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# ALZHEIMER EUROPE NEWSLETTER

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## WELCOME



To mark World Alzheimer's Day this year, we were delighted to launch a new initiative called "What Makes You, You?", a collaborative effort between Roche, the European Working Group of People with

Dementia (EWGPWD) and Alzheimer Europe. It is a series of videos sharing the stories of three members of the EWGPWD, looking beyond an Alzheimer's diagnosis and celebrating people for who they are.

The new EWGPWD, whose two-year mandate begins after our Annual Conference, has been confirmed. The current group held its final meeting in Brussels and welcomed new members, as well as saying goodbye to departing members. Our Brussels meetings also included a Board meeting, a company round table, a European Parliament lunch debate and an Alzheimer's Association Academy looking at aspects of employment and dementia. The lunch debate was hosted by Sirpa Pietikäinen, MEP and discussed artificial intelligence and big data in research. Other Alzheimer Europe activities this month included co-authoring a new study on "Development and design of a diagnostic report to support communication in dementia: Co-creation with patients and care partners"; joining members of the EU4Health Civil Society Alliance in calling for the European Commission to include Operating Grants in the EU4Health 2023 Work Programme; and signing an agreement to support the International Psychogeriatric

Association's Older Adults Mental Health Awareness Week, from 1 to 10 October.

Our members have been very busy too, with World Alzheimer's Day (and month) activities. You can read about some of these in a special section, starting on page 20. Congratulations to them all, for their many and varied campaigns and events.

On the policy front, the Commission launched a European Care Strategy, aiming to ensure quality, affordable and accessible care services across the EU and to improve the situation for people receiving or giving care. In addition to this, the Commission also launched an online campaign, "Together for Rights", to raise awareness of disability rights across the EU.

In the field of dementia research, one of the major EU-funded projects in which Alzheimer Europe is a partner, the Amyloid imaging to prevent Alzheimer's disease (AMYPAD) initiative, has just come to a close, holding its final General Assembly meeting in Amsterdam.

At a global level, Eisai and Biogen announced positive top-line results from a Phase III trial of lecanemab for the treatment of early Alzheimer's disease. We welcome the encouraging data reported and look forward to hearing more at the upcoming Clinical Trials in Alzheimer's Disease conference.

Last but not least, our own conference is nearly here! Please make sure you register before 9 October and join us in Bucharest!

**Jean Georges**  
Executive Director

## ***Sponsors of the month***

Alzheimer Europe would like to express its gratitude to two more sponsors.

Read more about sponsorship opportunities here:

<https://www.alzheimer-europe.org/about-us/governance/finances/2022-sponsorship-opportunities>

**For our 2022 Annual Conference:**



**For our activities in 2023:**



GE Healthcare

## **ALZHEIMER EUROPE**

**21 September: “What Makes You, You?” This World Alzheimer’s Day, Alzheimer Europe is proud to collaborate on a new initiative that looks beyond an Alzheimer’s diagnosis and celebrates the person**



21 September is World Alzheimer’s Day, a day dedicated to raising awareness of Alzheimer’s and other types of dementia, as well as challenging the stigma surrounding dementia.

This year, to mark this important day, Alzheimer Europe is proud to collaborate on a new initiative called “What Makes You, You?” The initiative is a collaborative effort between Roche, the European Working Group of People with Dementia (EWGPWD) and Alzheimer Europe. It aims to help create a world where people living with diseases that affect the brain, like Alzheimer’s, can live life to the fullest and stresses the importance of looking beyond a person’s diagnosis and of valuing them for who they are.

Short videos (approximately three minutes each) have been created, featuring three members of the EWGPWD who are living with Alzheimer’s disease, together with some of their family members. Each tells the story of who they are, in their words.

In the first video, EWGPWD Vice-Chairperson Bernd Heise, who used to be an engineer and is still very keen on technology, appears alongside his wife Hilde, who is amazed at his continuing ability to work with technology, though she notes that it takes him much longer than it used to. Bernd says: “I try to be as much as I was before, but I was an engineer and very attached to technical solutions. This has changed a bit. Now I talk to and learn from other people more, rather than trying to do everything by myself. I change, but I am still me. You have to carry on and just try to live life as well and as enjoyably as possible.”

The second video features EWGPWD member Helen Rochford-Brennan, who stresses that it is vital for her to keep focusing on the same things she always has: “Working for the rights of all people is important to me to this day. Equality for all. I am also a political activist and I think I must keep doing that, to keep being the person that I am. All that has changed is that I have a short-term memory problem. Of course I forget, but that’s OK. That has not changed at all my passion about rights, about my rose garden and about the things that I believe in and the things that I love, like getting out in my car, walking my dog and enjoying my life. That’s Helen.”

EWGPWD member Stefan Eriksson and his daughter Janni Ahlgren feature in the third video. Janni shares her father’s and the rest of the family’s positive outlook on life and the importance they all place on Stefan continuing to enjoy life as much as possible and staying as active as he always has been:

“Even though he has Alzheimer’s now, he still has goals in his life and he still wants to achieve them and continue doing the things he loves. My dad is always going to be dad, he’s always going to be Stefan. Just because he has Alzheimer’s doesn’t mean he is going to become a totally different person. He still has his vision in life, his goals, his hobbies and interests that he loves to do. We always try to encourage him to stay the Stefan that he is.”

You can watch the videos on our YouTube channel, here:

[https://www.youtube.com/playlist?list=PLO-PgQHI1WQeFadlt9s2LurpMB\\_A9DHN](https://www.youtube.com/playlist?list=PLO-PgQHI1WQeFadlt9s2LurpMB_A9DHN)

Alzheimer Europe is delighted to have worked on this initiative in collaboration with Roche. We would also like to express our gratitude to Bernd, Hilde, Helen, Janni and Stefan for sharing their stories to help raise awareness, combat stigma and create a world where people with dementia can continue to be who they are, this World Alzheimer’s Day and every day.

**Help us give a voice to people  
with dementia**

**Donate**



## **27 September: Alzheimer Europe organises a Company Round Table meeting in Brussels**



On 27 September 2022, Alzheimer Europe hosted a Company Round Table meeting in Brussels. The meeting was a hybrid event, with many participants attending in person and some joining remotely. It was attended by a total of 42 delegates, including 13 company representatives

(from Eisai, Essity, GE Healthcare, Grifols, Lilly, Roche and TauRx), 8 members of the Alzheimer Europe staff, Alzheimer Europe Chairperson Iva Holmerová, who hosted the meeting, members of the Alzheimer Europe Board and representatives from 16 member organisations of Alzheimer Europe.

During the meeting, four speakers provided updates on recent policy and research developments. Cindy Birck, Project Officer, gave an update on our [Clinical Trials Watch](#), while Owen Miller, Policy Officer, shared some recent Policy developments at WHO and EU level. Next, Jean Georges, Executive Director, informed participants about Alzheimer Europe's activities in 2022 and 2023, including 2023 sponsorship opportunities. The final two presentations of the meeting came from Anders Gustavsson of PAVE (Project Alzheimer's Value Europe) and Oana Scarlatescu with Audrey Wolf (EFPIA). Anders provided an overview of a recent PAVE initiative to estimate the numbers of people on the Alzheimer's disease spectrum, while Oana and Audrey spoke about developing medicines for high unmet needs, and how this is reflected in the new EU pharmaceutical legislation.

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

## **27 September: Alzheimer Europe hosts lunch debate on AI and big data in dementia research**



Alzheimer Europe held a lunch debate on 27 September 2022 in Brussels, Belgium, focused on "The role of artificial intelligence and big data in dementia research", attended by national member organisations, civil society representatives, industry partners, policy makers and members of the European Working Group of People with Dementia (EWGPWD).

Sirpa Pietikäinen MEP (Finland), Chairperson of the European Alzheimer's Alliance (EAA) hosted the session and opened by highlighting the opportunities that exist for big data and artificial intelligence to develop more effective treatments for dementia. She noted that considerable amounts of data were generated daily, yet much of it was not analysed or made use of, despite it having potential to improve understanding of the condition. Furthermore, she spoke of the need to balance the opportunities of big data and artificial intelligence, with the need to respect the rights of individuals in relation to their personal data.

In a pre-recorded video message, Deirdre Clune MEP (Ireland) welcomed participants to the meeting and highlighted her membership of the Internal Market and Consumer Protection Committee, noting that she would be keen to hear ideas and suggestions about the steps the EU can take to facilitate the use of data and artificial intelligence to support research into dementia. Furthermore, she highlighted the barriers identified in Alzheimer Europe's "Data Sharing in Dementia Research – the EU Landscape" report, outlining the role of the EU in addressing issues around infrastructure and regulation.

Petra Ritter, Co-Coordinator of the VirtualBrainCloud project, outlined the aims of the project, explaining they were able to integrate data from different measurements of brains (e.g. imaging data, biobank samples), accounting for differences between individual brains through complex mathematical modelling and using supercomputing capacity, to create "virtual brains", allowing analysis at the sub-cellular level. This allows researchers to undertake tasks including prediction in the



progression of Alzheimer's disease, as well as examining how different interventions and treatments affect this progression over time; this can be used in the development of future treatments. However, such research and approaches require significant investment in infrastructure, as well as common data standards across the EU.

Jesper Kjaer, Co-Chair of the Big Data Steering Group (BDSG) in the European Medicines Agency, highlighted some of the previous work of the group on this subject, including a report in 2021 which issued 10 recommendations to improve the use of big data for public health. He set the context of the use of big data as one of supply and demand, noting that implementation require a stepwise approach, with gradual changes required over time. He further explained that real world evidence supported regulators' decision-making by helping support planning and validity, the understanding of the clinical context, and the investigation of the associations and impacts. A key project ongoing project is the Data Analysis and Real-World Interrogation Network (DARWIN EU), a federated network of data, expertise and services that will support better decision-making throughout the product lifecycle by generating reliable evidence from real world healthcare data.

Andrzej Rys, Director for Health Systems, Medical Products and Innovation in the European Commission, spoke about two key pieces of legislation: the Organization of Health Data (European Health Data Space - EHDS) introduced May 2022 and the Development and Deployment of trustworthy AI systems (the AI Act), introduced in April 2021. He noted that the EHDS set out the manner of collection and registration of health data, as well as the obligations of data holders to make available health data available, e.g. for research or the development of medical devices. He moved on to explained that high-risk AI systems, including AI-based medical devices, were governed by the AI Act, which set out data governance obligations, as well as mandating human oversight, a robust risk management system and transparency and information to users.

Göedze Susuzlu Briggs, Project Coordinator for the DataSavesLives (DSL) initiative, outlined how the multi-stakeholder initiative (led by the European Patients Forum) aims to raise patient and public awareness about the importance of health data and how it is used. She noted that the fundamental principle of the initiative was transparency, ensuring patients were informed and meaningfully involved in processes related to the use of health data. DSL has undertaken a number of activities to spread knowledge and understanding, including the development of a toolkit, as well as a training programmes for "ambassadors", who will be given the information, skills and guidance to take actions to promote the use of health data in their countries. She also shared that work is underway by the Ministry of Health in Germany in this area.

During the open discussions, a number of contributions were made, including from members and supporters of the EWGPWD, who shared their poor experience of hospitals in

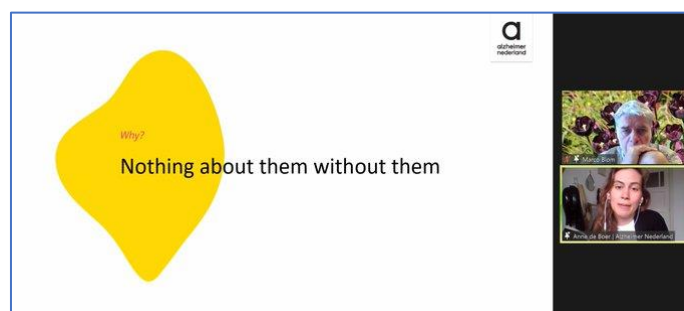
rural areas, as well as their hopes for the development of a cure or new treatment in the near future.

