they cause. He was particularly keen to point out that a dementia diagnosis need not mean the end of life.

Alzheimer Europe was delighted to have the support of EU Commissioners Helena Dalli and Stella Kyriakides, who each recorded a welcome video, addressing conference delegates during the Opening Ceremony. In her address, EU Commissioner for Equality Helena Dalli particularly highlighted the European Commission’s Strategy for the rights of persons with disabilities, which aims to ensure full participation of persons with disabilities in society and to prevent any discrimination based on the grounds of disability. She also reminded delegates that in June 2023, the Commission had adopted a Communication on a Comprehensive Approach to Mental Health, an initiative which aims to put mental health on par with physical health and to ensure a new, cross-sectoral approach to mental health issues. You can watch Commissioner Dalli’s video, here: https://youtu.be/_bUKC8rvdMnA

EU Commissioner for Health and Food Safety Stella Kyriakides began by thanking Alzheimer Europe and its members, for their dedication in tackling dementia and in supporting people living with dementia, their families and carers. Echoing Helena Dalli, she also highlighted the Commission’s Communication on a Comprehensive Approach to Mental Health. Commissioner Kyriakides also mentioned the “Healthier Together” initiative, which has one specific strand focused on neurological disorders and emphasises the need to make societies and communities more dementia friendly, and the EU Best Practice Portal which contains some of the best practices on health promotion all of which are publicly available. You can watch Commissioner Kyriakides’ video, here: https://youtu.be/_JHiqgcuj7M

The opening ceremony was followed by the first plenary session of the conference, which showcased the work conducted by the European Working Group of People with Dementia (EWGPWD) in relation to Public Involvement (PI) in dementia research and advocacy. Speakers drew on their personal experiences, both at national and European level.

This session was the first plenary session of its kind, organised, chaired and presented entirely by people living with dementia and Alzheimer Europe is extremely proud to be able to include this special and important plenary in its 2023 conference programme. You can read more about it in our separate article (also in the Alzheimer Europe news section) about the work of the EWGPWD in Helsinki, titled "[European Working Group of People with Dementia hosts pre-conference meeting and then takes centre stage at 33rd Alzheimer Europe Conference in Helsinki](#)".

To close day one of the conference, a Welcome Reception was held at Helsinki City Hall, hosted by the Mayor of Helsinki.

The second day of the conference had two plenary sessions, one focusing on brain health and prevention and the other on intersectionality in dementia, co-moderated by Jean Georges, Executive Director of Alzheimer Europe and Kim Coppes from Live Online Events, as were the fourth and fifth plenary sessions on 18 October. Professor Miia Kivipelto, University of Eastern Finland and Karolinska Institutet, was the first speaker at the plenary on "Brain health and prevention", discussing "Building the evidence base for multi-modal interventions through European and International collaborations". Nikolaos Scarmeas, Professor of Neurology, National and Kapodistrian University of Athens was next to take the floor, with his presentation "The role of nutrition in the prevention of dementia". The third speaker in this plenary session was Professor Katja Kanninen, A.I. Virtanen Institute for Molecular Sciences, University of Eastern Finland, who spoke about environmental factors and air pollution as risk factors for dementia, while the fourth and final speaker in this plenary session, Giovanni Frisoni, Director, Centre de la mémoire, Geneva University Hospital and Professor in Clinical Neurosciences, University of Geneva presented on "Dementia prevention in memory clinics: recommendations from the European task force for brain health services".

The third plenary of the conference covered topics related to intersectionality in dementia. A presentation on "Achieving Cultural Inclusivity in Dementia Care" was delivered by Karan Jutla, Head of Health Research Centre & Dementia Lead for the University of Wolverhampton. Dr Alain Dekker from Alliade Care Group and University of Groningen/UMCG (Netherlands) was the second speaker to take the stand and discussed "Dementia in people with intellectual disabilities: introduction to both Down syndrome and severely disabled populations". The next speaker was Linn Sandberg, whose presentation was called "Are they here, are they queer? LGBTQ People with Dementia and the limits of person-centred care". The fourth and final speaker was Päivi Topo, Ombudsman for Older People in Finland, who discussed "How to better support people living with dementia from socio-economically disadvantaged groups". The Ombudsman for Older People in Finland is an autonomous and independent authority that promotes the realisation of the rights and best interests of older people.

The third and final day of the conference, on 18 October, began with a plenary session focusing on "New opportunities" and the first speaker, Nicolas Villain, Associate Professor of Neurology at Sorbonne University, Paris, France and at the Institute of Memory and Alzheimer's Disease, Department of Neurology, Pitié-Salpêtrière Hospital, Assistance Publique – Hôpitaux de Paris, opened the plenary with a presentation looking at "How to evaluate the efficacy and safety of anti-amyloid treatments as a researcher, a clinician or patient". Ulrika Granér, Silvia Nurse, MSc Specialist Nursing – Elderly Care and Cognitive Impairment Care, Stiftelsen Silviahemmet, shared her presentation with the audience next, focusing on "Vision zero: A Swedish model for dementia care without restraint". The third speaker up to the podium was neurologist Eino Solje, Adjunct Professor and research director at the University of Eastern Finland and at the Brain Research Unit and Kuopio University Hospital Neuro Center. His talk was titled "Beyond Alzheimer's disease – the treatment and care of people with other types of dementia: Focus in FTD and LBD" (with FTD being frontotemporal dementia and LBD being dementia with Lewy bodies). Professor Martin Orrell, Director of the Institute of Mental Health at the University of Nottingham United Kingdom, was the fourth and final speaker in Plenary 4. He spoke about various ways to improve the lives of people with dementia through the use of technology.

The fifth and final plenary session at the conference, took the form of a roundtable discussion. To open the session, Dr Natasha Azzopardi Muscat, Director of the Division of Country Health Policies and Systems at the WHO Regional Office for Europe, addressed delegates on behalf of Hans Kluge, WHO Regional Director for Europe, in a video message. She welcomed everyone to the policy round table on "Dementia as a European public health and policy priority". The WHO is working with partners around world, implementing the Global action plan on the public health response to dementia 2017-2025 and has a number of tools and resources to support countries in achieving the 2025 targets therein. But, Dr Azzopardi Muscat noted, "we are in danger of falling short of the targets if we don't step up our work together and push for change". You can watch the video, here: <https://youtu.be/ZiOldzo90YA>

Roundtable panellists were: Andy Heffernan, Chief Executive, The Alzheimer Society of Ireland; Taru Koivisto, Deputy Director General, Department for Communities and Functional Capacity, Ministry of Social Affairs and Health, Finland; Sonata Mačiulskytė, Chairperson of the European Dementia Carers Working Group (EDCWG) and Board member of Dementia Lithuania; Anne Remes, Vice-Rector and Professor of Neurology at the University of Helsinki, Finland; Chris Roberts, Chairperson of the European Working

Group of People with Dementia (EWGPWD) and Elina Suzuki, Health Policy Analyst, Organisation for Economic Co-operation and Development (OECD).

The closing ceremony of the conference included closing comments by Anne Remes, in her capacity as President of the Union Council of The Alzheimer Society of Finland (Muistiliitto) and by Rosário Zincke dos Reis, Chairperson of Alzheimer Europe, who then invited Stefanie Becker, Executive Director of Alzheimer Switzerland up to the stage to share her excitement that the 34th Alzheimer Europe Conference will be held in Geneva, from 8-10 October 2024. Save the dates - see you there!



Plenary 1



Plenary 2 speakers



Plenary 3 speakers



Plenary 4 speakers



Plenary 5 roundtable



Welcome reception at Helsinki City Hall

17 October: Black and Minority Ethnic Dementia Service wins Alzheimer Europe’s Anti-Stigma Award at a special ceremony in Helsinki



On 17 October 2023, at a special award ceremony during the Networking Dinner of the 33rd Alzheimer Europe Conference, Touchstone’s BME (Black and Minority Ethnic) Dementia Service was announced as the winner of Alzheimer Europe’s

2023 Anti-Stigma-Award. Touchstone provides health and wellbeing services to thousands of people across Yorkshire, in the United Kingdom.

Alzheimer Europe, in collaboration with the Alzheimer Europe Foundation, Lilly and Roche launched a call for applications in April 2023, with the aim of giving recognition to an outstanding initiative combating stigma and promoting a positive image of dementia and people living with dementia. This year’s call focused on initiatives and campaigns addressing the stigma experienced by people with dementia and their carers from minority ethnic groups, the LGBTQ+ community, people with intellectual disability and/or Down syndrome and from socio-economically disadvantaged groups. Applications were open to individuals and organisations established in a member country of Alzheimer Europe for initiatives and projects which were developed and/or implemented in the past three years (2020-2023).

The first place award, together with a cash prize of EUR 5,000 was presented by Iva Holmerová, the Treasurer of the Alzheimer Europe Foundation.

The second place award, with a cash prize of EUR 3,000, was presented by Helen Rochford-Brennan from the Alzheimer

Europe Foundation. It was awarded to Brighton and Hove LGBT Switchboard's initiative "Rainbow Neighbours". Switchboard is a charity for LGBTQ people looking for a sense of community, support or information.

The third place, with a cash prize of EUR 1,500, was scooped up by Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for its campaign "Assess your assumptions". The award was given by Heike von Lützu-Hohlbein, Chairperson of the Alzheimer Europe Foundation.

During the Networking Dinner on the evening of 17 October, held at The Old Student House in Helsinki and moderated by Kim Coppes from Live Online Events, the three finalists were invited to present their initiatives, before the winner and runners-up were announced.

The winning initiative was presented by Ripaljeet Kaur from Touchstone for its project BME Dementia Service. BME Dementia Service provides specialist support to people living with memory problems or a diagnosis of dementia and their carers/family members from Black and Minority Ethnic communities predominantly South Asian community living in and around Leeds. "Rainbow Neighbours", the initiative winning second prize was presented by John Hammond from Brighton and Hove LGBT Switchboard, which takes a creative approach to addressing the stigma, loneliness and isolation that can be experienced by LGBTQ+ people living with dementia, particularly those who are living in residential care settings. Rainbow Neighbours provides transport for LGBTQ+ people living with dementia at residential care settings to join Switchboard's fun and engaging peer support activities and broader wellbeing events. The project also gives those living at residential care settings access to ongoing multi-generational support from other LGBTQ+ people - a "Rainbow Neighbour".

Third place was awarded to Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for "Assess your assumptions". The campaign was presented by Gili Yaron. Studies by the Hogeschool Windesheim research group "Living Well with Dementia" found that health and social care professionals hold stereotypical beliefs about people with dementia especially those from minority ethnic communities. Addressing these beliefs is vital to ensure this group receives good care and support. Based on input from professionals and informal carers, the Hogeschool developed a pocket-sized card deck featuring 16 common misconceptions about culturally sensitive dementia care, to be used as conversation starters or 'serious games' (e.g. stereotype bingo) in practice and education.

More information about the Anti-Stigma Award can be found at:

<https://www.alzheimer-europe.org/our-work/anti-stigma-award>

Alzheimer Europe gratefully acknowledges the support of the sponsors of the Alzheimer Europe anti-stigma award: Alzheimer Europe Foundation, Lilly and Roche.