Alzheimer Europe Chairperson Iva Holmerová thanked attendees and speakers for their contributions to the lunch debate.

EAA member Tilly Metz MEP (Luxembourg) closed the session, sharing how this subject related to her work as a member of the Environment and Health Committee, as well as shadow rapporteur for the Greens on the EHDS. She thanked the speakers and those who had shared their personal experiences during the debate. Ms Metz noted the need for coordinated involvement of all stakeholders to drive change in this area, across public, private, research and civil society organisations. She highlighted that where discoveries and outputs were developed from public-private partnerships, the public needed to benefit from the investment made, with good practices and developments translating into improvements in health systems and clinical practice. The videos of the presentations from the Lunch Debate will be available at:

<https://www.youtube.com/playlist?list=PLO-PgQH1WQV3Ttlo2sbF4c9YyXfgi21B>

## **27 September: Alzheimer Europe hosts Academy session focusing on dementia and employment**



On 27 September, various representatives from Alzheimer Europe's member organisations and staff came together to learn about the current state of play when it comes to policies & activities around dementia and employment on a national as well as EU level.

Alzheimer Europe's Policy Officer, Owen Miller, opened the Alzheimer's Association Academy welcoming in-person as well as online attendees of the hybrid workshop aimed at promoting exchange between member organisations and to enable the uptake of best practice examples, amongst others.

The first presentation was given by Owen Miller. He spoke about the upcoming Alzheimer Europe 2022 Yearbook, entitled "Employment and Social Protections for people living with dementia and their carers" that will be published at the end of 2022. His presentation was entitled "Employment and social security rights for people with dementia – some findings of the Alzheimer Europe survey". Owen started introducing the European and international policy context, the overarching frameworks and conventions related to the field, including the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) to which the UN Committee on the Rights

of Persons with Disabilities released its new General Comment 8, on the right to work and employment (article 27), as well as the Charter on Fundamental Rights and the European Pillar of Social Rights. Some of the national findings from the survey included that there are few examples within national dementia strategies in relation to employment or social protections, noting that a number of countries (Czech Republic, Ireland, Netherlands) referenced the matter without including specific commitments or activities to resolve it. Conversely; Germany, Greece, Malta, Spain and Slovenia (tentatively), did have measures in their strategies. France was notable in that its neurodegenerative disease plan did have measures for other conditions, but not for dementia. Some countries highlighted other plans or strategies which focus on people with disabilities, or people who were not active in the labour market, which included measures relevant for people with dementia or their carers (Czech Republic, Estonia, Finland, France, Germany, Malta as well as Portugal).

The next part of his presentation revolved around legislation, in which he highlighted that all respondents (except one), had laws relating to the protection of persons in employment and the prevention of discrimination for people living with a disability or with a carer. Another aspect he highlighted, was that it is incredibly difficult to draw meaningful comparisons between countries, due to the different models, payments, criteria. Nevertheless, there are common complaints with regards to social protection including; bureaucratic systems/complicated applications, insufficiency of benefits, restrictive eligibility criteria (age, hours worked etc.) amongst others. He closed his presentation noting that the Yearbook will also include examples and experiences of people living with dementia/carers/national members as well as good practice examples.

The next presentation was provided by Lorène Gilly from France Alzheimer. It focussed on supporting carers of people with dementia in employment – the White Paper of France Alzheimer. Lorène started her presentation by giving some context to the situation of people living in France where an estimated 11 million provide support to a person living with a disability or in loss of autonomy, of which over half are women and increasingly (66%) pursue a professional activity. Given the high amount of unmet needs for these people, France Alzheimer issued a [white book](#) for supporters following a profession in 2016, this publication was updated in 2018, with the aim to involve the mobilization of public authorities, civil society and economic players around four pillars:

1. Communicate to raise awareness and encourage a concrete change;
2. Act on the financial consequences of a possible suspension of work and promote the continued employment of carers;
3. Promote good health at work and meet the "need for time" by allowing respite solutions for caregivers;
4. Encourage companies and all economic players to find ways to better support caregivers.

The final part of Lorene's presentation focussed on that legislative progress around paid leave. In 2018, at the initiative of MP's, the provision of leave days between employees was extended to carers of people with a loss of autonomy, no matter the cause.

In September 2020, the daily caregiver allowance compensated up to 66 days of the caregiver leave. It is "for anyone residing in France who reduces or ceases their professional activity and wishes to take care of a loved one with a disability or particularly serious loss of autonomy. Paid by family allowance funds, or agricultural social mutuality funds for people covered by the agricultural scheme, it is granted under certain conditions." The latest update from January 2022 was a decree that reevaluates the allowance and lifts the condition of the level of dependency or disability of the person cared for.

The following presenter was Gavin Terry from the Alzheimer's Society, UK. He spoke about supporting people with dementia in employment and the situation in the United Kingdom. He started his presentation by explaining that they also developed a [support guide](#) for people who work as well as provide informal care. He then explained that the Equality Act 2010 is aimed to protect people in England and Wales from discrimination and being unfairly treated at work, including people who have been diagnosed with dementia. In his presentation, Gavin emphasised that under the act, employers must only make adjustments when they know about the diagnosis and that this comes with the side-issue that some people may not want their employer to know about their diagnosis (about which they only have to tell their employer in case work safety could be affected).

Furthermore, he explained that drivers will need to tell their insurance company as well as the safety authority about their diagnosis. He then stressed that having a conversation with the employer is really important, which they stress in their brochure. A problem they have encountered is that people have been fired as a consequence of their diagnosis. He stressed that if the employer hasn't adjusted the workspace, affected people can challenge this action if the employer didn't do what he should have (in reference to the Equality Act 2010). The association also helps with this on their help line. From the experiences they've made during conversations with affected people on their helpline, some feel relieved to leave work others don't – they stress that these people didn't fail. Making an informed decision about leaving work as well as legal advice on life insurance etc. are important.

The last presentation was provided by Marco Blom and Anne de Boer from Alzheimer Nederland. It revolved about meaningful volunteering opportunities for people with dementia through DementTalent. Through this initiative, the association helps people to find volunteering opportunities in their communities. Anne de Boer went on to provide some real-life examples as part of her presentation.

The first volunteering example she introduced was Lotte, who used to work as gardener. She was diagnosed with dementia

and needed a bit of guidance to help in a local garden. This was a bit difficult for her as she needed to be allocated to clear tasks, once these were explicit she enjoyed working. What made it great for her, was that she could see the results and that she did something that lasted.

The next volunteering example was about Peter. He was also retired but wanted to use his talent. As he used to work in restaurants and found great enjoyment working in a meeting centre for people with dementia and their carers. This was extremely helpful for the manager but also enjoyable to Peter as he likes the social interaction but wants to be host rather than guest.

The third example was about Ed who is volunteering at a school. As expert by experience he shared how it is to live with dementia to students. Before his diagnosis, he used to be scared to talk before in front of big groups and now he enjoys this as he made great experiences.

The last example was about Bob. He also has dementia and lives close to a Kindergarten with a playground. At this playground, he thought there could be improvements and make use of his talent to make it bigger and nicer for kids. They found another man who was eager to help in this and together they did a makeover as volunteers.

Conclusions about their initiative were that people with dementia showed fewer neuropsychiatric symptoms (anxiety, apathy, depression & agitation), informal caregivers felt much less emotionally burdened and that DementAlent is cost effective. Anne noted that the "Restaurant that makes mistakes" which will go into a third season in two weeks and DementAlent have a lot in common, It is about a restaurant where people living with dementia work and shows show people that people with dementia are capable of a lot. And that they can still contribute to society. And it shows the variety of talents people with dementia have.

The difference is mainly the fact that people in the series work together with other people with dementia. At DementAlent that is not necessary.

There was ample time for lively discussion and questions to the speakers after each presentation. At the end, Jean Georges closed the session thanking all participants and speakers.

## **27-28 September: Members of the European Working Group of People with Dementia meet in Brussels**

On 27 and 28 September, members of the current and new European Working Group of People with Dementia (EWGPWD) met in Brussels. The meeting started with a farewell to members of the EWGPWD leaving the group, Stefan Eriksson (Sweden) and Idalina Aguiar (Portugal) (pictured) who were recognised and thanked for their valuable contributions to the EWGPWD and to Alzheimer Europe's work.

During the meeting, members discussed the various contributions of the EWGPWD to the upcoming AE conference

in Bucharest including the plenary, special symposium and parallel session speeches.

The second day started with a presentation about research, Public Involvement and the work of the EWGPWD. This was followed by a session where members continued the discussions around issues related to ethical and inclusive communication and the portrayal of dementia which is part of the group's annual work.

All members and supporters provided a range of valuable ideas, perspectives and comments during the consultations. Dianne Gove (Director for Projects), Ana Diaz (Project Officer), Soraya Moradi-Bachiller (Project Officer), Daphné Lamirel (Project Officer) and Beliz Budak (ESR from the DISTINCT project) participated in the meeting and facilitated the discussions.



## **29 September: New European Working Group of People with Dementia confirmed for 2022-2024 term**



We are pleased to announce that the membership of the European Working Group of People with Dementia (EWGPWD) has been confirmed for the 2022-2024 term. The new group will officially begin its mandate after the upcoming Alzheimer Europe Conference, taking place from 17-19 October 2022.

The EWGPWD for 2022-2024 is composed of the following 15 members:

### **Chairperson**

- Chris Robert, Wales, United Kingdom

### **Vice-Chairpersons**

- Margaret McCallion, Scotland, United Kingdom
- Kevin Quaid, Ireland

### **Members**

- Bernd Heise, Germany
- Nigel Hullah, United Kingdom
- Erla Jónsdóttir, Iceland
- Marguerite Keating, Ireland
- Lieselotte Klotz, Germany



- Pia Knudsen, Denmark
- Petri Lampinen, Finland
- Real Larnou, Belgium
- Stephen John McCleery, Italy
- Angela Pototschnigg, Austria
- Shelagh Robinson, United Kingdom
- Věra Ryšavá, Czech Republic.

The EWGPWD was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently and members elect their own Chairperson and Vice-Chairpersons. The Chairperson is also an *ex-officio* member on the Board of Alzheimer Europe, with full voting rights.

During the group's previous terms of office, members have actively participated in Alzheimer Europe's annual conferences and contributed towards public involvement (PI) work for EU-funded research projects in which Alzheimer Europe is involved, as well as to other areas of Alzheimer Europe's work. They have also contributed to research conducted by external organisations on a wide variety of topics including outcome measures that are meaningful to people with dementia and their carers, social health, people with dementia as peer-researchers and dementia-inclusive initiatives, and have attended a number of international events, including at the European Parliament, as representatives of the group.

For more information about the group, see: [www.bit.ly/EWGPWD](http://www.bit.ly/EWGPWD)

The 2020-2022 group met for the final time in Brussels on 27 and 28 September 2022. We would like to express our gratitude to outgoing members Idalina Aguiar, Stefan Eriksson, Tomaž Gržinič, Danny McDonald, Helen Rochford-Brennan and Geert Van Laer for their important contributions and wish them well. They will be missed!

### **30 September: The 32<sup>nd</sup> Alzheimer Europe Conference is nearly here – register before 9 October!**



The 32<sup>nd</sup> Alzheimer Europe Conference (#32AEC) is fast-approaching, with only two weeks to go! The event will take place under the banner "Building Bridges, from 17 to 19 October. We are really excited about our first hybrid conference which is being held in person in Bucharest, with some carefully selected

sessions broadcast for our online audience. Spots for the in-person conference are filling up quickly, so please book your place now, to avoid missing out! [https://www.alzheimer-](https://www.alzheimer-europe.org/conferences/2022-bucharest/online-conference-registration)

[europe.org/conferences/2022-bucharest/online-conference-registration](https://www.alzheimer-europe.org/conferences/2022-bucharest/online-conference-registration)

View the agenda, here: <https://www.alzheimer-europe.org/conferences/2022-bucharest/detailed-programme>

You can find out more about all the keynote speakers, here: <https://www.alzheimer-europe.org/conferences/2022-bucharest/keynote-speakers>

Join the online conversation, before and during the event, using the hashtag #32AEC.



**CLICK HERE TO  
REGISTER  
for our conference**

### **1 October: Alzheimer Europe officially endorses Older Adults Mental Health Awareness Week**



International Psychogeriatric Association  
Better Mental Health for Older People

Alzheimer Europe has signed an agreement to become an Endorsing Partner of the International Psychogeriatric Association's Older Adults Mental Health Awareness Week, from 1 October, the United Nations' International Day of Older Persons until 10 October, World Mental Health Day. This is the 2<sup>nd</sup> Annual ten-day initiative, launched by the International Psychogeriatric Association (IPA) and focused on raising awareness of the importance of Better Mental Health for Older People.

The IPA (<https://www.ipa-online.org/>) is focusing on raising awareness around the impact of ageism on health outcomes and to support the protection of human rights of older persons with mental health conditions. Older Adults Mental Health Awareness Week aims to highlight both older persons mental health as well as promoting healthy ageing initiatives around the globe. Alzheimer Europe is pleased to support this initiative.

<https://awarenessweek.ipa-online.org/>



**Follow us on Twitter**

## Alzheimer Europe networking

On 5 September, the Alzheimer Europe Membership Committee met to discuss membership applications of organisations interested in joining Alzheimer Europe.

On 5-6 September (Bucharest, Romania), Gwladys and Cristina had a site inspection for the 32AEC.

On 6 September, Owen attended an online meeting of AIM on the subject of the European Care Strategy.

On 6-8 September (Barcelona, Spain), Angela participated in the General Assembly meeting of the PRIME project.

On 7 September (Munich, Germany), Jean attended a Multistakeholder Forum organised by Lilly.

On 8 September, Ana participated in a Lethe Advisory Board meeting.

On 9 September, Jean met with the EFPIA AD Platform.

On 11 September (Luxembourg, Luxembourg), Jean met with a delegation of the European Federation of Neurological Associations.

On 12 September, Angela participated in the RECOGNISED General Assembly meeting.

On 13 September, Alzheimer Europe organised an Alzheimer's Association Academy on "Intellectual disability, Down Syndrome and Dementia".

On 14 September, Alzheimer Europe organised an information meeting with TauRx.

On 14 September, Kate met with Producer Estephania Bonnett Alonso from film production company Playlab Films.

On 15 September, Jean met with a representative of AC Immune.

On 15 September, the Alzheimer Europe Anti-Stigma Award Committee met.

On 15 and 21 September, Ana and Cindy participated in joint Lethe and EU-FINGERS Advisory Boards.

On 19 and 20 September (Luxembourg, Luxembourg), Alzheimer Europe hosted the Annual General Meeting of PRODEMOS.

On 21 September, Jean attended the Ethics Committee of the Luxembourg Alzheimer's Association.

On 21 and 22 September (Amsterdam, Netherlands), Angela participated in an EMA multi-stakeholder workshop and meetings of the Patients' and Consumers' Working Party.

On 22 and 23 September, Cindy attended the final AMYPAD General Assembly Meeting in Amsterdam.

On 26 September (Brussels, Belgium), the Alzheimer Europe Board met.

On 27 September (Brussels, Belgium), Alzheimer Europe organised a company round table meeting.

On 27 September (Brussels, Belgium), Alzheimer Europe organised a European Parliament lunch debate on "The role of artificial intelligence and big data in dementia research".

On 27 September (Brussels, Belgium), Alzheimer Europe organised an Alzheimer's Association Academy on the topic of "Employment and dementia".

On 27 and 28 September (Brussels, Belgium), Dianne, Ana, Daphné and Soraya participated in the meeting of the EWGPWD.

On 28 September, Owen attended the online launch of the European Commission's Together for Rights campaign.

On 29 September, Owen attended a European Commission stakeholder meeting on Cross Border Protection of Vulnerable Adults.

On 29 September (Amsterdam, Netherlands), Ana and Dianne attended the RADAR-AD Consortium Meeting.

On 29 November (Monheim am Rhein, Germany), Angela participated in a sustainability workshop for the EPND project.

On 30 September, Ana participated in the Interdem taskforce on primary prevention Webinar.

On 30 September, Chris and Kate attended a Zoom meeting with the European Disability Forum, to discuss communications.

## EU PROJECTS

### 6-8 September: PRIME project convenes its 2022 General Assembly meeting

The Horizon 2020-funded PRIME project is investigating how insulin might connect seemingly different diseases, such as diabetes, obesity, obsessive-compulsive disorder, and Alzheimer's disease. The last time PRIME partners met face-to-face was just prior to the pandemic, in January 2020. Two and a

half years later, we were delighted to join the PRIME General Assembly (GA) meeting, which was held in Barcelona, and welcomed colleagues from the 17 partner institutions of the project.

The GA meeting was preceded by a masterclass for Early-Career Researchers (ECRs), led by Angela with participation from Kristien Aerts (European Brain Council), Rosanna Artems (ECNP) and Janette Mostert (Radboud UMC). During the masterclass, panellists discussed tips and learnings for science communication to different audiences, and attendees



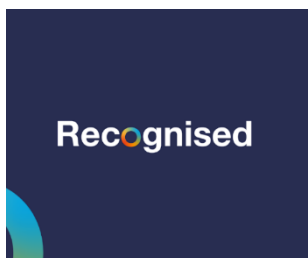


participated in an interactive workshop to develop short elevator pitches about their research.

PRIME brings together a wide range of disciplines and stakeholder groups, including laboratory scientists, clinical researchers, metabolic disease specialists and experts working in non-governmental organisations. The General Assembly (GA) meeting was kicked off by Janita Braalten of Radboud University Medical Center (RUMC), who co-coordinates PRIME with Barbara Franke (RUMC) and Geert Poelmans (Drug Target ID). The first morning of the GA was dedicated to presentations from workpackages that include studies of clinical data. Work in these WPs is looking at the prevalence, mechanisms and interventions for insulin signalling disorders. The afternoon session was focused on WPs which are dealing with communication, exploitation, ethics and training for PRIME researchers. In addition, EBC organised a brainstorming session to consider the societal impact of PRIME, needs, gaps, priorities and enabling actions, and audiences.

The final day of the PRIME meeting was mainly focused on the preclinical research activities being carried out in WP2 and WP3. WP2 is led by Simone Macri (Istituto Superiore di Sanita, Rome), and is focused on mechanism validation and refinement in animal models of disease; WP3, which is similarly looking at mechanism refinement and validation, but in cellular models of disease. Both workpackages have generated interesting results over the last year, identifying potential biological links between obesity and traits such as compulsivity, anxiety and attention. Following these presentations, Geert Poelmans drew the meeting to a close, thanking attendees for their valuable input and contributions.

### **13 September: RECOGNISED convenes its annual General Assembly meeting, updating on project progress and outputs**



On 13 September, partners working on the H2020-funded RECOGNISED project met during a General Assembly meeting, held online and in-person in Barcelona, co-Chaired by Profs. Rafa Simo (Vall d'Hebron

University Hospital) and Noemi Lois (Queen's University, Belfast), the co-Leads of the project. Attended by representatives of the 21 Institutions participating in RECOGNISED, including academic institutions, SMEs and patient organisations, the General Assembly (GA) meeting summarised recent project developments and provided a forum for discussing upcoming plans. Alzheimer Europe was represented by Angela Bradshaw.

The four-year long RECOGNISED project is studying the biological mechanisms that cause structural and functional alterations in the retina in people with type 2 diabetes, to determine whether these same pathways play a role in the events observed in the brain during the development of cognitive impairment and dementia. Importantly, RECOGNISED is assessing whether evaluating the retina, easily accessible with non-invasive tests, could help in identifying earlier cognitive impairment in people with T2D, so that appropriate support can be given.

During the General Assembly meeting, RECOGNISED workpackage leaders provided brief summaries of ongoing activities, updating project partners on recent advances and discoveries. Despite interruptions caused by the COVID-19 pandemic, preclinical research on animal models of diabetes and Alzheimer's disease are progressing well, with efficient collaborations between laboratories based in different countries, generating extensive genetic, behavioural, cognitive and imaging datasets for analysis. Of note, RECOGNISED partners highlighted the successful recruitment of participants to the RECOGNISED clinical studies, which are recruiting from 11 centres based in 8 different countries. Over 250 participants have been recruited to the RECOGNISED longitudinal study, which is assessing retinal biomarkers (measured using eye tests) in older people with diabetes, with or without cognitive impairment. RECOGNISED partners then discussed additional analyses that could be performed on the collected cross-sectional data, which might provide extra disease insights. The afternoon sessions of the GA were focused on exploitation, dissemination and communications, highlighting some of the considerations for business development and underlining the importance of disseminating RECOGNISED outputs to relevant stakeholders. RECOGNISED partners provided their views on the key stakeholders and audiences to reach with RECOGNISED communications, and also worked together on messaging to capture advances in RECOGNISED research.

Prof. Lois and Pascal Kahlem, project manager of RECOGNISED, closed the General Assembly meeting by thanking all attendees for their valuable input, and continued efforts on behalf of the project.



## 15 September: Members of the EU-FINGERS and LETHE Advisory Boards participate in a new consultation



On 15 and 23 September, Alzheimer Europe (AE) and Karolinska Institute (KI) co-hosted a consultation with the members of the EU-FINGERS and LETHE Advisory Boards respectively. The topic of the meeting was to provide feedback to the CAIDE (Cardiovascular Risk

Risk Score. The CAIDE Risk Score is a tool which estimates the risk of a middle-aged person to develop dementia at older age. This risk score is based on non-modifiable factors (age, sex, education) and modifiable factors, which can be improved (high blood pressure, high blood cholesterol, physical inactivity, obesity). During the meeting, members discussed on the idea of a digital version of the CAIDE risk score, the different possibilities on how it could be used including the benefits and challenges.

The discussions were co-facilitated by Ana Diaz (AE), Francesca Mangialasche (KI) and Anna Rosenberg (THL). Both meetings were very interactive and lively and the feedback received was very valuable for the project. Project officers Cindy Birck and Ana Diaz participated in the meetings.

For more information about EU-FINGERS and LETHE projects, visit: [www.eufingers.com](http://www.eufingers.com) and [www.lethe-project.eu](http://www.lethe-project.eu)

## 19 September: The PRODEMOS project holds its General Assembly meeting in Luxembourg



On 19-20 September, the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project held its General Assembly meeting in Luxembourg. The project is aiming to make an evidence-based dementia prevention strategy using mobile Health (mHealth), accessible to those at

increased risk of dementia.

Alzheimer Europe is a partner in the project and was pleased to host the meeting. The meeting commenced with Jean Georges welcoming delegates in Luxembourg. Then, Edo Richard introduced the meeting and highlighted the achievements of the past year. Following on from the introductory session, a session was dedicated to the health economic aspects including the cost-effectiveness analysis. Next, Cindy Birck presented the news items that are published on the PRODEMOS application

and adapted to the target population. This was followed up by a recap of the analysis plan and the presentation of a new cross border project between Academic Medical Centre Amsterdam (AMC) and the French National Institute for Health and Medical Research (INSERM). The first day was brought to a close with two break-out rooms dedicated to future projects and the challenges of the lifestyle intervention.