15 applications were received in 2023 and were reviewed by the Anti-Stigma Award Jury, which was comprised of the following representatives:

- 2022 Anti-Stigma Award Winner: Niels Janssen (Alzheimer Centre Limburg, Maastricht, Netherlands)
- Alzheimer Europe: Maria do Rosário Zincke Dos Reis and Mario Possenti
- Alzheimer Europe Foundation: Heike von Lützu-Hohlbein (Chairperson), Helen Rochford-Brennan and Iva Holmerová
- European Dementia Carers Working Group: Magnús Karl Magnússon and Zornitsa Karagyozyova
- European Working Group of People with Dementia: Chris Roberts and Kevin Quaid
- Lilly: Laura Campo
- Roche: Jannice Roeser.

17 October: 33rd Alzheimer Europe Conference keynote speakers interviewed by Finnish television channel MTV3

During the 33rd Alzheimer Europe Conference (33AEC) which took place in Helsinki from 16 to 18 October 2023, Finnish television channel MTV3 interviewed two of the conference's Finnish keynote speakers, Petri Lampinen and Miia Kivipelto.

Petri Lampinen, a member of the European Working Group of People with Dementia (EWGPWD), was a speaker at the Opening Ceremony of 33AEC. In his television interview, he discussed the importance of openness and shared how he manages to live a good life alongside his dementia. He told MTV3 interviewer Salla Hekkala about his feelings when dementia came into his life, how he cried at night but that while out walking in nature, he got a new grip on life and realised that life does not end with a diagnosis. He is now an active advocate for dementia both in Finland with the Alzheimer Society of Finland's "Memory Activists" and at a European level with the EWGPWD. He also spoke about the Conference and about the support his wife Nina gave him while attending the event, as well as in everyday life.

You can watch the interview (in Finnish), here:

<https://www.mtv.fi/klipit/7e53bdc7cf96fa478cc8/petri-lampinen-sai-muistisairausdiagnoosin-52-vuotissyntym%C3%A4p%C3%A4iv%C3%A4n%C3%A4n-%C3%B6isin-itkin-ja-mietin-ett%C3%A4-t%C3%A4ss%C3%A4k%C3%B6-el%C3%A4m%C3%A4ni>



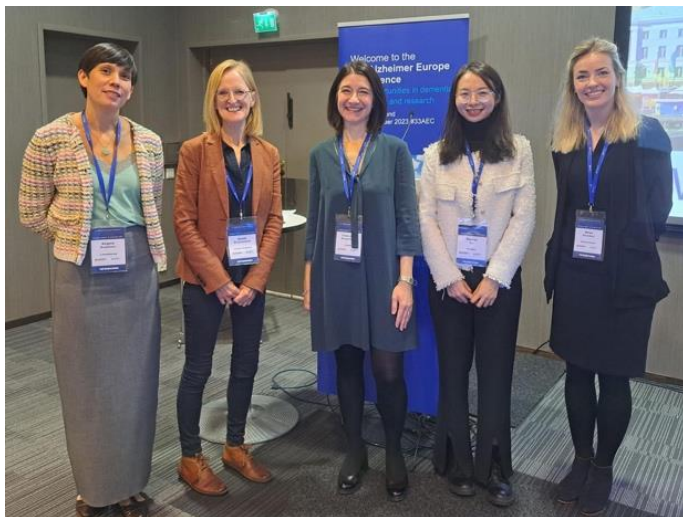
<https://www.mtv.fi/clipit/08614f837bb448ec08e4/eurooppalaiset-muistisairauksien-asiantuntijat-ovat-parhaillaan-koolla-helsingissa-mitk-ovat-uusimmat-tiedot-alzheimerin-hoidosta>

Professor Miia Kivipelto, University of Eastern Finland and Karolinska Institutet, was a speaker during the 33AEC plenary session on “Brain health and prevention”. Her presentation was on “Building the evidence base for multi-modal interventions through European and International collaborations”. In her interview with Salla Hekkala for MTV3, she discussed the latest information on the treatment of Alzheimer's disease.

You can watch the interview (in Finnish), here:

<https://www.mtv.fi/clipit/08614f837bb448ec08e4/eurooppalaiset-muistisairauksien-asiantuntijat-ovat-parhaillaan-koolla-helsingissa-mitk-ovat-uusimmat-tiedot-alzheimerin-hoidosta>

18 October: Special Symposium at 33AEC highlights the value of data sharing, showcasing insights from FINGER, SveDem and other clinical studies



Over the last decade, substantial efforts have been invested in the development of initiatives, resources and infrastructures for data sharing from clinical research studies. Data sharing has the potential to accelerate and advance dementia research, allowing scientists to make new discoveries using existing data from clinical cohorts, trials and registries. In a Special Symposium organised at the 33rd Alzheimer Europe conference in Helsinki, panellists showed how shared data has generated important insights on the causes, risk factors, diagnosis and treatment of dementia, discussing past challenges and future prospects.

The concept of data sharing is not a new one: long before the advent of computers, health economists performed secondary analyses on data from government reports, and meteorologists shared information on weather patterns. However, as our technological ability to handle data has increased over time, so has the size of research datasets. Nowadays, clinical studies

commonly involve hundreds and sometimes thousands of participants, depending on study phase and design. With such breadth and scale, however, comes meaning. Linking data from these analyses can help clinical researchers to identify connections between biomarkers and cognitive symptoms, link alterations in brain scans to behavioural changes, and understand which risk factors may contribute to dementia. Sharing this data adds a further, essential dimension: research findings can be compared, contrasted – and corroborated.

The special symposium featured four expert speakers, who showcased different facets and outputs from data sharing. First, Sarah Bauermeister (University of Oxford), provided an overview of the Dementias Platform UK (DPUK) data sharing platform. DPUK gives researchers anywhere in the world access to high-quality, multi-modal data from 63 population and clinical cohort studies. Sarah also explained how analysis of shared data was able to reveal connections between early life adversity and mental health issues in later life, including depression, partner relationship strain, and poorer cognition. The next speaker was Francesca Mangialasche (Karolinska Institutet), Executive Director of the World Wide FINGERS global Scientific Coordinating Center. The World Wide FINGERS network comprises research teams from over 60 countries across the globe, and Francesca detailed their efforts to harmonise global data from the FINGERS studies, to generate robust evidence on dementia prevention. The Alzheimer's Disease Data Initiative is supporting permissioned, secure access to FINGERS study data via the AD Workbench – a data sharing platform that also powers the EPND (European Platform for Neurodegenerative Diseases) hub.

The third speaker in the special symposium was Sandar Aye (Karolinska Institutet). Sandar brought the health economics perspective, showing how data from the SveDem population registry can inform mortality and cost analyses for new dementia treatments. SveDem is a Swedish registry study that was initiated in May 2007, recruiting patients from memory clinics across Sweden. To date, over 100,00 patients with a dementia diagnosis have been included in the registry, with yearly follow-up. Closing the special symposium, Stina Saunders (Linus Health and University of Edinburgh) brought the focus back to the participant perspective. Focusing on the European Prevention of Alzheimer's Dementia (EPAD) longitudinal cohort study (LCS), Stina highlighted the valuable contributions of over 2,000 research participants from several countries in Europe. Thanks to their efforts, the EPAD-LCS has generated a valuable biobank and a vast, rich dataset, which is available on the AD Workbench.

To learn more about data sharing in European dementia research projects, read our 2021 report:

<https://www.alzheimer-europe.org/policy/positions/data-sharing-dementia-research-eu-landscape>

ALZHEIMER EUROPE NETWORKING

On 4 October, Jean attended a European Parliament meeting on the EU Cross Border Associations Directive organised by Sergey Lagodinsky, MEP.

On 5 October, Ange participated in the final review meeting of the VirtualBrainCloud project.

On 5 October, Owen attended the European NGO meeting hosted by the European Disability Forum.

On 10 October (Lausanne, Switzerland), Ange participated in a steering group meeting of the PAVE project.

From 10-12 October (Lausanne, Switzerland), Ange attended Lausanne X Workshop.

From 10-12 October (Lisbon, Portugal), Owen attended the "Regional summit on policy innovation for healthy ageing in the WHO European region" hosted by WHO Europe.

On 11 and 12 October (Prague, Czechia), Martina Mátlová, Board member of Alzheimer Europe, attended the conference Prague Days of Gerontology 2023.

On 13 October, Jean attended the presentation of the report on persons with disabilities by the European Court of Auditors.

On 15-16 October (Helsinki, Finland), Ana, Daphné, Owen, Ange and Soraya participated in the EWGPWD and EDCWG meetings.

On 16 October (Helsinki, Finland), Alzheimer Europe organised its Annual General Meeting.

From 16-18 October (Helsinki, Finland), Alzheimer Europe organised its 33rd Annual Conference "New opportunities in dementia care, policy and research".

On 18 October (Helsinki, Finland), Ana, Angela and Cindy organised an AI-Mind ethics workshop.

On 19 October (Helsinki, Finland), Cindy and Soraya attended the Pattern-Cog General Assembly Meeting.

On 19-20 October (Helsinki, Finland), Cindy attended the AI-Mind General Assembly Meeting.

On 24 October, Angela participated in a NovoNordisk panel at an AD strategy summit.

On 25 October (Liverpool, United Kingdom), Chris presented at the 5th Annual Liverpool Dementia & Ageing Research Conference.

Sponsors of the month

Alzheimer Europe would like to express its gratitude to three new sponsors for 2024!

Read more about sponsorship opportunities here:

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



disease? The RADAR-AD consortium publishes a series of videos in which RADAR-AD researchers, clinicians, industrial partners and patient representatives explain their work, highlight preliminary results and share their learnings and experiences with the RADAR-AD studies. There are **seven** videos in total:

1. RADAR-AD: research, results, future steps

RADAR-AD's academic lead - Dag Aarsland (King's College London), and industrial lead - Gayle Wittenberg (Janssen Pharmaceutica NV), elaborate on the research done in the project, its clinical studies, the devices used, and consortium partners. They share preliminary results from RADAR-AD and outline plans for their exploitation and sustainability.

Watch video 1: <https://www.youtube.com/watch?v=4y54Qx1G-AE>

2. Public involvement in RADAR-AD

"Being part of RADAR-AD's Patient Advisory Board has been an empowering experience" – Helen Rochford-Brennan, living with Alzheimer's dementia, explains. "As a member, I was able to see first-hand the benefits of us all being involved in this together. We met on a regular basis with researchers and had lots of interaction about the devices that were to be used by the participants in the RADAR-AD study, such as watches, cameras and sensors. Our feedback was highly valued and we were able to influence change."

Watch video 2: <https://www.youtube.com/watch?v=F1AfZe3n3uw>

3. Functional domains, use of Machine Learning and Artificial Intelligence

"We need a way to monitor the progression of Alzheimer's disease. Besides the conventional traditional questionnaires

EU PROJECTS

13 October: RADAR-AD videos explain its research, results and patient experiences



What is the potential of digital technologies such as wearables, sensors, mobile apps and cameras to improve the assessment of Alzheimer's

that track changes in cognition and memory, other assessment methods track limitations in patients' functions or activities of daily living. We refer to functional domains as those activities of daily living that may impair patient's quality of life and are important to patients. In RADAR-AD, these were based on a literature search and patient's advisory board's input." - Neva Coello (Novartis), RADAR-AD modelling work.