The second day of the meeting started with a session dedicated to the trial, both in UK and China, including the feedback from the coaches and the final assessments. The recruitment in the main PRODEMOS study was formally ended in April and the study succeeded in recruiting 600 participants in UK and 886 participants in China. After a short break, an overview of the baseline data was presented, then followed by a session on dissemination, management and finances. Eric Moll Van Charante then drew the meeting to a close, thanking all the participants for their active contribution to the meeting.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 779238 and the National Key R&D Programme of China (2017YFE0118800). Further information on the PRODEMOS project can be found here: <https://www.prodemos-project.eu>

## 19 September: RADAR-AD project announces one-year extension



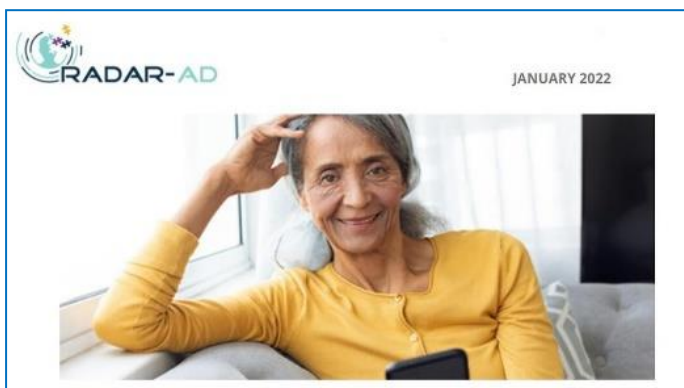
Earlier this year (in May) the RADAR-AD consortium was granted a one-year extension to make up for delay caused by the COVID-19 pandemic. RADAR-AD aims to find new digital biomarkers for cognition and function in people living with Alzheimer's disease. Due to the restrictions surrounding the COVID-19 pandemic, enrolment of research participants in the RADAR-AD clinical studies was severely hampered. The need for a project extension was therefore clear to all consortium members, and after making some adjustments in the project timeline as well as in the budgets, a new RADAR-AD end date was agreed upon: the new project end date is 30 June 2023.

Find out more [here](#).





## 19 September: RADAR-AD project publishes its fourth newsletter

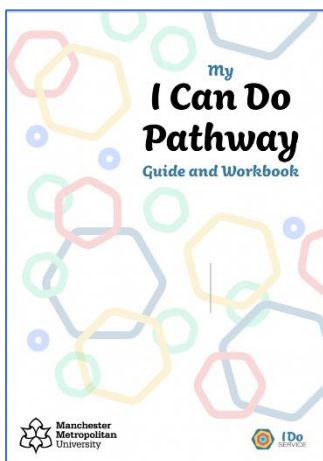


The RADAR-AD (Remote Assessment of Disease and Relapse – Alzheimer's Disease) project has published the fifth edition of its newsletter. These e-newsletters are sent out twice a year, covering news over the past six months and provide readers with the latest project updates.

Among others, in the past six months, the RADAR-AD consortium has been successfully enrolling participants to its studies, analysing gathered data and continuing with the performance of modelling work.

In March, RADAR-AD consortium members gathered for a third annual meeting, held online. They discussed the progress of RADAR-AD's clinical study over the past year, the data platform and devices used in the project, as well as the regulatory and ethics work, and the activities on engagement with people living with Alzheimer's. Read the full newsletter [here](#).

## 19 September: IDoService project tests its I Can Do Pathway with participants



As the IDoService project draws to a close, it shares the results of developing and testing the service prototype. Based on stakeholders' inputs, in the spring, the research team developed the "I Can Do Pathway" framework, comprising a set of three coaching sessions to deliver the service. The framework is manifest in an illustrated booklet that provides the guidance and activities for delivering the sessions. The aim

is to help support people living with mild dementia to better identify opportunities for participation in meaningful activities. The sessions are designed to explore people's strengths and preferences to offer concrete guidance about how to access these activities. A special focus is put on volunteering as it can offer an especially rewarding experience and satisfaction to help others.

In the test sessions, the programme was delivered by Emma from Age UK Salford, who took the role of "wellbeing mentor" to support people to explore: their strengths and interests; what they want to do and what's on offer around them; what to do and what support they need. The I Can Do Pathway booklet was used to guide people with dementia as well as mentors through the activities of the sessions.

Initial results of evaluating the prototype demonstrated its usefulness in supporting people to consider their strengths and interests in a convivial atmosphere, to help them build their confidence and identify suitable activities. It highlighted that there are many activities people can participate in, but also that support through spouses or other care partners is key to people being able to attend and try out the chosen activity for the first time.

The project will report on the results in a public symposium on 6 October 2022: <https://www.eventbrite.com/e/i-do-service-symposium-tickets-425048159487>

For more information see [www.idoservice.org](http://www.idoservice.org)

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

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

## 22 September: The AMYPAD project holds its final General Assembly meeting in Amsterdam



On 22 and 23 September, more than 80 representatives from the AMYPAD consortium came together in Amsterdam (Netherlands) to attend the final AMYPAD General Assembly Meeting. The 2-day event celebrated the progress and main achievements. Recent results, future planning and activities were the main focus of the meeting.

Frederik Barkhof and Gill Farrar, coordinators of the AMYPAD project, kicked off the General Assembly. Following on from the introductory session, the first session was held on the Diagnostic and Patient Management Study (DPMS). With a total of 844 patients randomized on 900 originally planned, the study recruited 245 people with Subjective Cognitive Decline, 342 with Mild Cognitive Impairment and 258 with dementia. All visits and scanning activities have been completed by sites. Primary and secondary endpoint results as well as health-economics analyses were presented. After that, a session was



dedicated to the Prognostic and Natural History Study (PNHS). The study comprises collaboration among sites and parent cohorts in several countries across Europe. In addition to EPAD, there were 9 other Parent Cohorts actively recruiting into AMYPAD. These are: EMIF-AD (60++ and 90+), ALFA+, FACEHBI, FPACK, UCL 2010-412, Microbiota, AMYPAD DPMS (VUMC) and H70. The recruitment was formally ended on 30 April 2022 and the study succeeded in recruiting 1,321 participants. The number of prospective scans collected within AMYPAD PNHS is 1,419 (1,192 baseline and 227 follow-up). The non EPAD Parent Cohorts also shared their historical data and therewith the total number of scans in AMYPAD PNHS is over 2700. Harmonization, integration, and the data-base were also reported. Following on from this presentation, a session around dissemination was held, where Cindy Birck presented the communication activities of the project. After a short break, the screen was given in turn to John Clifford (IHI) who gave feedback on the AMYPAD progress and presented the new IHI initiative. Next, updates were provided on the project management perspective including the final reports and administrative closure. The first day was brought to a close with a discussion on the AMYPAD post-IMI period including approaches on sustainability, funding opportunities and scientific initiatives. Data governance with DTA, data-access and publication policy post-IMI were also presented.

On the second day, the AMYPAD consortium gathered for a scientific exchange and discussion on the technical

developments. The WP2 “Tracer delivery, PET scanning and image analysis” team presented main findings and quantifications results from both clinical studies. Next, the floor was given to nine AMYPAD researchers to showcase their respective work and results. Gill Farrar and Frederik Barkhof then drew the meeting to a close, thanking all the participants for their active contribution to the meeting and all AMYPAD members for their enthusiasm and dedication during the last six years!

Alzheimer Europe (AE) co-leads the communication and dissemination Work Package of AMYPAD. Cindy Birck, AE Project Officer joined the AMYPAD final General Assembly meeting. For more information about the project, visit:

<https://amypad.eu/>



### 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:

**AMYPAD** – grant agreement 115952

**LETHE** – grant agreement 101017405

**PRIME** – grant agreement 847879

**PRODEMOS** – grant agreement 779238

**RADAR-AD** – grant agreement 806999

**RECOGNISED** – grant agreement 847749



**EU-FINGERS** is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND [www.jpnd.eu](http://www.jpnd.eu): Finland, Academy of Finland; Germany, Federal Ministry of Education and Research; Spain, National Institute of Health Carlos III; Luxembourg, National Research Fund; Hungary, National Research, Development and Innovation Office; The Netherlands, Netherlands Organisation for Health Research and Development; Sweden, Swedish Research Council. Grant agreement: INTER/JPND/19/BM/14012609.

## Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **91**, representing **26** Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

**Austria:** 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); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina 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 (ALDE); Deirdre Clune (NI); 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 (NI); Brando Benifei (S&D); Pierfrancesco Majorino (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); Manuel Pizarro (S&D). **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 (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).

## EU DEVELOPMENTS

### 7 September: Alzheimer Europe signs joint statement on WHO Europe digital health plan



Alzheimer Europe has signed a joint statement coordinated by EuroHealthNet, on the Regional Digital Health Action Plan, which was approved at 72<sup>nd</sup> Session of

the World Health Organization's Regional Committee for Europe.

The joint statement welcomes the plan and its guiding principles, as well as its vision to improve health outcomes for everyone in an equitable manner. In addition, it notes existing challenges such as a lack of capacity, training, and resources to ensure appropriate use of digital tools and technologies. The signatories of the statement call for elaboration on the following four elements:

- A focus on up- and re-skilling of the European health workforce to support implementation of digital transitions in health ecosystems at all levels.
- Clear digital health governance mechanisms to safeguard privacy and trust, and which also permit for meaningful and inclusive public and patient involvement in the digital

health transformation and for consistent access to data for research across Member States.

- Providing guidance for engaging with industry and establishing labelling and certification schemes to help identify trustworthy digital health tools and applications.
- Standardisation of digital tools and technologies to foster greater accessibility, transferability, and integration, both across countries as well as sectors.

The full statement is available at:

<https://www.who.int/europe/publications/m/item/joint-statement-by-eurohealthnet-and-other-non-state-actors>

### 8 September: European Commission launches European Care Strategy

The European Commission has launched a European Care Strategy which aims to ensure quality, affordable and accessible care services across the European Union and improve the situation for both care receivers and the people caring for them, professionally or informally. The Strategy is accompanied by two Recommendations for Member States on the revision of the Barcelona targets on early childhood



education and care, and on access to affordable high-quality long-term care.

The Commission recommends that Member States draw up national action plans to make care in the EU more available, accessible and of better quality for all. In addition, the Commission recommends that Member States do more to attract more people, in particular men, to the care sector.

The Commission has committed to:

- Explore the creation of a new sectoral social dialogue for social services at EU level.
- Promote the establishment of a skills partnership under the Pact for Skills for the long-term care sector.
- Fund projects and research to assess the social and economic value of work and working conditions in the care sector.
- Review the application of EU standards governing working conditions.
- Map the current admission conditions and rights of long-term care workers from non-EU countries and explore the feasibility of developing EU-level schemes to attract care workers.
- Promote the opportunities available for early childhood education and care staff under the Erasmus+ programmes.

The Commission's proposals for Council Recommendations will be discussed by Member States with a view to adoption by the Council. According to the Commission proposals, Member States should inform the Commission on measures to implement the Recommendations one year after adoption. For each Recommendation, the Commission will publish an in-depth report within five years to give an overview of the state of play of implementation.

The European Care Strategy is available at:

<https://ec.europa.eu/social/main.jsp?langId=en&catId=89&furtherNews=yes&newsId=10382#navItem-relatedDocuments>

## 8 September: EU4Health Civil Society Alliance issues joint statement on operating grants



Alzheimer Europe has joined with 14 other members of the EU4Health Civil Society Alliance (CSA) in calling for the European Commission to include Operating Grants for health NGOs in the EU4Health 2023 Work Programme.

In a joint statement, the organisations highlighted that operating grants are the sole financial mechanism allowing health NGOs, civil society organisations, and professional and patient groups to play an independent, constructive and meaningful role in EU policymaking, whilst also ensuring that NGOs maintain capacity to support citizens during regular and crisis times. The statement further noted that whilst the grants were reinstated

and their value recognized within the EU4Health Work Programme 2022, so far, there is no clear commitment to continue this funding beyond 2022.

The EU4Health therefore calls for the continuation of the Operating Grants as a financial mechanism providing a strong foundation for health organisations' contribution to EU policy processes beyond 2022. Additionally, the EU4Health Civil Society Alliance calls for the inclusion of a 3-4-year multi-annual framework agreement for Operating Grants in the EU4Health Work Programme 2023.

The full statement is available at:

<https://eu4health.eu/joint-statement-on-the-provision-of-operating-grants-to-health-ngos/>

## 14 September: WHO Europe commits to disability-inclusive health systems

Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022-2030

- Ensure equitable access to quality health care services
- Promote health and well-being
- Ensure disability-inclusive health policies and plans
- Build an evidence base on disability and health



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At the 72<sup>nd</sup> session of the WHO Regional Committee for Europe, the 53 countries of the WHO European Region adopted "The WHO European framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030".

The commitment will see governments in the WHO Europe area work together to ensure that health systems and societies remove barriers for people with disabilities. The framework sets out four key principles to move the agenda forward:

- Human rights – people with disabilities should enjoy the same rights on an equal basis with others
- Universal design – health-care services, equipment, products and environments must be accessible and useable by all people
- A life-course approach – health services need to consider the needs of people with disabilities in all stages of life



- Inclusive health systems – disability inclusion should be integrated across all areas in national health systems.

The full framework is available at:

<https://apps.who.int/iris/handle/10665/360966>

## 20 September: European Commission launches disability employment package



The European Commission has launched a disability employment package during the “Conference on Integration of People with Disabilities into the Labour Market”, an event

organised by the Czech presidency of the Council of the EU.

The package is a flagship initiative previously announced in the Strategy for the Rights of Persons with Disabilities 2021-2030. Its intention is to address barriers which negatively affect the inclusion of persons with disabilities in the labour market across the EU.

Whilst not introducing new legislation or programmes, the package of measures aims to support the implementation of existing EU legislation across six areas:

- Strengthening the capacities of employment and integration services
- Promoting hiring perspectives through affirmative action and combating stereotypes
- Ensuring reasonable accommodation at work
- Preventing disabilities associated with chronic diseases
- Securing vocational rehabilitation schemes in case of sickness or accidents
- Exploring quality jobs in sheltered employment and pathways to the open labour market.

Details on the disability employment package are available at:

<https://ec.europa.eu/social/BlobServlet?docId=26060&langId=en>

## 21-22 September: European Medicines Agency organises multi-stakeholder workshop on patient experience data, convening a joint meeting of its Working Parties for patients, consumers and healthcare professionals



On 21-22 September, the European Medicines Agency (EMA) convened a multistakeholder workshop with patients, healthcare professionals,

academia, regulators, and industry to discuss ways to improve the collection and use of patient experience data to achieve patient-centred medicine development and regulation. During this workshop, which was organised into five sessions, attendees listened to short presentations by expert speakers from patient organisations, EMA committees, data initiatives and industry, contributing their views and discussing gaps and

priorities. Sessions addressed the following topics: patient engagement in medicines development, patient preference elicitation, patient-reported outcomes, digitalisation for patient-generated health data, and guidance on collection and use of patient data. Feedback from workshop attendees included the need to involve and engage more diverse and representative patient populations, and the importance of end user involvement in the development and validation of patient-reported outcomes and digital methodologies.

Meetings of the EMA patients’ and consumers’ working party (PCWP) and healthcare professionals’ working party (HCPWP) were held the next day, on 22 September. These meetings were the first to be held face-to-face since the start of the COVID-19 pandemic in 2020, and represent the first meetings of the new EMA mandate (2022-2025). The morning sessions were dedicated to electing new co-Chairs for the PCWP and HCPWP, with Marilena Vrana (European Heart Network) and Rosa Giuliani (European Society for Medical Oncology) elected to this role in the PCWP and HCPWP, respectively. Marilena and Rosa will co-Chair the PCWP and HCPWP together with the EMA co-Chair, Juan Garcia Burgos.

In the afternoon, the joint meeting of the PCWP and HCPWP was held. Marco Cavaleri provided a detailed situation report of vaccines and treatments for COVID-19 and monkeypox, highlighting recent developments showing that dual boosters using the original COVID-19 were able to effectively protect against severe disease caused by the new Omicron variants, BA.4 and BA.5.

Next, attendees discussed recent progress on the PCWP/HCPWP contribution to the ICH guidance on good clinical practice. This guidance document lays out quality standards for designing, conducting, recording and reporting clinical trials. Maria Mavris (EMA) then provided feedback on a recent webinar on advanced therapy medicinal products (ATMPs; medicines based on genes, tissues or cells), followed by an update from Priya Bhari (EMA) on new EMA initiatives for risk minimisation and pharmacovigilance, including PRISMA, the PRAC risk minimisation alliance.

The final session was dedicated to the “members’ voice”, with presentations from Ancel-la Santos of the European Consumer Organisation (BEUC) and Isabel Proano Gomez of the European Lung Health Group (EFA). Ancel-la spoke about a recent survey carried out by BEUC on drug shortages, highlighting this as a real issue for many EU citizens with a significant impact on their day-to-day lives. Isabel presented the recent EFA policy brief on medicines for rare disease and children, which calls for greater investment in basic research and improved frameworks for medicines development, and also outlined the results of a recent survey on digital technology use in patients with asthma and COPD. The PCWP and HCPWP co-Chairs, Marilena, Rosa and Juan, drew the meeting to a close by thanking all attendees for their contributions.

## 28 September: European Commission launches Together for Rights



On September 28, the European Commission launched “Together for Rights”, an online campaign aimed at raising awareness of the rights of persons with disabilities across the EU. The campaign will run solely online and will continue until the summer of 2023.

The campaign was envisaged by the European Strategy on the Rights of Persons with Disabilities 2021-2030 and was developed by the European Commission in consultation with a number of civil society organisations, including the European Disability Forum (EDF).

It features a number of “Champions” whose stories and experiences will be told as part of the initiative and will focus around six themes that address separate issues related to disability rights:

- Together for rights – introduction to the Strategy
- Together for inclusive culture, leisure and sports
- Together for inclusive education and work opportunities
- Together for independent living
- Together for participation – on the right to vote and stand for election
- Together for accessibility – in the virtual or physical worlds.

The Commission is encouraging organisations to support the campaign and has produced a media toolkit which can be accessed at:

<https://ec.europa.eu/social/main.jsp?catId=1558&langId=en>

Further details on the Together for Rights campaign are available at:

<https://ec.europa.eu/social/main.jsp?langId=en&catId=1556>



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## POLICY WATCH

### 2 September: Alzheimer Europe signs Oslo Declaration

Alzheimer Europe has signed the Oslo Declaration, which calls for the implementation of a range of measures intended to reduce alcohol harms. The declaration was made



during the 9<sup>th</sup> European Alcohol Policy Conference Statement, which took place in Oslo, Norway, on 16 and 17 June 2022. The key messages of the declaration include:

1. National governments and the EU should regulate alcohol based on the WHO’s evidence-based Global Alcohol Action Plan to achieve its ambitious targets by 2030
2. National governments should cooperate to implement the evidence-based WHO Best Buys and SAFER recommendations, focussed on price, availability and marketing of alcohol
3. EU level regulation should reflect public support for mandatory ingredient, nutrition declaration and warning labels on alcohol products, so empowering properly informed consumer decisions
4. National governments and the EU should make sure that health policy-making processes are protected from alcohol industry interference
5. National governments should tax alcohol products related to alcohol content. This should be index-linked and increased regularly in line with economic and health indicators
6. National governments should restrict or ban the marketing exposure of alcohol products, particularly to young people and children and other vulnerable groups
7. Governments should recognise and support the pivotal role of civil society organisations in preventing and reducing alcohol harm.

The full declaration is available at:

<https://europeanalcoholpolicyconference.org/the-oslo-declaration/>



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## 9 September: CRPD Committee publishes General Comment 8 on employment and disability



The UN Committee on the Rights of Persons with Disabilities has published General Comment 8, outlining the Committee's interpretation of Article 27 of the Convention on the Rights of Persons with Disabilities (CRPD), which focuses on work and employment.

The Committee drew upon its own jurisprudence, as well as that of the Committee on Economic, Social and Cultural Rights and other human rights treaty bodies, to develop the general comment. In addition, the Committee consulted with external civil society organisations, including the European Disability Forum (EDF).

The text clarifies how the provisions on work and employment in the CRPD (Article 27) should be interpreted by State Parties of the Convention. As such, the General Comment should guide signatories of the CRPD in their future reporting obligations.

Specifically, the document provides clarity on the Committee's position in relation to the following issues:

- Open labour market and sheltered employment
- Discrimination at work or during recruitment
- Reasonable accommodation
- Working conditions and pay
- Open labour market and sheltered workshops.

The full text of the General Comment is available at:

<https://www.ohchr.org/en/documents/general-comments-and-recommendations/crpdgc8-general-comment-no-8-2022-right-persons>

## SCIENCE WATCH

### 31 August: Korea Institute of Science and Technology develops a new type of protein for AD without inflammatory side effects



During August, a research team from the Korea Advanced Institute of Science and Technology in South Korea reported the development of a new type of protein treatment to reduce the side effects,

including severe inflammation, from existing Alzheimer's disease (AD) treatments.

Researchers developed a novel fusion protein drug, called anti-Abeta-Gas6, targeting beta-amyloid. In an AD mouse model, it significantly reduced the amount of beta-amyloid accumulated

in the brain via an entirely different mechanism than Aβ antibody-based immunotherapy. It works by simultaneously using two brain cells called microglial cells and astrocytes. Importantly, the novel fusion protein drug showed no signs of inflammation and neurotoxicity, which contrasts the neurotoxic inflammatory side effects associated with conventional Aβ monoclonal antibody treatments. Findings were published in the journal Nature Medicine.

This fusion protein type treatment is the first to apply this new mechanism of action. It can be applied to other neurodegenerative and autoimmune diseases, according to the authors.

<https://doi.org/10.1038/s41591-022-01926-9>

### 31 August: Study looks at supporting continued work for employees living with mild cognitive impairment or early onset dementia



A paper on "Supporting continued work under the UNCRPD – views of employees living with mild cognitive impairment or early onset dementia" was published in the International Journal of Discrimination and the Law, in August 2022. This article reports the results of a socio-legal investigation into how continued work among people living with progressive cognitive impairments such as mild cognitive impairment (MCI) or early onset dementia (EOD) can be supported.

The study, which makes use of empirical data collected in Finland, Sweden and Canada, sought to give a voice to people living with MCI or EOD, sharing their experiential knowledge and exploring it in the context of equality rights-related tools provided by the UN Convention on the Rights of the Persons with Disabilities (UN CRPD).

The results illustrate that there are effective tools available that remove barriers to participation, and support continued work of employees living with cognitive impairments, at least while impairments are mild. Ideally, flexibility and solidarity in the workplace automatically eliminates the effects of individual impairment, the authors comment, however, they continue, cognitive impairments are often such that individual accommodations are needed, along with general accessibility measures.

Supporting continued work expands the freedom to continue meaningful work in the preferred manner and offers people the means to gain a livelihood and participate in society as



members of the work community, on an equal basis with others.