Find out more about the functional domains chosen in RADAR-AD, the way patient representatives were involved in the process and the machine learning and artificial intelligence models applied to the RADAR-AD data.

Watch video 3: <https://www.youtube.com/watch?v=eaRfnYD1xjk>

4. Digital technologies and data analysis in RADAR-AD

The RADAR-AD technical team leads Srinivasan Vairavan (Janssen Pharmaceutica NV), Jelena Curcic (Novartis) and Spiros Nikoulopoulos (CERTH) shed light on the way digital devices were used in the RADAR-AD studies, the main findings from this work and the significance of these results for the wider field of Alzheimer's research.

Watch video 4: <https://www.youtube.com/watch?v=npjQx01mBNY>

5. RADAR-AD smart home study

What is a smart home and how does it help people living with Alzheimer's disease? RADAR-AD smart home lead Spiros Nikoulopoulos (CERTH) introduces the research conducted in the RADAR-AD's smart home facility and shares his team's result and conclusions.

Watch video 5: <https://www.youtube.com/watch?v=VQY1Y2XYsDI>

6. Towards regulatory acceptance of remote monitoring technology-based assessment of functioning in Alzheimer's disease

Why is it important to engage with regulators when developing novel tools and methodologies? What are RADAR-AD's key learnings from its interactions with regulatory bodies such as the European Medicines Agency and how will RADAR-AD's partners use these results? Hear from the RADAR-AD regulatory workstream leads Vera Nies (Lygature), Gul Erdemli (Novartis) and Suzanne Foy (Janssen Pharmaceutica NV).

Watch video 6: <https://www.youtube.com/watch?v=rOCGnAAcpeU>

7. RADAR-base platform

RADAR-base is an open source software platform for remote clinical trials, provided to the RADAR-AD project by The Hyve. In RADAR-AD, RADAR-base has been used to collect data from various data sources. "The need in RADAR-AD was to incorporate many types of devices such as accelerometers, cameras, apps in the RADAR-AD studies and collect data from those devices into one central data platform." – Joris Borgdorff (The Hyve) explains. Learn more about the use of RADAR-base in RADAR-AD and the lessons learned in this video.

Watch video 7: https://www.youtube.com/watch?v=Ce9z-dRcT_Q



15-16 October: INTERDEM network hosts its Annual Meeting in Helsinki prior to Alzheimer Europe Conference



INTERDEM is a network of researchers interested in psychosocial interventions. It is made up of 229 researchers and academics with different professional disciplines, spread across 21 countries (19 of which are in Europe). The INTERDEM network held its Annual Meeting at the conference centre in Helsinki on 15 and 16 October 2023, just prior to the 33rd Alzheimer Europe Conference (33AEC).

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 and a keynote presentation delivered by Justine Schneider in a session chaired by Myrra Vernooij-Dassen. The keynote discussed "Working with artist to communicate research findings: examples from film, theatre, cartoons and opera". The AGM also looked back at some highlights from the past year, as well as giving an update on projects and on the task force initiative. Alzheimer Europe is proud to be a key partner of INTERDEM.

<https://interdem.org/>

16 October: EU-FINGERS project supplement published with new Dementia in Europe magazine at 33rd Alzheimer Europe Conference

A new publication about the EU-FINGERS project has been launched as a supplement to the 43rd edition of Alzheimer Europe's policy magazine, "Dementia in Europe". Both publications coincided with the first day of the 33rd Alzheimer Europe Conference (33AEC), in Helsinki and all delegates received a copy of the magazine and EU-FINGERS supplement in their conference bags.



EU-FINGERS is a project funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND), the largest global

research initiative aimed at tackling the challenge of neurodegenerative diseases. EU-FINGERS is a multinational interdisciplinary consortium that has been growing since its launch in 2020 and is part of the global World-Wide FINGERS® network of multidomain trials for dementia risk reduction and prevention. It gathers world-renowned experts in the field of Alzheimer's disease and dementia, who are leading pioneering multidomain prevention trials.

It builds upon the successful experience of FINGER: the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability, which demonstrated that a two-year multimodal life-style intervention consisting of nutritional guidance, exercise, cognitive training and control of vascular risk factors benefitted cognition in older people at increased risk of dementia. In EU-FINGERS, the partners aim to develop tools to advance, optimise and scale-up the FINGER model across Europe. You can download the EU-FINGERS supplement, here:

https://www.alzheimer-europe.org/sites/default/files/2023-10/dementia_in_europe_magazine_issue_43_october_2023_-_eu_fingers_supplement.pdf

16 October: eBRAIN-Health partners present their work on ethics and data privacy at 33AEC in Helsinki



eBRAIN-Health is a Horizon Europe-funded research project which will develop a data privacy-compliant research platform to support the development of digital representations of the human

brain. These digital brain twins use artificial intelligence (AI) models to simulate some of the brain's complex neurobiological phenomena, and aim to facilitate research into neurodegenerative conditions such as dementia. On 16 October, Lukas Faymann (University of Vienna) and Daphne Lamirel (Alzheimer Europe) co-presented their work on regulatory, legal and ethical issues relating to digital brain twins and AI, in a parallel session entitled "Ethical and Legal issues".

Lukas kicked off the presentation by outlining the goals of eBRAIN-Health, setting the scene for this ambitious project by describing EU legal frameworks including the AI Act, Medical Devices Regulation (MDR) and the General Data Protection Regulation (GDPR). Lukas asked whether these interconnected regulations sufficiently equip individuals, whose personal data is used to train and run AI, with rights to protect themselves. He also highlighted possible solutions to legal challenges raised by this new regulatory landscape, such as accountability mechanisms, increasing digital literacy, and increasing the frequency of post-market surveillance.

Next, Daphne presented their critical evaluation of ethical concerns about the AI Act, related to the accessibility of AI systems for people with disabilities, stakeholder participation in AI design and development. Drawing on consultations with the

eBRAIN-Health Public and Patient Advisory Group (PPAG), which is composed of members of the public, people with or at risk of dementia, and relatives of people with dementia, Daphne emphasised that specific actions are needed to ensure broad accessibility to health-related AI systems (e.g. adopting universal design principles) and that stakeholder participation in the design and development of health-related AI systems is essential. eBRAIN-Health is currently developing guidelines for professionals on how, after demonstrating compliance with the new legal framework, they can promote trustworthy and ethical use of AI. Learn more about the eBRAIN-Health project:

<https://ebbrain-health.eu/vision.html>

16 October: EU-FINGERS features prominently at #33AEC



During the 33rd Alzheimer Europe Conference (#33AEC) "New opportunities in dementia care, policy and research" held in Helsinki, Finland, a session entitled "Precision prevention of Alzheimer's disease and dementia: advancing multidomain interventions" was dedicated to the EU-FINGERS project. Miia Kivipelto (Karolinska Institutet, Sweden) project coordinator of EU-FINGERS moderated the session. First, Francesca Mangialasche (Karolinska Institutet, Sweden) gave an overview of the JPND-supported project, aiming at developing a novel methodology for precision prevention of Alzheimer's disease and dementia, based on the successful experience of the multidomain, lifestyle-based Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER). Next, Mariagnese Barbera, (University of Eastern Finland, Finland) gave an update on MET-FINGER, which is the first trial combining a multimodal lifestyle intervention with a putative disease-modifying drug for cognitive decline prevention, named Metformin. Alara Abaci (Karolinska Institutet, Sweden) then presented the results of a study investigating the perspectives of memory clinic patients regarding research participation. Findings showed considerable variation in memory clinic patient perspectives regarding research participation, and identified facilitators and barriers for intervention trials. To close the session, Ana Diaz (Alzheimer Europe, Luxembourg)

pointed out the importance of exploring and involving members of the public in brain health research and described the approach used to set up the EU-FINGERS Advisory Board as well as its impact on the project. Finally, Anna Rosenberg (Finnish Institute for Health and Welfare) and Petri Lampinen (Finnish EU-FINGERS Advisory Board member) shared both their views on the EU-FINGERS Advisory Board, which provides feedback and advice to the EU-FINGERS researchers about various topics and issues linked to the research activities conducted by the consortium.

In addition to the EU-FINGERS session, Miia Kivipelto was the first speaker of the second plenary of the conference on "Brain health and prevention", discussing "Building the evidence base for multi-modal interventions through European and International collaborations". With an increasing body of evidence from clinical trials to show that multidomain interventions targeting several risk factors are effective and feasible, the EU-FINGERS and World-Wide FINGERS networks are now working on further developing and adapting these interventions to different target populations and settings.

Several members of the EU-FINGERS Advisory Board were in attendance and were able to join on-site and online. More information about EU-FINGERS's work can be found in the recently supplement published with new Dementia in Europe magazine at 33rd Alzheimer Europe Conference:

https://www.alzheimer-europe.org/sites/default/files/2023-10/dementia_in_europe_magazine_issue_43_october_2023_-_eu_fingers_supplement.pdf

16 October: ADAIR project featured at 33rd Alzheimer Europe Conference in Helsinki



Emerging evidence indicates that exposure to environmental toxins such as air pollutants is detrimental to brain health and associated with cognitive decline and dementia. Air pollution was recently added to the list of modifiable risk factors for dementia by the Lancet commission, and a growing body of evidence from experimental studies shows that exposure to air pollutants impairs the brain.

The JPND-funded ADAIR-project on Air Pollution and Alzheimer's Disease had a special session at the Alzheimer Europe Conference in Helsinki on 16 October 2023, on the topic of "Air Pollution and Dementia". Presentations of ADAIR partners at this session focused on epidemiological evidence, omics approaches and data integration, as well as impacts of air pollution on immune cell signatures and new approaches in human *in vitro* modelling.

The coordinator of ADAIR, Professor Katja Kanninen (pictured, furthest left), also gave a talk at the conference during the second plenary session, which looked at topics around brain health and prevention. Her talk was on "Environmental factors and air pollution as risk factors for dementia".

As the ADAIR project concludes at the end of 2023, it is expected that results from the consortium will provide detailed insight into air pollution exposure effects on the brain.

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

17 October: Dementia Prevention Insights from LETHE project at Alzheimer Europe Conference



On 17 October, two researchers from the LETHE project presented on their work at the Alzheimer Europe Conference in Helsinki, Finland during a session dedicated to brain health and prevention.

Jeroen Bruinsma presented his recent qualitative work on lifestyle behaviour change for dementia risk reduction. His study reveals that dementia risk often seems abstract, as people believe dementia occurs decades into the future. While many have positive attitudes towards a healthy lifestyle, they struggle to initiate change. This seems particularly evident for those who perceive limited control over their behaviour. Sharing these insights with the Alzheimer research community is vital because this highlights the need for research on effective behaviour change methods that support individuals with reducing dementia risk. Read more about the research here:

<https://pubmed.ncbi.nlm.nih.gov/37718799/>

Dr Anna Rosenberg from the Finnish Institute for Health and Welfare presented the study design of the LETHE pilot RCT and

updates on study progress. The two-year LETHE trial tests the feasibility of a digitally supported lifestyle program to promote brain health and reduce dementia risk among older adults. Participant recruitment started in September 2022 and was successfully completed in Spring 2023, with 156 individuals randomised to the study. Recruitment is balanced across the four sites: Medical University of Vienna (Austria), Finnish Institute for Health and Welfare (Finland), Karolinska Institutet (Sweden), and University of Perugia (Italy). So far, participant experiences are very positive and engagement in the intervention is active.