One of the co-authors of the article is Anna Mäki-Petäjä-Leinonen from the University of Eastern Finland, who has contributed to a lot of Alzheimer Europe's work on legislation, in the past, and who has participated in a number of our ethics working groups, more recently. Read the full paper, here: <https://doi.org/10.1177/13582291221115266>

### **6 September: New study on "Development and design of a diagnostic report to support communication in dementia: Co-creation with patients and care partners" co-authored by Alzheimer Europe**



Alzheimer Europe is delighted to have co-authored a new paper, published in the journal *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring* and entitled "Development and design of a diagnostic report to support communication in dementia: Co-creation with patients and care partners". The paper was authored by Aniek van Gils and her colleagues Leonie Visser, Heleen Hendriksen, Wiesje van der Flier and Hanneke Rhodius-Meester at the Alzheimer Center Amsterdam, together with Jean Georges, Executive Director, Alzheimer Europe.

In this international publication, the researchers share the importance of using a "results page" in memory clinics, to help the patient (and their carer/supporter) understand and remember what is happening to them. Many different tests are often done before doctors make a final diagnosis and previous research has shown that people going through this process often feel that the results of these tests are not communicated to them clearly. Oncology studies, for example, have shown that a hard-copy results page can help with understanding and absorbing the information given. That being said, a diagnostic report page including test results is not yet in use in memory clinics.

The **DAILY study**, which aims to translate digital technology into clinical practice so as to support physicians in the daily challenge of dementia diagnosis, looked at creating such a

paper as a useful tool in the memory clinic setting. Aniek van Gils and colleagues investigated what this page might look like, designing it together with patients and their carers/supporters. The page was designed in focus group meetings with a number of patients and their care partners. The overview includes the diagnosis, followed by a short explanation. The various test results are shown (memory tests and epidural). Focus group members also wanted to see pictures of their own brain scans. The second page contains information about the course of the disease, tips to keep the brain healthy for as long as possible, practical matters, and where to find more information about the disease. Finally, the prototype of the diagnostic report was presented to a larger group of patients, who in turn gave their feedback.

In this manner, the researchers have taken a first step towards using a results page in memory clinics. The ultimate goal is to improve communication between doctor and patient, helping patients understand what is happening and feel more comfortable with the diagnostic process. This investigation and its results are shared in this new paper, published in the journal *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, to which Alzheimer Europe is delighted to have contributed.

In a follow-up study, the team is currently testing this prototype results page in a number of memory clinics in the Netherlands. Furthermore, Aniek van Gils presented the research at the International Conference of Communication in Healthcare (ICCH) which took place in Glasgow, Scotland, from 5 to 9 September 2022. Read the full paper, here:

<https://doi.org/10.1002/dad2.12333>

### **6 September: New study evaluates the association between daily step count and dementia**



On 6 September, a team of researchers from Australia and Denmark reported that middle-aged and older people who took just under 10,000 steps per day were half as likely to develop dementia within 7 years as were their sedentary peers. Findings were published in the journal *JAMA Neurology*.

Researchers looked at data from the UK BioBank. A total of 78,430 people aged 40 to 79 years were included (44.7% were male and 55.3% female). All participants were free of

cardiovascular disease and dementia when they enrolled in the study. Participants had to wear an accelerometer to monitor physical daily activity. The aim of the study was to examine the dose-response association between daily step count and intensity and incidence of all-cause dementia among adults in the UK.

After a seven-year follow-up period, results showed that a higher number of steps per day was associated with a lower risk of dementia, with optimal walking of 9,826 steps reducing the risk by half. For less active individuals, the study reported that as low as 3,800 steps a day can cut the risk of dementia by 25%. The researchers noted that the study is observational and that the age range of participants may have resulted in limited dementia cases.

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2795819>

## 7 September: BioVie announces topline results from its AD Phase II trial



On 7 September, BioVie, a clinical-stage company developing innovative drug therapies for the treatment of advanced liver diseases and neurodegenerative disorders, announced topline results from its Phase II clinical trial of NE3107 for the treatment of Alzheimer's disease (AD).

The trial measured changes in cognition through verbal and visual test procedures and changes in biomarkers of AD, inflammatory and metabolic parameters. A total of 23 US participants received NE3107, twice daily for three months. 17 participants had a MMSE score greater than or equal to 20 (mild cognitive impairment (MCI) to mild AD and 6 participants had a score <20 (moderate AD).

Initial results showed that the vast majority of participants with MCI and mild AD saw a significant improvement in cognition and daily abilities, as measured by the ADAS-Cog12, MMSE and Global Rating of Change scores. Reductions in TNF $\alpha$  (considered to be an initial factor driving inflammation) were observed after NE3107 treatment and significantly correlated with improvement in cognition. In addition, no drug-related adverse events were reported.

Detailed results will be presented at the CTAD Annual Conference, to be held in San Francisco (US) on November 29 – December 2, 2022. The company is currently conducting a Phase III trial in mild to moderate AD in US. Topline results are expected in mid-2023.

<https://feeds.issuereirect.com/news-release.html?newsid=5033321173028888>

## 8 September: Axsome Therapeutics initiates a new Phase III study for the treatment of AD agitation

On 8 September, the biopharmaceutical company Axsome Therapeutics, which develops therapies for the management of central nervous system disorders, announced that it has started a Phase III clinical trial with AXS-05 for the treatment of Alzheimer's disease (AD) agitation.



The first participant has been enrolled in the Phase III ADVANCE-2 trial of AXS-05. It is a randomised, double-blind, placebo-controlled and multicentre trial aiming to assess the efficacy and safety of AXS-05 for the treatment of agitation associated with AD. Approximately 350 patients will be enrolled to receive either AXS-05 or placebo for 5 weeks. The primary efficacy measure is the Cohen-Mansfield Agitation Inventory (CMAI).

AXS-05 has been granted US Food and Drug Administration (FDA) Breakthrough Therapy designation for the treatment of Alzheimer's disease agitation. A Breakthrough therapy designation is a process to expedite the development and review of drugs for serious or life-threatening conditions.

<https://axsometherapeuticsinc.gcs-web.com/news-releases/news-release-details/axsome-therapeutics-initiates-advance-2-phase-3-trial-axs-05>

## 12 September: Exploratory post-hoc analyses of TRAILBLAZER-ALZ study are published in JAMA Neurology



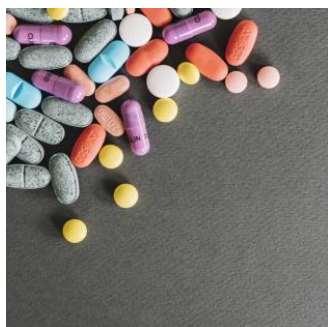
Donanemab is a monoclonal antibody which targets a specific form of the amyloid beta protein that is present in mature amyloid plaques, which accumulate in the brains of people with Alzheimer's disease (AD). The clinical efficacy of donanemab was evaluated in the TRAILBLAZER-ALZ study, a phase 2, placebo-controlled randomized clinical trial that was conducted



in the US and Canada between 2017 and 2020. TRAILBLAZER-ALZ met its primary objective, with monthly doses of donanemab slowing the clinical decline of AD by 32% compared to placebo. This slowing of clinical decline was associated with substantial amyloid plaque lowering, with 68% of donanemab-treated participants achieving amyloid-negative status after 76 weeks of treatment.

On 12 September, researchers published the results of post-hoc analyses of TRAILBLAZER-ALZ data, in the JAMA Neurology journal. These analyses were aimed at mapping the course of amyloid clearance by donanemab, and also looked at correlations between amyloid clearance and clinical decline, as well as the amount of tau tangles in the brain. The post-hoc analyses showing that participants who experienced complete clearance of amyloid plaques often had lower amounts of brain amyloid at baseline. Once complete amyloid clearance was achieved and participants switched to placebo infusions, plaques did not regrow substantially over 1 year without treatment. Donanemab also slowed tau accumulation in a region-dependent manner, as measured using brain PET imaging. Statistical analyses found an association between percentage amyloid reduction and clinical decline, but only in carriers of the apolipoprotein E (APOE)  $\epsilon 4$  risk gene. Further studies are now required to confirm these trends.

## 28 September: Eisai and Biogen announce top-line results from the Clarity AD Phase III trial of lecanemab



On 28 September, Eisai and Biogen announced positive top-line results from the Phase III Clarity AD trial of lecanemab (also known as BAN2401), an investigational anti-amyloid beta ( $A\beta$ ) protofibril antibody, for the treatment of early Alzheimer's disease (AD).

Clarity AD was a global confirmatory Phase III placebo-controlled, double-blind, parallel-group and randomised study evaluating lecanemab in 1,795 people with mild cognitive impairment due to AD or mild AD dementia with confirmed amyloid accumulation in the brain. Participants from US, Australia, Canada, China, Europe and Japan received either lecanemab (10 mg/kg) or placebo biweekly via an intravenous infusion.

Top-line results revealed that the study met its primary endpoint, showing a significant reduction of cognitive decline on the global cognitive and functional scale, CDR-SB, by 27% at 18 months for participants receiving lecanemab compared to those receiving placebo.

Additionally, the companies announced that all key secondary endpoints were met with highly statistically significant results. Key secondary endpoints were the change from baseline at 18 months compared with placebo of treatment in amyloid levels

in the brain measured by amyloid positron emission tomography (PET), the AD Assessment Scale-cognitive subscale14 (ADAS-cog14), AD Composite Score (ADCOMS) and the AD Cooperative Study-Activities of Daily Living Scale for Mild Cognitive Impairment (ADCS MCI-ADL).

For safety, the findings revealed that the profile of side effects such as brain swelling or microbleeds also known as amyloid-related imaging abnormalities (ARIA) incidence was within expectations. The total incidence of ARIA was 21.3% in the lecanemab group and 9.3% in the placebo group.

Eisai announced plans to discuss this data with regulatory authorities with the aim to file for traditional approval in the US and to submit marketing authorisation applications in Japan and Europe by the end of March 2023.

Alzheimer Europe welcomes the encouraging top-line results data reported today by Eisai and Biogen on the Clarity AD Phase III clinical trial of lecanemab and looks forward to hearing more at the upcoming Clinical Trials in Alzheimer's Disease (CTAD) conference on 29 November (San Francisco, US).

<https://www.eisai.com/news/2022/news202271.html>



## WORLD ALZHEIMER'S DAY

### 21 September: Serbian Society for Alzheimer's Disease marks World Alzheimer's Day with event in Belgrade and canvasses city authorities to increase availability of and funding for daycare centres



The Serbian Society for Alzheimer's Disease (SSAD), in partnership with the Serbian Red Cross and in cooperation with other civil society organisations that provide support to people with dementia and their families, marked World Alzheimer's Day with an event on Belgrade's main Republic Square. Speakers at the event emphasised the importance of raising public awareness of dementia, as well as highlighting the importance of prevention and early diagnosis. The lack of



services for people with dementia and carers was also pointed out. The message of the participants at the event was also sent by the president of the Serbian Academy of Sciences and Arts, neurologist Vladimir Kostić, and one of the other speakers was the Commissioner for the Protection of Equality, Brankica Janković.

The president of SSAD, Nadežda Satarić, stressed that people with dementia are not visible in public health planning and that this must change. She informed the audience that, in less than a month, 5,639 signatures were collected on the petition "Dementia isn't picky", as part of a SSAD campaign run with the support of the Swiss Government project "Together for an active civil society". The petition asks Belgrade City authorities to include in the social welfare legal framework the right to daycare centres for people with dementia and to plan funds for the development and functioning of this service in the city's budget for 2023. The petition was supported by experts in this field, many prominent public figures and all 13 citizens' associations from Belgrade that provide some form of support to patients and their families.

Once SSAD succeeds in Belgrade, it will start advocating that other local governments also develop this much-needed service for people with dementia and counselling centres for their family carers.

## **21 September: Institute for Alzheimer's Disease and Neuroscience - North Macedonia marks World Alzheimer's Day with "Alzheimer's Matinée"**



The Institute for Alzheimer's Disease and Neuroscience - North Macedonia marked World Alzheimer's Day with an event called "Alzheimer's Matinée", which took place in the city square in Skopje, North Macedonia. It was attended by 150 people including the first lady of the country, the mayor of Central County, the director and doctors from the Neurology Clinic, and representatives from the Red Cross and the Clinic for geriatric and palliative care. A number of people with dementia were also in attendance.