Presenting the LETHE trial at the conference was a great opportunity to showcase this work to not only the research community, but also members of the public who are affected by dementia. It was delightful to see that brain health and prevention was the focus of several sessions, and many innovative projects in this area are ongoing across Europe.

More information about LETHE's work and the start of the dementia risk-reduction study can be found in the recently launched Dementia in Europe Magazine:

<https://www.alzheimer-europe.org/resources/publications/dementia-europe-magazine-issue-43>

19 October: AI-Mind holds its General Assembly Meeting in Helsinki



Following the success of the 33rd Alzheimer Europe Conference that attracted over 1,000 participants, the AI-Mind Project consortium gathered for its 7th General Assembly meeting, hosted by partners from BioMag Laboratory HUS Medical Imaging Center, Helsinki University Hospital, and Aalto University in Helsinki, Finland on October 19 and 20.

The meeting brought together 68 in-person attendees and an additional 13 joining online, representing both the AI-Mind consortium and external speakers. Prior to the General Assembly Meeting, on October 18, part of the consortium convened for a pre-General Assembly ethical workshop, conducted by Alzheimer Europe and delivered by Angela Bradshaw and Ana Diaz. This workshop was aiming to learn more about discrimination and bias in AI-based risk prediction research, and to reflect on what this means in the context of AI-

Mind, looking at systemic, societal, personal and inter-personal issues as well as technical sources of bias.

The AI-Mind General Assembly commenced with a warm welcome from the local hosts, setting the stage for two days of enriching discussions and insights into the project's progress. The project coordinator, Ira Hebold Haraldsen from Oslo University Hospital provided a comprehensive overview of the significant strides made thus far. The meeting's agenda included multidisciplinary presentations from AI-Mind experts and cross-work packages (WPs) meetings. The agenda also featured a series of insightful lectures encompassing topics such as:

- Focal excitation-inhibition dysregulation in Alzheimer's disease, presented by Heikki Tanila (University of Eastern Finland)
- Hypersynchronization as an MEG biomarker for tracking the AD continuum by Fernando Maestu (UCM)
- Early diagnosis and care of Alzheimer's disease is cost-effective and supports quality of life by Anne Koivisto's (HUS)
- The challenges of transfer and implementation in the clinical practice by Ole Petter Ottersen (UiO).

A highlight of the second day was the panel discussion led by Vebjørn Andersson (OUS), featuring young researchers from the project, namely Robin Vermeulen, Daniel Irabien, Mats Tveter, Federico Toraño and Claudia Carrarini. Their insights shed light on the advantages of cross-disciplinary collaboration, emphasising the value of diverse perspectives and innovative thinking.

You can read the full summary of the 6th AI-Mind General Assembly on the project website:

<https://www.ai-mind.eu/blog/takeaways-from-ai-minds-7th-general-assembly/>

19 October: Pattern-Cog holds its first General Assembly Meeting in person in Helsinki



On 19 October, partners working on the Pattern-Cog project met during a General Assembly meeting, held online and in-person in Helsinki, Finland. Funded by ERA Per-Med, the overarching goal of this project is to improve dementia prevention strategies by developing support tools for the

detection of earliest signs of impending cognitive decline which would allow early and personalised multidomain interventions. During the meeting, partners highlighted key project developments and achievements. The meeting's agenda included multidisciplinary presentations from the different work packages (WPs) leaders. Alzheimer Europe was represented by Project Officers Cindy Birck and Soraya Moradi-Bachiller. Cindy provided an update on the done for the dissemination and communication tasks, including the project's brand identity, website and communication channels. Soraya

presented the work already done with the Pattern-Cog Advisory Board, composed of members of the European Dementia Carers Working Group. The agenda also featured discussions on collaborations and dissemination plans.

The meeting was attended by representatives of the six Institutions participating in Pattern-Cog and was chaired by Jussi Tohka, project leader, who thanked all attendees for their participation, valuable input, and continued efforts on behalf of the project.

EU project acknowledgements



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

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PatternCog - This project is supported by the Luxembourg National Research Fund (INTER/PerMed21/15748787/Pattern-Cog), under the frame of ERA PerMed

Members of the European Alzheimer's Alliance



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

Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (Renew Europe); Deirdre Clune (EPP); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (EPP); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:**

Vilija Blinkeviciute (S&D). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens/EFA); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Peter Lundgren (ECR).

EU DEVELOPMENTS

10 October: European Commission holds conference on World Mental Health Day



To mark World Mental Health Day on 10 October 2023, the European Commission held a half-day, high-level conference in Brussels, Belgium, hosted by Stella Kyriakides, European Commissioner for Health and Food Safety.

The event brought together hundreds of representatives from the EU institutions, national governments, international organisations and other interested stakeholders to raise awareness of the work undertaken, and supported by, the European Commission.

In particular, the European Commission highlighted its “comprehensive approach to mental health” which was published this year. Additionally, the conference heard from experts and people with lived experience, as well as providing an opportunity for the exchange of good practices linked to:

- Mental health across all policies
- Promotion and prevention
- Equal access for all.

More information and videos from the event are available at:

https://health.ec.europa.eu/events/world-mental-health-day-conference-eu-comprehensive-approach-prioritises-sound-mental-health-all-2023-10-10_en

10 October: WHO Europe launches Lisbon Outcome Statement

During the “Regional summit on policy innovation for healthy ageing in the WHO European”, hosted by World Health Organization (WHO) Europe in Lisbon, Portugal, on 10–11 October 2023, the Lisbon Outcome Statement was launched.

The Statement acts as a concise guide, encapsulating the key priorities and actions outlined during the Regional Summit, identifying key areas for work to ensure a good quality of life for older people. It advocates a life-course approach to healthy ageing, noting the importance of embedding development and

maintenance of functional abilities. Furthermore, it recognises the diverse capacities and life experiences of older adults, whilst noting the need to address persistent inequities tied to socioeconomic status, gender, disability, ethnicity and other social determinants of health. It also contains references to dementia and cognitive issues, including:

- 3A (iii) development and implementation of comprehensive plans for mental and brain health, including neurodegenerative conditions and dementia, to ensure equitable access to prevention, diagnosis, treatment and care services;
- 3B (iv) addressing intersectionality of disability and ageing, and supporting individuals with physical, cognitive and mental impairments, along with their families and caregivers who provide a pivotal caring role for older people with comorbidities, including cognitive impairment.

The full statement can be read at: <https://www.who.int/europe/publications/m/item/lisbon-outcome-statement>

11 October: European Commission launches tools on demographic change

The European Commission has adopted a Communication, presenting a set of policy tools for Member States for managing demographic change and its impacts on the EU’s society and economy. The Communication outlines the wide range of tools including regulatory instruments, policy frameworks and funding, which can be combined with national and regional policies.

The demography toolbox draws on experiences from across the EU and sets out a comprehensive approach to demographic change structured around four pillars. The third pillar is the



most relevant for dementia, as it is focused on empowering older generations and sustaining their wellbeing, through reforms combined with labour market and workplace policies. Additionally, the Communication recognises the need to consider the territorial dimension of demographic shifts, specifically in regions that experience population decline and outward mobility of young workers.

In addition to regulatory instruments and policy frameworks, a number of financing instruments are available at EU level to support Member States, such as the Recovery and Resilience Facility and the European Social Fund Plus (ESF+). Further information is available at: https://ec.europa.eu/commission/presscorner/detail/en/ip_23_4807

17 October: Fundamental Rights Agency publishes report on civil society space



The European Union Agency for Fundamental Rights (FRA) has published its "Civic space update 2023" highlighting the challenges faced by civil society organisations operating across Europe, including actions against those involved in representing vulnerable groups, as well as issues

around funding for civil society

The report highlighted a number of key issues which require action, including:

- Tackling restrictive laws which hamper civil society organisations in protecting human rights and prevent access to information or engagement in policy dialogue.
- Countering threats and attacks against civil society persist, with some policy areas having become more hostile and human rights defenders facing worsening intimidation.
- Providing funding to address the constraints faced by civil society, with some donors adjusting funding to support capacity building and advocacy. In addition, the EU raised its civil society funding.
- Engaging meaningfully in policymaking to address sporadic and ad hoc engagement of civil society in the policymaking process.

The FRA drew its findings from research across the EU, Albania, North Macedonia and Serbia, including responses collected from almost 400 human rights civil society organisations. The full report is available at:

<https://fra.europa.eu/en/publication/2023/civic-space-2023-update>

POLICY WATCH

2 October: At Defeating Dementia conference in Netherlands outgoing Health Minister Conny Helder urges "doing nothing is not an option"

On 2 October 2023, the Dutch Ministry of Health, Welfare and Sport in collaboration with the World Dementia Council organised a conference under the resounding title "Defeating Dementia". Outgoing Minister Conny Helder hosted the

meeting, commenting, "The enormous challenge dementia poses to societies worldwide needs more structural attention. We see hopeful developments in scientific research, but much more effort is needed and we are also in a hurry. It is crucial that we join forces internationally to improve the lives of people living with dementia and ultimately, together, get dementia out of the world."



The beautiful venue - the Museum of Art in The Hague - lent a positive atmosphere to the event from the off. Policymakers and governments, scientists, industry, patients and informal carers gathered to discuss together what has already been achieved and where acceleration of research is needed. It ended with a call to governments worldwide, reaffirmed by Prime Minister Mark Rutte, to double investment in research.

<https://www.alzheimercentrum.nl/blogartikel/defeating-dementia-2023/>

10-12 October: Lausanne X Workshop focuses on "10 Years of Strategic Partnership to End Alzheimer's Disease"

From 10 to 12 October 2023, the 10th annual Lausanne Workshop (Lausanne X) was held, focusing on "10 Years of Strategic Partnership to End Alzheimer's Disease". The Lausanne series of workshops was launched in 2014, as a response to the challenge articulated at the UK G8 Dementia Summit, to stop dementia by 2025. It takes place each year in Lausanne, Switzerland.



Lausanne X recognised important progress in the global fight against Alzheimer's disease and dementia over the past decade and looked to the next set of immediate and longer-range opportunities and challenges. These are the seven high-level areas for action and collaboration that were highlighted:

- Seize policy opportunities to accelerate Alzheimer's innovation in medicines, risk mitigation and health system delivery.
- Challenge the *status quo* to democratise access to affordable Alzheimer's detection, diagnosis, and treatment for all persons with or at risk of Alzheimer's, particularly in resource-constrained settings.
- Integrate blood-based biomarkers, digital cognitive assessments and other new tools for detection and diagnosis into routine clinical care.
- Create and align large-scale risk mitigation strategies, brain health assessments and interventions in resource-constrained settings.

- Define and accelerate the delivery of improved high-performing Alzheimer’s interventions, including active immunotherapies and vaccines.
- Harness innovative models for financing, regulatory reviews, real-world evidence, brain health assessments, clinical trials, and other key areas for delivery and adoption of evidence-based interventions.
- Build the political willpower to link and scale global efforts, including in low-resource settings, to fund and deliver innovation at pace.