There was a performance from the students from the School of Music Arts in Skopje and there were talks from the Heads of the University Clinics of Neurology and Psychiatry, as well as

readings from a book by a dementia caregiver, activities for the elderly, and some music.

The event not only marked World Alzheimer's Day but also aimed to raise awareness of dementia and address shortcomings in the management of dementia and the lack of support for people affected by it.

A teaser video of the event can be viewed, here: [https://drive.google.com/file/d/1T2NR\\_I9D2pLUpicrgyiUJaY11Tl2tn4L/view](https://drive.google.com/file/d/1T2NR_I9D2pLUpicrgyiUJaY11Tl2tn4L/view)

## **21 September: This World Alzheimer's Day, Alzheimer Switzerland calls for basic health insurance to reimburse non-pharmacological interventions for people with dementia**



For World Alzheimer's Day 2022, Alzheimer Switzerland sent out the following release, about researching, promoting and funding non-drug treatments and called for of basic health insurance to reimburse non-pharmacological interventions for people with dementia:

Some 150,000 people with dementia are currently living in Switzerland and there are 32,200 new cases each year. As age remains the main risk factor, this trend will continue: it is estimated that by 2050, some 315,400 people will have Alzheimer's disease or another form of dementia. To support them and their families, it is essential to intensify research into non-drug treatments, promote them and ensure that they are covered by basic insurance throughout the course of the disease.

Based on the latest population census (2021), Alzheimer Switzerland estimates that 150,000 women and men in Switzerland are currently affected by Alzheimer's disease or another form of dementia. By 2050, the number of people with dementia in our country is expected to be around 315,400. Alzheimer's disease and other dementias often occur at an advanced age. Since women have a longer life expectancy, they are more heavily affected (66%). However, the disease can also affect young people who are still professionally active, though less frequently: only 7,700 or 5% of people with Alzheimer's disease or another form of dementia are under 65.

The diagnosis of dementia causes a radical change in life, both for the person with the disease and for their relatives. As the disease progresses, the latter are heavily involved: of the 11.8 billion Swiss francs that all care and support tasks cost each year, they provide an estimated 5.5 billion francs of unpaid work. The constraints on patients and their families are considerable, especially since there is currently no effective medication and future treatments will not be suitable for everyone.

In this context, non-drug treatments such as speech therapy, psychotherapy, music therapy or art therapy play an essential role: they contribute to a good quality of life and prolong the autonomy of people with dementia, while relieving the burden on their relatives. However, even today, too many patients do not have access to these approaches because they cannot pay for them or because their GP does not prescribe them. For Alzheimer's Switzerland, it is urgent that the basic insurance reimburses non-drug treatments, so that they are accessible to all, and that studies finally demonstrate their effectiveness. To this end, in March 2022, Alzheimer Switzerland submitted a request for the establishment of a national research programme on psychosocial interventions.

Related downloads (in French):

- Dementia in Switzerland 2022, Facts and Figures: <https://www.alzheimer-schweiz.ch/fr/publications-produits/produit/les-demences-en-suisse-faits-et-chiffres-1>
- Alzheimer Switzerland Dementia costs 2019: <https://www.alzheimer-schweiz.ch/fr/les-demences/article/etude-dalzheimer-suisse-sur-les-couts-des-demences-2019-perspectives-sociales>

## 21 September: Confederación Española de Alzheimer (CEAFA) organises conference "InvestigAcción" on the occasion of World Alzheimer's Day



On the occasion of World Alzheimer's Day 2022, the Spanish Alzheimer Confederation (Confederación Española de Alzheimer - CEAFA), organised a Conference called "InvestigAcción".

The conference took place at the Carlos III Institute in Madrid and was attended by the president of

CEAFA, Mariló Almagro, who presented this year's demands to all those present. She stressed the need to "act in a concrete and specific way" throughout the entire dementia pathway, as well as to promote the culture of research, both biomedical (to achieve a diagnosis and treatment of the disease) and social (to improve the quality of life of those affected).

The meeting was attended by health experts who spoke about biomedical research, recognising the great progress made with the appearance of biomarkers for diagnosing Alzheimer's and different genes associated with Alzheimer's disease. This makes it possible to have a greater understanding of the causes of the disease in order to be able to find better treatments.

The economic cost of dementia and the importance of early diagnosis, to be able to start the corresponding treatments, were then discussed, as well as a recent study carried out, which revealed that 39% of the people who were given the IQCODE test were at risk of cognitive deterioration.

The day ended with the participation of a person diagnosed with Alzheimer's disease, which made the need for this research real and tangible. The fight against Alzheimer's disease and the effects and consequences it has on people, families and society was highlighted, as was the importance of making a new group visible, that of people diagnosed early, and encouraging their participation in "PEPA" (panel of experts for people with Alzheimer's disease). This speaker took the opportunity to call for the implementation of active policies to support dementia through three key tools, which exist but which need to be reviewed and funded: the Dependency Law, the Strategy for Neurodegenerative Diseases of the National Health System and the Comprehensive Plan for Alzheimer's and other Dementias (2019-2023).

## 21 September: Turkish Alzheimer Association organises Artificial Intelligence-based exhibition to mark World Alzheimer's Day



Artificial Intelligence (AI) is used in the area of dementia increasingly, because it promises identifying Alzheimer disease (AD) -related structural changes in brain scan images and accommodates huge potential for more accurate, early diagnosis of the condition and its progression.

AI technology helps people affected by dementia in several ways. First of all, it supports early diagnosis. Big data are used to identify changes to the physical structure of the brain and the energy use and chemical makeup of the brain to spot the earliest signs of dementia. Technology can also be used to spot patterns or changes to memory and thinking, using data collected from thousands of people, over time, through written tests or even testing on smartphone apps.

Secondly, AI can help explain how dementia symptoms develop. Dementia is a progressive condition, and it affects people differently over time therefore, AI can be used to predict how the condition will affect the brain physically over time by analysing genetic profiles and creating models to predict who might be more likely to develop dementia, later in life.

Furthermore, AI can be used to enhance care and support so that people affected by dementia can live at home for longer. For example, sensors can be used around the house to intelligently monitor a person's behaviour and to spot risky behaviour or signs of health deterioration.

The Turkish Alzheimer Association closely follows AI technology and, this year, as part of its awareness-raising activities on World Alzheimer's Day, it used a more enjoyable form of AI, namely "Midjourney" which is a text-to-image AI technology,



used to produce virtual art. A digital exhibition was launched with the pieces produced by Midjourney, based on the key question: "How would Picasso / Dalí ... picture Alzheimer's disease?". As the key words were prompted to the app, paintings were created by Midjourney, using the information about and the assumptions of Salvador Dalí, Gustav Klimt, Leonardo da Vinci, Vincent van Gogh, İbrahim Çallı, Adnan Çokar and others. The association used AI as a fun tool, but AI technology may soon play an important role in the treatment of Alzheimer's as well, it stressed.

## **24 September: Association Luxembourg Alzheimer hosts 21<sup>st</sup> Memory Walk to mark World Alzheimer's Day**



On Saturday 24 September 2022, the Association Luxembourg Alzheimer (ALA) organised its 21<sup>st</sup> Memory Walk on the Place Clairefontaine in Luxembourg City. From 11:00 to 17:00, visitors were able to learn about Alzheimer's disease and other forms of dementia at the information stands of the ALA. In a relaxed atmosphere, they had the opportunity to meet new people and take part in many discussions.

In addition to food stalls, there were various activities, including a concert by Serge Tonnar & Band and music by *Les Brasseurs*. The Memory Walk itself allowed participants to show their solidarity with people with dementia. The Walk, accompanied by a tourist guide, took participants to the Grand Ducal Palace, where they were given information about the Grand Duke's official residence in the city and about the Luxembourg-Nassau dynasty.

The theme of this year's Memory Walk was "Dementia, let's stand together". The inclusion of people with dementia and their relatives requires sensitivity and tolerance and means reacting flexibly to everyday obstacles. People with dementia and their relatives must feel that they are accepted and have a place in society despite their illness, insists the ALA.

The Minister for Family Affairs, Mrs Corinne Cahen, also honoured the ALA with her presence.

## **27 September: Info-Zenter Demenz organises conference on "Laughter, humour and dementia"**

On 27 September 2022, to mark the occasion of World Alzheimer's Day, the Info-Zenter Demenz, the national information centre on dementia in Luxembourg, organised a conference on the topic "Laughter, humour and dementia", with Colette Roumanoff, author, director, lecturer and trainer, followed by a round table discussion with Mathilde Guénard, alias "Nitouche" from *Ile aux*

Clowns, Luxembourg, Nadine Reitz, Head of supervision and animation at HPPA Clervaux and Colette Roumanoff.

The conference took place in the presence of Corinne Cahen, Luxembourgish Minister for Family and Integration.

The Info-Zenter Demenz is the national information and counselling centre in Luxembourg for all questions related to the topic of dementia. The team is available Monday to Saturday and can be reached by phone (+352 26 47 00) or email (mail@i-zd.lu).



## **27 September: Czech Alzheimer Society hosts mobile counselling centres in Prague, Hradec Králové and České Budějovice for World Alzheimer's Day**

This year, to mark World Alzheimer's Day, the Czech Alzheimer Society built on the success of the Prague Mobile Counselling



Centre and organised the same event in Prague and two other regional cities during September.

These mobile counselling centres, which the Czech Alzheimer Society organised in Southbohemian České Budějovice and Eastbohemian Hradec Králové, in cooperation with the local



contact point of the Czech Alzheimer Society, were opened for seven days and were attended by almost 3,000 people in a large local shopping centre. Some visitors came just for information materials, others got a more in-depth consultation. The event, supported this year by the Ministry of Social Affairs, the City of Prague and Roche, was a success.

Every year, the Czech Alzheimer Society associates the mobile counselling with a reaction from people passing by. Last year it was: "How can you promote such a terrible disease?!" And this year: "I don't have time for dementia!" Of course, there were fortunately also many people who received support on the spot or made an appointment at the contact point.

The most frequent visitors were people who were worried about dementia. Similarly, those who were already experiencing some memory difficulties also attended. In the regions, three times more women, and in Prague almost four times more women visited the mobile counselling centre.



## LIVING WITH DEMENTIA

**25 September: Idalina Aguiar write about her slow recovery from a bad fall and her return to advocacy work**



Idalina Aguiar is a Member of the European Working Group of People with Dementia and is supported by her daughter Nélide, to whom we are grateful for her help in translating Idalina's words to English:

Three months have passed...and now, I write these words with the vital help of my daughter, Nélide.

On 5 June, my life, which is already very limited, had another setback. The bad fall that my daughter Nélide and I had together, proved to be quite limiting for both of us, though with far more complicated consequences for me: Within one month, I had to be in the operating theatre to undergo four general anaesthetics, due to a prosthesis placement, two dislocation reductions and a new more restrictive prosthesis placement.

These were very complicated days in which despair swept

through my family, the uncertainty of the success of any intervention, but above all the chance of survival in these cases, for patients with dementia.

Weeks of recovery followed, a lot of waiting, a lot of commitment and above all a lot of exhaustion for those who are here, at home, giving me constant care. I often had to use physical restraints, but above all, surveillance became constant. Having Alzheimer's dementia, I do not always remember that I fell (my recent memory is almost non-existent), so it has been necessary to use a physical restraint that consists of a series of techniques whose purpose is to limit my body movement, which are only to be used for my security. Right now, my family has to focus on avoiding any kind of falls.

In these past three months, my life has changed a lot, but I have always stuck to my supplements, medication, and therapies. They had to adapt my room and now at home there is an electric bed and an anti-bedsore mattress with a motor that works 24 hours a day, which helped in my recovery. I started to have social support that is restricted to home support in hygiene care (twice a day). I was bedridden and I went through moments where I didn't even recognise myself and others, and with moments of hallucinations during my hospitalisation. At home, I was recovering with the intense support of my family. I started to have 24-hour follow-up as well.

But, I will continue to struggle, despite my limitations, as I still struggle with enormous mobility difficulties. Against most expectations, I started to take steps, with the help of a walker, and we are committed to using a cane for short distances. Once again, I managed to demonstrate that I am a clear example of resilience and I have been a constant fighter and demonstrated that it is possible to live with dementia, despite limitations. I am proud!

After just over three months, I returned to my advocacy work, and on 21 September, in celebration of World Alzheimer's Day, I participated in two actions:

**Action 1:** The Municipality of Funchal (the city where I live, on Madeira island, Portugal) marked World Alzheimer's Day, as a way of showing its support and sensitivity towards people with dementia and their families. I participated in the information action

held in the *Paços do Concelho* building, in partnership with Alzheimer Portugal's Delegation of Madeira. My daughter took the opportunity to emphasise the role of caregivers, who are often forgotten, despite the fact that their role is vital. We remain attentive to inclusion policies, where everyone is important and decisive in the development of mechanisms that can collaborate to improve the quality of life for patients and their families, thus making our society more just and more human.

**Action 2:** The National Association of Gerontologists called on my experience and availability, and that of my daughter Nélida, to share our perspectives and the challenges of what it means to (co)live with dementia. Gerontologists, professionals, students, and others interested in the subject were able to learn more about what it means to receive a diagnosis of a chronic, irreversible and highly stigmatising condition in today's society. Acceptance, integration, inclusion and empathy were our key words. Despite the inevitable catalogue of weaknesses and difficulties that people with dementia and care partners face on a daily basis, this "Gerochat" essentially served to reflect on the true meaning of person-centred care; on needs, preferences and wishes. We emphasised, also, the importance of taking an optimistic (rather than fatalistic) view, whenever possible. We also highlighted the importance of training of professionals (both in the social and health sectors on dementia and its conditions) and informal caregivers; implementation of specialised and differentiated care, namely non-pharmacological therapies; awareness and demystification around dementia; and last but not least, inclusion, at all times. We are certain that the gerontologists have the necessary skills to respond to all the challenges posed by dementia.

## DEMENTIA IN SOCIETY

### 31 August: Meet the 2022–2023 Atlantic Fellows for Equity in Brain Health



To protect the world's population from threats to brain health, a new group of emerging leaders has joined a global movement: the 2022–23 Atlantic Fellows for Equity in Brain Health at the Global Brain Health Institute (GBHI).

Hailing from 19 countries spanning Africa, Asia, Europe, North America, South America and Oceania—and various

disciplines such as economics, film, neurology, psychology and public health—the 32 fellows reflect a diverse range of geographies, expertise and life experiences. Find out more:

<https://www.gbhi.org/news-publications/meet-2022-2023-atlantic-fellows-equity-brain-health>

### 19 September: Well-known fairy tales "brought to life" at Foundation Compassion Alzheimer Bulgaria theatre workshop for residents and staff at care home in Zheleznitsa

On 19 September 2022, the residents and the specialists from the "Family-type Accommodation Center" for people with dementia in the village of Zheleznitsa, Bulgaria had the opportunity to experience the magic of the theatre, thanks to Foundation Compassion Alzheimer Bulgaria. The Foundation successfully worked together with actors Teodor Kukov, Aladdin Aliybrahim and Alexander Itev for the second year running, in presenting creative theatre plays for people with dementia.

The plays are implemented in the framework of the project "STAR — Support and Training for People and Families affected

by Alzheimer's Disease for Building Sustainability", with the financial support of *Otto per mille*, the Valdesian Church of Italy.

Creative theatre is an art form that is used in the field of care for people with dementia. It creates an opportunity to introduce them to a positive environment, promoting humour and fun, where the residents have the opportunity to enjoy the moment. Theatre allows people to communicate socially and can help form meaningful relationships in which participants feel involved in a group. It is an art that reduces feelings of apathy, depression, negative emotions and social isolation, that people with dementia may feel.

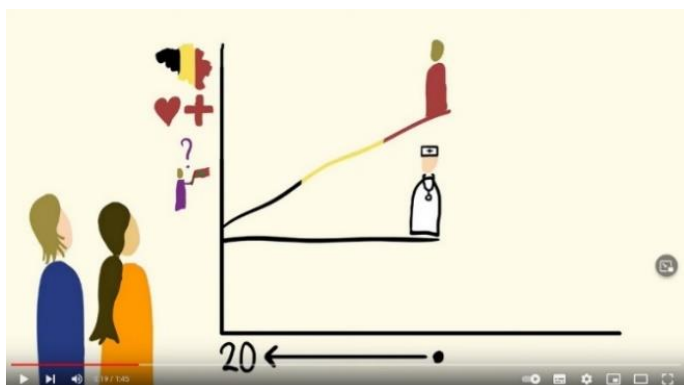
Foundation Compassion Alzheimer Bulgaria notes that these theatre events, which are based on well-known fairy tales and where the residents, with some help from assistants, can make their own dolls and act out the plots, lead to an improvement in the participants' communication, relationships and self-esteem, in a fun way that improves mood and reduces stress for people with dementia and caregivers.



## NEW PUBLICATIONS AND RESOURCES

### 7 September: New animated video shares research into the state of service provision in Belgium for older people with a migration background and dementia

In Belgium, the number of older people with a migration background who develop dementia is growing. At the same time, the care services available in Belgium for this group have remained unchanged for twenty years, meaning that they no longer suit the target population today, and certainly not for the



future. A new animated video, published online on 7 September 2022, highlights why it is important to adapt dementia care services.

The video was created by researchers Saloua Berdai-Chaoui and Ann Claeys and is based on findings from six years of their research involving older migrants with dementia from Italian, Moroccan, and Turkish backgrounds, as well as family carers and professional carers in Belgium. The easy-to-understand, bite-size video ends with a link to further information about their research, the major findings of which are collected in their book "Dementia among older migrants" (available in Dutch and French). Find out more about the book, here:

<https://www.maklu.be/MakluEnGarant/BookDetails.aspx?id=9789044138276>

Watch the video, here:

<https://www.youtube.com/watch?v=JJVx9XrNjZ0&t=16s>

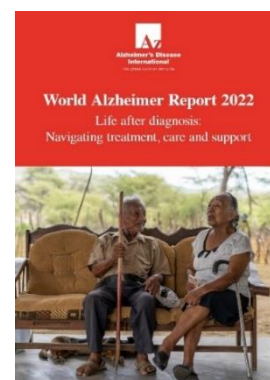
More information about the research, the video and the publication can be found on the Omed Instagram and Facebook account @ouderenmigratiedementie

## 21 September: Alzheimer's Disease International publishes World Alzheimer Report 2022

On World Alzheimer's Day, 21 September, Alzheimer's Disease International published its World Alzheimer Report 2022. This year's report shines a light on the "Life after diagnosis: Navigating treatment, care and support". The report contains 119 essays across 24 chapters covering the many facets of life following a diagnosis of dementia, written by researchers, health and social care professionals, informal carers, and people living with dementia.

Some of the key topics covered in the report include: The importance of staging dementia and the specificities of different forms of dementia; The practical considerations in managing symptoms of dementia; The impact of diagnosis on people living with dementia, their carers, relatives and communities; International and national perspectives on models of care; and the significance of dementia awareness and education to combat stigma and ensure better care. Read the report:

<https://www.alzint.org/resource/world-alzheimer-report-2022/>



Reminder  
**LATE CALL FOR ABSTRACTS**  
September 15-30

November 29-December 2, 2022  
San Francisco, USA

[www.ctad-alzheimer.com](http://www.ctad-alzheimer.com)  
Email: [ctad@ant-congres.com](mailto:ctad@ant-congres.com)



**11. KONGRESS DER DEUTSCHEN ALZHEIMER GESELLSCHAFT**  
vom 29. September bis 1. Oktober 2022 in Mülheim an der Ruhr  
[www.demenz-kongress.de](http://www.demenz-kongress.de)



### Contact Alzheimer Europe:

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**Administrative Assistants:** Cristina Pencea, Grazia Tomasini.

## AE CALENDAR

Date	Meeting	AE representative
3 October	Online meeting of EDF ENGO	Owen
3 October	Meeting with Alzheimer's Research UK	Jean
3-4 October	Lethe project General Assembly	Ana and Chris
3-5 October	Patient Engagement Open Forum (PEOF) (Barcelona, Spain)	Soraya
4 October	Launch of the WHO Dementia Blueprint	Angela and Owen
10 October	EDF Training on financial sustainability	Jean
10-11 October	DataSavesLives Bootcamp (Prague, Czech Republic)	Angela
11 October	WW Fingers Network Meeting	Jean
12 October	Astellas Roundtable on multimorbidities in cancer and cognitive decline	Jean
13 October	Meeting with Vlaamse Alzheimer Liga (Luxembourg, Luxembourg)	Jean
17 October	Alzheimer Europe Annual General Meeting (Bucharest, Romania)	AE members and staff
17-19 October	Alzheimer Europe Annual Conference "Building bridges" (Bucharest, Romania)	AE members and staff
24-25 October	Finding Alzheimer's Solutions Together (FAST) Council	Jean

## CONFERENCES 2022

Date	Meeting	Place
5-8 October	Croatian Congress on Alzheimer's Disease with International Participation, CROCAD-22, <a href="http://www.alzheimer-croatia2022.com/">http://www.alzheimer-croatia2022.com/</a>	Supetar, Brač island, Croatia
13-15 October	In and Out of Your Mind conference, focusing on early intervention services for individuals experiencing a psychotic illness, co-organised by EUPHA Public Mental Health section, <a href="https://inandoutconference.com/">https://inandoutconference.com/</a>	Zagreb, Croatia
17-19 October	32 <sup>nd</sup> Alzheimer Europe Conference "Building bridges", <a href="https://www.alzheimer-europe.org/Conferences/2022-Bucharest">https://www.alzheimer-europe.org/Conferences/2022-Bucharest</a>	Bucharest, Romania
7-10 November	EMBO-EMBL Symposium on "The neurovascular interface", <a href="https://www.embl.org/about/info/course-and-conference-office/events/ees22-11/">https://www.embl.org/about/info/course-and-conference-office/events/ees22-11/</a>	EMBL Heidelberg and Virtual
9-12 November	15 <sup>th</sup> European Public Health Conference 2022 "Strengthening health systems: improving population health and being prepared for the unexpected", including EUPHA Public Mental Health section sessions, <a href="https://ephconference.eu/">https://ephconference.eu/</a>	Berlin, Germany

<b>29 November - 2 December</b>	Clinical Trials on Alzheimer's Disease (CTAD 2022), <a href="http://www.ctad-alzheimer.com">www.ctad-alzheimer.com</a>	San Francisco, USA
<b>23-25 March 2023</b>	17 <sup>th</sup> World Congress on Controversies in Neurology (CONy), <a href="https://cony.comtecmed.com/supporting-partners/">https://cony.comtecmed.com/supporting-partners/</a>	Dubrovnik, Croatia
<b>1-4 July 2023</b>	9 <sup>th</sup> EAN Congress - Budapest 2023: Neurology Beyond the Big Data, <a href="http://www.ean.org">www.ean.org</a>	Budapest, Hungary



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# 32<sup>nd</sup> Alzheimer Europe Conference

## Building bridges

### Bucharest, Romania

### 17 to 19 October 2022

[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

 #32AEC