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. Angela Bradshaw represented Alzheimer Europe at Lausanne X. Read the full conference report, here: <https://web.cvent.com/event/fb455c2b-9f58-4b6b-91b1-211319d55fa4/summary>

30 October: G7 Leaders’ Statement welcomes outcome of Hiroshima AI Process



Following the work of the Hiroshima AI Process, started under Japan’s Presidency of the G7 Group in 2023, the G7 has issued a Leaders’ Statement welcoming the publication of International Guiding Principles on Artificial Intelligence (AI) and a voluntary Code of Conduct for AI

developers.

President of the European Commission, Ursula von der Leyen, was among those who subscribed to the G7 leaders' statement issued by the 2023 Japan G7 Presidency. The principles and the voluntary Code of Conduct will complement the EU AI Act, which is currently being finalised at an EU level.

There are 11 Guiding Principles aimed at organisations developing, deploying and using advanced AI systems in order to promote safety and trustworthiness of the technology. This includes commitments to mitigate risks and misuse, identify vulnerabilities, encourage responsible information sharing, report incidents and investment in cybersecurity, as well as labelling systems to enable users to identify AI-generated content. The Code of Conduct provides detailed and practical guidance for organisations, as well as promoting the responsible governance of AI globally.

The Leaders’ Statement calls on organisations developing advanced AI systems to commit to the application of the International Code of Conduct. The Leaders’ Statement, Guiding Principles and Code of Conduct are available at:

https://ec.europa.eu/commission/presscorner/detail/en/ip_23_5379

CTAD WATCH



24 October: Phase 2 trial of ABvac40 vaccine reports positive results at CTAD, showing a robust immune response and potential cognitive benefits in very early AD

In a late-breaking presentation at the 2023 Clinical Trials on Alzheimer’s Disease (CTAD) conference, researchers from Araclon Biotech shared positive results from their Phase 2 trial of ABvac40. According to these results, ABvac40 has a favourable safety profile, is able to induce a robust immune response, and may also have some potential cognitive benefits in early Alzheimer’s disease (AD).

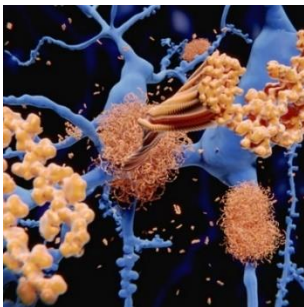
ABvac40 is an investigational vaccine which targets an amyloid beta peptide called AB40. AB40 is one of the amyloid beta peptides that builds up in the brain during the development of AD, and is one of the main components of amyloid plaques. ABvac40 uses vaccine technology to “immunise” patients against AB40, stimulating them to produce antibodies that could help remove amyloid beta peptides from the brain.

Araclon Biotech launched its Phase 2 trial of ABvac40 in 2018, aiming to enrol 120 participants with mild cognitive impairment or very mild AD in Spain, France, Italy and Sweden. This multicentre, randomised, double-blind, placebo-controlled Phase 2 trial was divided into two parts with a total enrolment of 134 patients. Patients in the first part of the trial were randomized to receive a total of six doses: monthly injections of ABvac40 or placebo for 5 months, followed by a delayed booster of ABvac40 or placebo at month 10. The second part of the trial was an extension study with cross-over of treatment, in which placebo patients in the first part received ABvac40, and ABvac40-treated patients received placebo and a booster of ABvac40. Primary endpoints were immunogenicity, safety, and tolerability.

A final analysis of trial results showed that it had reached its primary endpoints, confirming vaccine safety, tolerability and a robust immune response against the AB40 peptide. Evaluation of neuropsychological test scores showed up to a 38% reduction in decline on the Mini-Mental State Examination score, pointing to a potentially beneficial effect on cognition. In their press release, the company also stated that they found favourable results on the RBANS and TMT scales, although no differences were found between placebo and treatment groups for the functional outcomes.

Read the Araclon Biotech press release: <https://www.grifols.com/en/view-news/-/news/araclon-biotech-presents-positive-final-results-from-phase-2-clinical-study-of-abvac40-alzheimer-s-vaccine-at-ctad>

25 October: Biogen presents new findings of its Phase I study of BIIB080 in mild AD



On 25 October, Biogen, a leading global biotechnology company that has pioneered multiple breakthrough innovations, presented new findings from its Phase Ib study of BIIB080 in mild Alzheimer’s disease (AD) at the 2023 Clinical Trials on Alzheimer’s Disease (CTAD) meeting held in Boston.

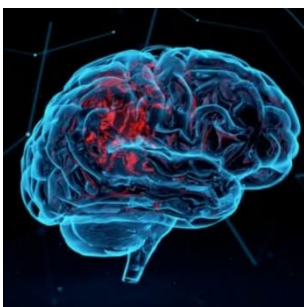
The Phase Ib trial and its long-term extension study (LTE) were designed to assess the safety and tolerability of multiple doses of BIIB080 in people with mild dementia due to AD. BIIB080 is designed to target microtubule-associated protein tau (MAPT) mRNA and reduce production of tau protein.

The company reported that it is the first study of a tau targeting drug that shows reduction of aggregated tau pathology with favourable trends on clinical outcomes. Findings previously reported showed a reduction of tau protein in the cerebral spinal fluid (CSF) and aggregated tau pathology as measured by positron emission tomography (PET) across all brain regions assessed. In the results presented at CTAD, favourable trends were observed on cognition and activities of daily living including the global Clinical Dementia Rating Sum of Boxes (CDR-SB), Mini-Mental State Exam (MMSE) cognitive scales and Functional Activities Questionnaire (FAQ) at week 100 in groups treated with a high-dose of BIIB080. Treatment was generally well tolerated throughout the study. The majority of adverse events were mild or moderate in severity, of which the most common were headache, back pain, pain in extremity, post-lumbar puncture syndrome and procedural pain.

Recruitment for the Phase II CELIA study evaluating the potential of this compound in mild cognitive impairment or mild dementia due to AD, is underway in North America, Europe and Asia Pacific.

<https://investors.biogen.com/news-releases/news-release-details/new-data-biogens-investigational-antisense-oligonucleotide-aso>

25 October: Eisai plans to submit a biologics license application for a subcutaneous formulation of lecanemab to the FDA



On 25 October, Eisai presented new data on lecanemab during a late breaking symposium at the Clinical Trials on Alzheimer’s Disease (CTAD) conference held on October 24-27 in Boston.

In July 2023, the US Food and Drug Administration (FDA) has granted traditional approval to lecanemab for the treatment of

early Alzheimer’s disease (AD). The approval was based on positive results from the CLARITY-AD Phase III clinical trial, which enrolled 1,795 participants who received either

lecanemab or a placebo biweekly via intravenous infusion. The trial showed a 27% reduction in clinical decline for participants receiving lecanemab.

Eisai showed results from a new novel subcutaneous form of lecanemab. Weekly subcutaneous administration of lecanemab resulted in greater (14%) amyloid plaque removal than biweekly intravenous administration. These results are based on a preliminary analysis from a subgroup of participants using amyloid PET at 6 months of treatment. This analysis evaluated the subcutaneous formulation in an open-label extension (OLE) of the Clarity-AD study, which included 72 participants who received lecanemab for the first time as the subcutaneous formulation and 322 participants who received intravenous lecanemab in the Clarity-AD core study followed by subcutaneous administration. In addition, lower systemic injection rates were observed with subcutaneous administration compared to intravenous administration and the incidence of ARIA-E (Amyloid-related imaging abnormalities - cerebral oedema) was similar with both administrations. The company plans to submit a biologics license application for the subcutaneous formulation to the FDA by March 31, 2024.

Eisai also presented results from the optional Tau PET substudy. In the low-tau subpopulation, which is in the earlier stages of early AD, 76% of the participants who received lecanemab showed no deterioration and 60% showed clinical improvement after 18 months of treatment in the primary endpoint, Clinical Dementia Rating - Sum of Boxes (CDR-SB), compared with 55% and 28% of the placebo group, respectively.

In the open-label extension of Clarity-AD, participants continued to received treatment for 24 months. In the 18-month core study, findings showed a statistically significant difference in global cognition and function as measured by CDR-SB between the lecanemab and placebo groups. Differences between treatment and placebo across clinical end points increased over time during the first 18 months. The separation in CDR-SB between the group that continued to receive lecanemab (early start group) and the group who switched from placebo to lecanemab (delayed start group) was maintained during the 6-month open-label extension following the 18-months core study.

https://media-us.eisai.com/2023-10-25-EISAI-PRESENTS-NEW-LEQEMBI-R-LECANEMAB-IRMB-INVESTIGATIONAL-SUBCUTANEOUS-FORMULATION-INTERIM-STUDY-RESULTS-AND-CLINICAL-IMPROVEMENT-DATA-IN-EARLIER-STAGES-OF-EARLY-ALZHEIMERS-DISEASE-FROM-ADDITIONAL-ANALYSES-OF-CLARITY-AD-AT-THE-CLINICAL-TRIALS?utm_source=twitter&utm_medium=social

25 October: Hummingbird Diagnostics presents its latest research at CTAD

Hummingbird Diagnostics GmbH, a leader in blood-based small RNA detection and characterisation, presented its latest research at the Clinical Trials in Alzheimer’s Disease (CTAD) conference held between 24 and 27 October in Boston (US). The company is pioneering the development of novel small RNA-based blood diagnostics for early disease detection of a broad range of indications. Its novel small RNA discovery “mirCator” platform breaks new ground and sets the standard

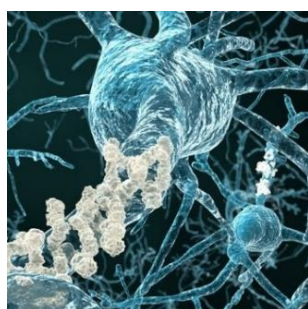
for analysing and mapping small RNAs from blood. The company said that the mirCator platform combines proprietary wet lab innovations, largely automated workflows and advanced machine learning data analysis to deliver unprecedented technical performance. The company has applied its state-of-the-art “mirCator” platform to answer critical questions related to Alzheimer’s disease (AD). This holds the potential for early disease detection, disease-specific prognostics, treatment response prediction, and the development of patient-centric therapies.

The featured work in AD was made possible through funding by the Alzheimer’s Drug Discovery Foundation (ADDF) and the collaboration with researchers from the European Prevention of Alzheimer’s Dementia Project (EPAD) and their Longitudinal Cohort Study that screened over 2,000 participants and collected a wide range of cognitive, clinical, neuroimaging and biomarker data in people at risk of Alzheimer’s disease. In his poster presentation entitled “Blood-Based small RNA Biomarkers and the ATN(V) Framework: Predicting Neurodegeneration and Vascular Profiles in the EPAD Cohort”, BrunoSteinkraus, CSO of Hummingbird Diagnostics, presented a study aiming to identify specific blood-based miRNA signatures in people with AD. Findings suggested the potential of a small RNA-based blood test as a viable complement to the ATN (Amyloid, Tau, Neurodegeneration) framework for the management of people at risk for AD.

<https://www.hummingbird-diagnostics.com/newsroom/press-releases/Hummingbird-Diagnostics-GmbH-to-Unveil-Pioneering-Alzheimer-s-Disease-Biomarker-Research-at-CTAD-Conference/>

SCIENCE WATCH

21 September: Findings from the A4 Study of solanezumab for preclinical AD have been published



Launched in 2013, the A4 study was a double-blind and placebo-controlled Phase III study testing the anti-amyloid drug, solanezumab, in cognitively normal older people (65-85 years old) who had brain PET scans showing evidence of amyloid build-up. The study included more than 1.100 participants

who were randomised to receive either solanezumab or placebo every four weeks during approximately 4.5 years.

Earlier this year, the pharmaceutical company Eli Lilly reported that the trial failed to meet its primary goal of slowing cognitive decline in the Preclinical Alzheimer Cognitive Composite (PACC) score. Secondary clinical outcome results were consistent with the primary outcome. Solanezumab, which targets monomeric amyloid in people with elevated brain amyloid levels, did not slow cognitive decline as compared with placebo over a period

of 240 weeks in persons with preclinical AD. Findings have been recently published in The New England Journal of Medicine:

<https://www.nejm.org/doi/full/10.1056/NEJMoa2305032>

26 September: Synaptogenix reports new findings from its Phase II trial of Bryostatin-1 in AD

On 26 September 2023, Synaptogenix, a clinical-stage biopharmaceutical company developing therapeutics for neurodegenerative disorders, announced a peer-reviewed publication of data from its Phase II trial of Bryostatin-1 for Alzheimer’s disease (AD) in the Journal of Alzheimer’s Disease.



The Phase II trial was a 6-month randomised, double-blind and placebo-controlled study comparing Bryostatin-1 to placebo for long-term efficacy in the treatment of advanced and severe AD in the absence of memantine. A total of 221 participants were enrolled in the study. The overall treatment emergent adverse event profile was similar between the placebo and Bryostatin-1 groups. Findings showed that six months of treatment with Bryostatin-1 slowed cognitive decline in participants from the moderate group (MMSE 10-14) compared to placebo group. This effect was maintained four months after stopping treatment.

<https://content.iospress.com/articles/journal-of-alzheimers-disease/jad230868>

27 October: Alector announces completion of enrolment in INFRONT-3 trial of latozinemab for frontotemporal dementia

On 27 October, Alector announced the completion of target enrolment to INFRONT-3, their Phase 3 trial of latozinemab for a heritable form of frontotemporal dementia, linked to mutations in the progranulin gene (FTD-GRN). INFRONT-3 is evaluating the safety and efficacy of latozinemab in slowing disease progression, aiming to recruit 90-100 symptomatic participants with FTD-GRN. Recruitment has now been completed, with 101 participants from north America, Europe, Argentina and the Asia-Pacific region.

FTD is a rare neurodegenerative disease that affects over 100,000 people in Europe. There are many different forms of FTD, and one of the most common heritable forms of FTD is caused by mutations in the progranulin gene. Progranulin is a key regulator of immune activity in the brain, and loss-of-function mutations in the progranulin gene causes inflammation and progressive loss of brain cells, leading to FTD. Alector’s drug Latozinemab, which is being developed in collaboration with GSK, is a monoclonal antibody designed to block sortilin, a protein that is involved in the degradation of progranulin. Latozinemab was designed to slow down the degradation of progranulin, thereby enhancing the activity of microglia, the primary cells of the brain’s innate immune system.



INFRONT-3 is a pivotal, randomised, double-blind, placebo-controlled Phase 3 clinical trial, which is enrolling symptomatic and at-risk participants with FTD-GRN. Participants are randomized to receive latozinemab or placebo intravenously every four weeks for the duration of the 96-week trial and are being given the option to continue receiving treatment in the open-label extension (OLE) study after the 96-week treatment period. The primary endpoint in INFRONT-3 is disease progression as measured by cognitive and functional scales that assess the severity of FTD. INFRONT-3 will also assess progranulin levels in cerebrospinal fluid and plasma, mapping how levels change in response to treatment and in relation to FTD symptoms.

Read the Alector press release: <https://investors.alector.com/news-releases/news-release-details/alector-announces-achievement-target-enrollment-pivotal-infront>

31 October: Electroencephalogram (EEG) headset could help spot early Alzheimer’s disease



Researchers at the University of Colorado Anschutz Medical Campus have developed a technique that may spot the very early signs of Alzheimer’s disease (AD), years before symptoms arise. The method

involves using a simple electroencephalogram (EEG) headband while sleeping. The researchers have identified EEG signatures in ageing adults that may indicate early AD pathology. These EEG phenomena relate to memory reactivation that occurs during sleep, and may reveal aspects of early-stage AD such as amyloid positivity and cognitive decline.

AD has significant consequences for those who experience it and those who support them. Moreover, with the ageing population, levels of AD are likely to significantly increase. Identifying the disease early is difficult and many people are diagnosed when symptoms such as memory loss have already manifested. However, this new method may alert patients and clinicians to an increased risk of the disease, potentially allowing them to take steps to slow progression. A study was recently published in the journal Alzheimer’s & Dementia:

<https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13420>



MEMBERS’ NEWS

28 September: Association Luxembourg Alzheimer inaugurate newly-expanded "Beim Goldknapp" residential and nursing home

The Beim Goldknapp nursing home opened its doors in 2007 in Erpeldange-sur-Sûre, Luxembourg. The home specialises exclusively in the care and support



of people with dementia. With the growing number of people living with dementia, it soon became clear that the demand for a specialist facility would only increase. This encouraged those in charge of the Association Luxembourg Alzheimer (ala) to take steps to expand the Beim Goldknapp residential and nursing home.

After careful planning and obtaining the necessary permits, work began in spring 2021 and after two years of construction, the new building welcomed its first residents in August 2023. It offers 36 additional rooms divided into three specialised units: "Am Weessefeld", "Beim Kiischtebam" and "Bei den Tulpen". Each unit comprises a living area and 12 single rooms, each measuring 24 m2.

- The "Am Weessefeld" living unit is reserved for people with dementia and special needs.
- Bei den Tulpen" is for young people with dementia.
- The "Beim Kiischtebam" living unit is for people with dementia and is identical to the existing units in the "Beim Goldknapp" residential and nursing home.

The new living units were inaugurated on 28 September 2023, in the presence of Max Hahn, Minister for the Family, Integration and the Greater Region, and Claude Haagen, Minister for Social Security.

11 October: The Alzheimer Society of Ireland honoured at Hidden Hearing Heroes Awards

Both The Alzheimer Society of Ireland (ASI) and Kevin Quaid, Chair of The Irish Dementia Working Group and Vice-Chair of the European Working Group of People with Dementia were honoured with awards at the Hidden Hearing Heroes Awards in Dublin, Ireland on 11 October 2023.



Kevin Quaid was awarded the Hard of Hearing Award, while the ASI received the Special Recognition Award. Now in its 25th Year, the Hidden Hearing Heroes Awards celebrates good



deeds and achievements, both big and small, of people across Ireland.

24 October: Scottish Dementia Working Group and National Dementia Carers Action Network members were at the heart this year's Alzheimer Scotland Conference



Alzheimer Scotland's Annual Conference is always a highlight in the Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN) calendar – it's a

great opportunity to listen, to learn, to catch-up with old friends, and to make new ones. It's a chance to engage and to share experiences. And this year's Conference was one of the best, with members of both groups at the heart of the day.

Welcoming delegates to the Conference, which took place in mid-September, SDWG member Stuart Dougall (pictured, left) spoke about the difference that Alzheimer Scotland support had made, early in his dementia journey and the importance of innovative practice in helping people to live well with dementia.

Anne Tierney, from NDCAN, highlighted the work of the group and the challenge that current carers have in finding time to campaign for change. She took the opportunity to encourage delegates, both current and former dementia carers, to consider joining NDCAN so that their personal experiences can help shape the group's campaigning and awareness-raising work.

The first session of the day looked at how innovative work and progressive practice is helping to support the dementia community. SDWG and NDCAN members Christine and Bill Alexander shared their story of living together with dementia; highlighted the support and dedication of Alzheimer Scotland staff and front-line services where they live; and spoke about the opportunity they have to shape policy, practice and care through their Active Voice work.

During lunch, delegates were entertained by the Every Voice Community Choir, including SDWG members Tony Worthington and Danny McDonald, following which the Conference explored the issue of women's brain health and dementia, to get a better understanding of the issues facing women today. Introducing the session, NDCAN member Thea Laurie emphasised that women's brain health must be a priority; highlighted that brain health is not mentioned in the Scottish Government's Women's Health Plan; and called for data on women living with dementia to be included in the Plan. "It is as if a vital chapter has been missed out", she said.

The final session of the day considered how research, learning and developments are offering hope for the future. SDWG member Rynagh Flynn kicked off this session by sharing personal experiences of her diagnosis; speaking about her

membership of Join Dementia Research; her contact with Scottish Brain Sciences; and her participation in dementia research which has offered her hope and helped improve her quality of life.

Throughout the day, SDWG and NDCAN members engaged with representatives from the dozens of organisations represented at the Conference, and provided information on their campaigning and awareness-raising work, to the steady stream of delegates who visited the Active Voice information stand. Recordings of all the Conference sessions are available on the Alzheimer Scotland website: <https://www.alzscot.org/conference23>

25 October: The Alzheimer Society of Ireland launches new report called "The Experience of Dementia in Ireland: A Snapshot in Time"

As part of World Alzheimer Month, The Alzheimer Society of Ireland launched "The Experience of Dementia in Ireland: A Snapshot in time". This national report captures the experience of living with dementia and caring for someone with dementia in Ireland in 2023. The results highlight the multi-faceted and complex challenges facing those affected by the condition.



This new research was carried out in early summer with almost 670 people, including both carers and people living with dementia. Many are struggling with issues such as burnout, isolation, poor mental and physical health against the backdrop of the Cost of Living Crisis. Respondents highlighted the importance of their local communities and staying connected to prevent loneliness and isolation.

Read the full report and plain language summary here:

<https://alzheimer.ie/creating-change/research/dementia-in-ireland2023/>

27 October: The Alzheimer Society of Finland writes "Co-hosting the 33rd Alzheimer Europe Conference – the Finnish experience"

The Alzheimer Society of Finland, Muistiliitto, welcomed the conference to Helsinki after 26 years. Bringing insights from the Finnish dementia scene, we were



glad to have the opportunity to work with the dedicated Alzheimer Europe team to build a topical programme. With a multitude of plenaries, parallel sessions, quick oral

presentations and posters we wanted to reflect the richness of approaches to dementia in current research, care and best practices.

– With prevention potential of 40 percent, promoting brain health during the whole life course needs to be a worldwide priority in tackling the growing number of diagnoses in the future. Finland has been paving the way in dementia prevention research; thus, latest developments in FINGER trials around the world took centre stage in the programme, Katariina Suomu, Executive Director, points out.

An emerging theme, inclusion aroused interest among many delegates. Both research findings and personal accounts stressed the importance of equal access and opportunities to all people living with dementia and their carers. Overall, the voice of people living with dementia was perhaps stronger than ever. The work of EWGPWD members and other individual sharing their stories is key to making sure that people living with dementia remain the common thread of our work. Finally, it was a great delight to see a new generation of researchers joining the conference. We need passionate professionals also in the future.

A special programme of Finnish sessions offered (Finnish) delegates an opportunity to learn in depth about developments in Finland as well as to network with their local colleagues. Among other things, it provided a sneak peek of latest statistics of prevalence and incidence of dementia in our country. A session with the Finnish Institute of Health and Welfare shed light on their long-standing memory service path project that aims to provide older population and at-risk groups with preventive measures and to strengthen equality of services and works in close cooperation with a number of actors to implement lifestyle interventions.

A live event is very much about networking, building bridges between countries and individuals, theory and practice. The buzz created by over 1,000 delegates sent a strong message about our common will to work towards a dementia-friendly world, and the ambitious steps taken in this direction.

Pictured: Professor Jenni Kulmala, Chairperson of Alzheimer Society of Finland at the opening ceremony

27 October: Alzheimer Scotland introduces its new Commission on the future of long-term Care



Alzheimer Scotland is pleased to announce the establishment of its Commission on the future of long-term care. Alzheimer Scotland is committed to improving the quality and the variety of long-term care options for people with dementia and their families and carers and, as Scotland continues to

recover from the effects of the pandemic and ongoing challenges in the delivery of health and social care services, we recognise that current options for the long-term care of people with dementia are not always designed to meet their complex and specific needs. We have taken steps to address this issue by establishing a Commission to consider alternative

approaches to delivering more effective long-term care and support.

The Commission, led by former First Minister of Scotland and Alzheimer Scotland Ambassador, Henry McLeish, will consider what changes and improvements are needed in the current environment to address issues including ensuring the provision of high quality care and support, tackling health inequalities and upholding human rights for people living with dementia. The Commission will seek to identify innovative, cost-effective, and affordable solutions for achieving any recommended changes to the current model of provision and will consider alternative approaches to care and support that will meet the needs of those who need it, in a way that they want to access and receive it.

The Commission will convene a number of meetings over the coming year and will hear from a number of key stakeholders as it seeks to establish a set of national recommendations for Scottish Government and other stakeholders which set out a new, fairer, more person-centred and sustainable policy, practice, and funding model for the long-term care of older people and people with dementia in Scotland. This includes input from people with lived experience through a series of public engagement events that will ensure the Commission is informed about public expectations and views on long-term care. The Commission will report its findings in Spring/Summer 2024.

30 October: Activities take place across Greece throughout World Alzheimer's Month (September) and October

Two months full of successful events were organised by the members of the Panhellenic Federation of Alzheimer's Disease and Related Disorders in order to celebrate the World Alzheimer's Month (WAM) 2023. Throughout Greece, speeches, festivals, memory walks, informational stands, free memory tests and many more awareness activities were hosted by the Alzheimer's associations.



Athens

"Alzheimer Athens" organised the 1st Alzheimer's festival with great success at the Stavros Niarchos Foundation Cultural Center. More than 3,500 people visited the festival, 300 memory tests were conducted and also an informational speech. The Greek Minister of Health attended the event and called dementia a "national issue". He committed to promote the draft law to defend the rights of people with dementia and their carers as well as the full implementation of the National Action Plan on Dementia-Alzheimer's. Finally, he announced the establishment of a National Alzheimer's Council. At the end, there was a performance by a famous stand-up comedian who highlighted her message "Live your life and don't be afraid of illness. Only fear makes it stronger". Alzheimer Athens also carried out informational activities in Peiraias, Neo Irakleio, Thrakomakedones and the city of Arta.

The association “Nestor” held a successful informative all-day session entitled “A hug for Alzheimer’s” at the conservatory of Athens. The association “Karreleio” held speeches, informative stand and free memory tests.

Thessaloniki

“Alzheimer Hellas” organised a successful theatre performance entitled “21” by the theatre group of Alzheimer Hellas - Agia Eleni (the group was created in 2013 from beneficiaries - the group has presented eight plays, performing ten shows in five different theatres with the participation of over 30 actors). 300 people enjoyed the evening promoting the motto “Never too early, never too late!” Alzheimer Hellas also held informational stands in “Balkan Square” for a week, in Menemeni square and at the Youth Volunteering Festival “Connected we stand”. Speeches and memory tests were also carried out in Thessaloniki and in the city of Giannitsa in collaboration with health structures and public libraries.

Crete

In Heraklion, the “ALLILENGII” Association for Alzheimer’s disease and healthy aging hosted a festive event at the Cultural Center of Heraklion on the occasion of completing five years since the first screening of the multi award-winning film REMEMBER ME, a film dedicated to carers of people with dementia, and its social impact.

Chania

The Alzheimer’s Association in Chania held an all-day scientific event aimed at informing and raising public awareness on the ethical, legal and social issues that arise after the initial diagnosis of the disease.

Patra

The “Frontizo” association organised an informative event entitled “Creating accessible services for dementia” and co-organised an intergenerational workshop with creative activities and games enjoyed by both young and elderly participants.

Larissa

Alzheimer’s Larissa fulfilled the 5th Memory Walk called “Mnemosyne”. The Walk constitutes an institution and a top festive event for the city. The Memory Walk consisted of the members of the Board of Directors, and accompanied by the music sounds of the Philharmonic, in the light of the purple fountains and hundreds of purple balloons that flew over the crowd of beneficiaries, volunteers, Dementia Friends and others. The event ended with a reception, within the historical site of the fortress. The aftermath of the Memory Walk was positive, due to the large crowd and huge promotion from the electronic media. A press conference, prior to the event, was given to the Thessalian TV and radio media, regarding the new developments around the treatment of Alzheimer’s disease, pointing out that prevention is the most important tool for reducing the prevalence of dementia.

Chalkida

REMIND-Alzheimer Chalkidas association carried out various awareness-raising actions and open discussions in health structures. Free memory tests and a campaign to promote a

new healthy ageing workshop for people over 60 were successfully carried out.

Ioannina

The association “EPSEP” held a speech on the benefits of physiotherapy in dementia, conducted free memory tests, gave information to the public about dementia and blood sugar measurement and took part in the 5km race of the Ioannina Lake Run with the motto “We run for dementia”.

Rhodes

The “Alzheimer’s Association Panakeia” carried out diet, physical exercise and social and spiritual activities. Also blood/pressure tests and memory tests on WAD in the centre of the city to promote the importance of healthy living.

Serres

The association “SOFPSI” included in the 15th Festival for Mental Health memory tests on people over the age of 60.

Katerini

The Day Care Center of Alzheimer Hellas organised a speech and a liaison action at two health care facilities and a two-day information action for citizens in the main town square.

Kozani

The Day Care Center of Nestor held an information event for the local community in the central town square, a speech and a visit of staff members and beneficiaries to a kindergarten school.

30 October: Panhellenic Federation delighted that a recently-created TV slot about Alzheimer’s disease is among its important 2023 activities under the auspices of the Ministry of Health

The Panhellenic Federation’s initiative to hold online lessons for health professionals every Monday morning and a monthly online informative session for the general public and health professionals has continued throughout 2023, under the auspices of the Ministry of Health.

The Panhellenic Federation is also very pleased to announce that, since March, another significant informative activity is available in Greece; this time a TV collaboration. Every Thursday morning, on the programme “We start together”, on DION TV, there is a fixed column for the presentation of topics related to Alzheimer’s disease and neurodegenerative diseases. The TV show is also broadcast nationally, live, through internet TV and the recordings are available on demand, online, via the Panhellenic Federation’s social media.

A huge number of 25 presentations have been held up until now, with experts on every topic and the public response has been great. More specifically, the topics on the TV show in September and October were: Sleep and dementia, Cardiovascular problems and dementia, Clinical diagnostic procedure, Neuropsychological Process, EEG and evoked potentials, Biomarkers and Digital markers. The Panhellenic Federation is confident that this initiative will lead to more publicity and awareness concerning every aspect of the disease.

LIVING WITH DEMENTIA

24 October: Scottish Dementia Working Group Member and European Working Group of People with Dementia Vice-Chair Margaret McCallion speaks at Global Ageing Conference



The 2023 Global Ageing Network Conference was held in Glasgow, in September, in conjunction with Scottish Care and the National Care Forum – leading care and support provider associations in Scotland and England. This provided an outstanding opportunity and venue for colleagues to gather in a unique forum dedicated to shared learning and professional networking.

The conference showcased innovative and forward-looking programmes and approaches from around the world, and offered a stimulating forum for the exchange of both practical knowledge and new strategies focused on the provision of high quality care and support. Delegates had the opportunity to learn about innovative practices, explore new ideas, and create environments that maximise the quality of life for those who require/access care and support.

Scottish Dementia Working Group (SDWG) Member and European Working Group of People with Dementia (EWGPWD)

Vice-Chair Margaret McCallion presented at the conference. Margaret was invited by the CEO of Scottish Care, Donald Macaskill to share her personal experience living with her diagnosis but also her aspirations for social care and services as she gets older. Margaret shared how she lives her "best life" and asked the audience to "see the person, not their age, not their illness but the whole person".

As part of the panel discussion Margaret McCallion shared the work of the Active Voice Team and how the SDWG makes a difference and tries to bridge the gap between policy and practice.

"Getting older has lots of challenges in itself without the worry of your needs being met within an already stretched social care system. What do I want for the Future ? I want to be listened to. I want to have choices. I want to stay in my community. I want to have my human rights upheld", said Margaret.

Pictured: Margaret with Active Voice Lead, Wendy Rankin-Smith and CEO of Scottish Care, Donald Macaskill.

29 October: "New opportunities for people with dementia" - Lieselotte (Lilo) Klotz, member of the European Working Group of People with Dementia, writes about the Alzheimer Europe Conference

Many months before our travel to Helsinki there was great excitement. The 33rd Alzheimer Europe Conference was sure to be another milestone for our entire European Working Group of People with Dementia (EWGPWD) team. Then, it was finally time. Speeches, interviews and texts for the manifesto were prepared and rehearsed. It could start. We were ready. And we had all prepared a lot!

The rain and cool temperatures could not dampen our spirits nor the joy of holding each other in person again and sharing our thoughts and stories from the past months.

The Opening Ceremony, on 16 October, was a firework display of fantastic speeches and enthusiasm and there was a record number of over 1,100 participants (including 1,000 in person) from 48 countries. The first plenary session was organised and moderated entirely by the EWGPWD. It put people with dementia in the spotlight. This plenary session, "Transforming personal experiences into political advocacy and public involvement in dementia research" ended with a standing ovations for the Chair Chris Roberts (Wales, United Kingdom) and the four speakers, Kevin Quaid (Ireland), Pia Knudsen (Denmark), Věra Ryšavá (Czech Republic) and Nigel Hullah (Wales, United Kingdom); for their authenticity, their attitudes, their personal accounts and emotions. I was so touched by their speeches. It was incredible, it was wonderful. They thrilled the hall. The four speakers represented our EWGPWD so well. They can all be very proud of themselves. Well done!



In the late afternoon, I gave a speech, titled "Why is the National Dementia Strategy so important? The perspective of a person living with dementia from Germany", at a session on national dementia strategies. For me, national dementia strategies are indispensable, core elements in the fight against dementia - in every country in Europe and worldwide. We, in Germany, have such a strategy. But, as in almost all European countries, there is still a lot of room for improvement. That's precisely why I was very pleased to be able to give this speech in Helsinki. There is still a lack of strong common political will, joint strategic action and, above all, the necessary financial planning and binding commitments to provide the urgently needed financial resources. We can do better. We must!

Several members of the group also spoke at other sessions throughout the conference, including Margaret McCallion (Scotland, United Kingdom), Marguerite Keating (Ireland) and Real Larnou (Belgium). During the important policy round table in the final plenary session, Chris was brilliant as one of the participants and Petri spoke at several sessions throughout the event, with Finland being his home country.

The posters presented were visually impressive and conveyed the complex topics chosen in an understandable way. The speeches, lectures, presentations, meetings and conversations were not only informative but also inspiring. Everyone shared their expertise. The most complex topics were treated with so much enthusiasm and expertise that they will remain anchored in our minds. This is invaluable and will undoubtedly leave a long-lasting impression on all of us.

The EWGPWD team was able to contribute in a variety of ways with our own experiences, perspectives and concentrated knowledge and actively participate in the organisation of the Conference. The group plays a crucial and indispensable role at European level in actively representing the perspectives of people with dementia. All of this together has made Helsinki a place of lively learning and exchange and made the event very special.

From the bottom of our hearts, thank you to everyone for the incredible support before, during and after our wonderful and so meaningful conference in Helsinki. It was an unforgettable journey together and I am so grateful to be part of this remarkable community and am already looking forward to many more great projects and tasks. With this in mind, see you again at the 34th Alzheimer Europe Conference in Switzerland in 2024!



<https://news.liverpool.ac.uk/2023/10/25/university-convenes-dementia-conference/>



DEMENTIA IN SOCIETY

25 October 2023: 5th annual Liverpool Dementia and Ageing Research Conference



On 25 October, the University of Liverpool hosted the 5th edition of the annual Liverpool Dementia and Ageing Research Conference. The event brought together over 120 dementia researchers, care professionals, Third Sector organisations, and people with dementia and unpaid carers.

The one-day event was an opportunity for speakers to highlight their research and work aimed at improving the lives of people affected by dementia. Speakers and attendees discussed new research, care practices, and co-production and jointly thought about solutions at a live panel discussion.

Alzheimer Europe was pleased to be represented by Project Communications Officer Christophe Bintener, who held a presentation on our work and also disseminated some of our recent publications at a dedicated stand.

NEW PUBLICATIONS AND RESOURCES

16 October: Report on "Painting a common future in Alzheimer's disease", launched by the Finding Alzheimer's Solutions Together (F.A.S.T.) Council at Alzheimer Europe Conference

On 16 October 2023, at the 33rd Alzheimer Europe Conference, a new report sharing insights for fostering collaboration between the pharmaceutical industry and patient organisations was launched by the Finding Alzheimer's Solutions Together (F.A.S.T.) Council. The report, "Painting a common future in Alzheimer's disease", delves into best practices and explores topics such as how to optimise the journeys of people with dementia and their supporters, inclusive language, raising awareness and advocating for better care, conducting inclusive clinical trials, diversity and inclusion.



The F.A.S.T. Council is sponsored by Roche and includes members from patient organisations such as Alzheimer Europe. Jean Georges, Executive Director, Alzheimer Europe co-authored this report.

You can download the report, here:

https://www.rocheresources.co.uk/content/dam/hcp-portals/uk2/documents/alzheimers/AD_FAST_Roche_Report_Paintin_g_a_common_future_in_Alzheimers_disease_Aug23_M-GB-00013392.pdf

16 October: Report on "Advancing Diverse, Equitable and Inclusive Research in Alzheimer's Disease Clinical Trials " launched by Roche at Alzheimer Europe Conference



On 16 October 2023, at the 33rd Alzheimer Europe Conference, a new report on "Advancing Diverse, Equitable and Inclusive Research in Alzheimer's Disease Clinical Trials " was launched by Roche. For this report, Roche, in collaboration with patient organisations and experts in Diversity, Equity, and Inclusion (DE&I), examined the pressing need and challenges in achieving greater DE&I in Alzheimer's Disease (AD) clinical trials.

The result is a comprehensive report outlining aspirations for DE&I in AD research and the essential steps necessary to reach those goals. Dianne Gove, Director for Public Involvement and Ethics at Alzheimer Europe, contributed to this report.

You can download the report, here:

https://www.rocheresources.co.uk/content/dam/hcp-portals/uk2/documents/alzheimers/AD_DEI_Roche_Report_Advancing_Diverse_Equitable_and_Inclusive_Research_in_Alzheimers_Disease_Clinical_Trials_Sep2023_M-GB-00013700.pdf

24 October: Video of touchSATellite Symposium "Clinical care pathway for Alzheimer's disease: Driving improvements in diagnosis" at World Congress of Neurology is available



A new video published by touchNEUROLOGY features experts in neurology, geriatrics and neuroradiology, who came together at the World Congress of

Neurology (WCN) 2023 to highlight the importance of a timely and accurate biological diagnosis of Alzheimer's disease (AD) and provide practical insights into current and emerging diagnostic tools. The expert panel, which met during this year's WCN, from 15-19 October 2023 in Montreal, Canada, goes on to discuss the importance of patient-centred care and explore the role of the dementia care team in supporting the patient along the AD continuum. This symposium was jointly provided

by USF Health and touchIME (touch Independent Medical Education). Watch the full symposium video, here:

https://touchneurologyime.org/clinical-care-pathway-for-alzheimers-disease-driving-improvements-in-diagnosis/?_ga=2.168412264.814822317.1698145446-1801831410.1698145446

28 October: "Reconsidering Neighbourhoods and Living with Dementia: spaces, places and people" book published with a foreword by Alzheimer Europe's Executive Director Jean Georges

In late October 2023, a new book called "Reconsidering Neighbourhoods and Living with Dementia: spaces, places and people" was published, edited by Professor John Keady at the University of Manchester, United Kingdom (UK). It was launched at an event on 28 October, at the Whitworth Art Gallery, The University of Manchester, UK.

The book celebrates the main study outputs of the five-year "Neighbourhoods study" that took place in the UK and Sweden between 2014 and 2019. The study was funded by two research councils in the UK, the Economic and Social Research Council (ESRC) and the National Institute for Health and Care Research (NIHR), and Jean Georges, Executive Director, Alzheimer Europe, was a member of the International Scientific Committee of the Neighbourhoods study throughout its duration. He wrote one of the two forewords in the book and in his reflection of his time spent on the study, he shared:

I sincerely hope that the findings and results will be studied by other researchers and taken up and implemented by local politicians and administrations interested in improving the lives of people with dementia in their neighbourhoods.

Over its 13 chapters, "Reconsidering Neighbourhoods and Living with Dementia" brings together: the key findings of all eight work programmes that comprised the Neighbourhoods study; the main outcomes of the four PhD studies (all completed) that were attached to the programme of work; and a conversational chapter on large-scale project administration which is largely under-reported in dementia studies. The book is divided into five parts and people living with dementia were closely aligned to the Neighbourhoods study through advocacy groups such as the Scottish Dementia Working Group and the Open Doors Research Group in Salford, Greater Manchester. The book contains a wide range of approaches to better understanding the experience of living with dementia in the neighbourhood, including the use of Big Data sets and creative social research methods such as walking interviews, social network mapping and the co-production of films and animations by people living with dementia.

This range of approaches is illustrated throughout the book. The book is also part of a new series called "Reconsidering Dementia" edited on behalf of the Open University Press/McGraw-Hill by Dr Keith Oliver and Professor Dawn Brooker MBE.

Full details of the new Book: Reconsidering Neighbourhoods and Living with Dementia: spaces, places and people (John

Keady, Editor). Open University Press/McGraw-Hill, Maidenhead, UK. ISBN-13: 9780335251728. Book ordering link:

<https://www.mheducation.co.uk/reconsidering-neighbourhoods-and-living-with-dementia-spaces-places-and-people-9780335251728-emea-group> [mheducation.co.uk]



Pictured: The book launch at the Whitworth Art Gallery, The University of Manchester, UK. Pictured are the Editor (in the brown jacket) and some of the authors whose work is featured in the book.

30 October: Dementia Researcher podcast looks at highlights from Alzheimer Europe Conference in Helsinki

A new podcast by Dementia Researcher (UK), hosted by Adam Smith and recorded directly after the 33rd Alzheimer Europe Conference, in Helsinki, looks at some of the highlights from the event.

Host and Programme Director Adam Smith talks to Dr Victoria Shepherd, Senior Research Fellow and Nurse from Cardiff University, Dr Monica Leverton, Postdoctoral Researcher at King’s College London, Dr Danielle Jones, Associate Professor in Dementia Studies at University of Bradford and Caroline Bartle, Dementia Project Specialist at Ryman Health Care in New Zealand. You can find the podcast on the Dementia Researcher website:

<https://www.dementiaresearcher.nihr.ac.uk/podcast-alzheimer-europe-conference-roundup-2023/>



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Alzheimer Europe Board:

Chairperson: Maria do Rosário Zincke Dos Reis (Portugal); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: Mario Possenti (Italy); Honorary Treasurer: Marco Blom (Netherlands). Members: Stefanie Becker (Switzerland), René Friederici (Luxembourg), Lorène Gilly (France), Andy Heffernan (Ireland), Sonata Mačiulskytė, Chairperson of the European Dementia Carers Working Group (Lithuania), Martina Mátlová (Czech Republic), Mary-Frances Morris (United Kingdom), Chris Roberts, Chairperson of the European Working Group of People with Dementia (United Kingdom), Katariina Suomu (Finland), Jochen René Thyrian (Germany).

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AE CALENDAR 2023

Date	Meeting	AE representative
7 November	EFPIA roundtable event: Elevating Alzheimer's Timely Detection and Care: A European and Belgian Perspective (Brussels, Belgium)	Ange
9-10 November	Prominent General Assembly meeting (Stockholm, Sweden)	Ange, Daphné & Chris
10 November	X Congreso Nacional de Alzheimer CEFAA (Gijón, Spain)	Soraya
13 November	British Embassy life sciences conference "Unravelling Dementia Together: Innovations from UK and Belgium" (Brussels, Belgium)	Ange
13 November	Alzheimer's Association Academy on "Legal capacity and decision making"	AE members and staff
14 November	EU-FINGERS, LETHE and Multi-MeMo Advisory Board meeting (Luxembourg)	Ana and Cindy
14 November	WHO consultation on achieving health for persons with disabilities	Owen
14-15 November	EMA Patients' and Consumers' Working Party meeting	Ange
15 November	eBRAIN-Health Advisory Group Meeting (Luxembourg)	Ange and Daphné
15 November	EWGPWD Meeting (Luxembourg)	Ana and Soraya
16 November	ADIS Advisory Group Meeting (Luxembourg)	Ana and Soraya
22 November	EFPIA Patient Think Tank	Owen
28 November	EU4Health Civil Society Alliance	Owen
28 November	EDCWG consultation	Ana, Daphné, Dianne and Soraya
29-30 November	EPND General Assembly meeting (Athens, Greece)	Ange
30 November-1 December	European Day of Persons with Disabilities (Brussels, Belgium)	Daphné

CONFERENCES 2023-2024

Date	Meeting	Place
15-17 November	Université d'automne «Éthique et maladies neurologiques évolutives» 2023, https://www.espace-ethique.org/actualites/universite-dautomne-ethique-et-maladies-neurologiques-evolutives-2023	Marseille, France
8-10 October 2024	34 th Alzheimer Europe Conference: "New frontiers – Innovating for dementia"	Geneva, Switzerland



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34th Alzheimer Europe Conference
New frontiers –
Innovating for dementia
Geneva, Switzerland
8 - 10 October 2024 #34AEC
www.alzheimer-europe.org/conferences

