



Annual Report 2022



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Preface

A few words from our Chairperson



Maria do Rosário Zincke dos Reis

My term as Alzheimer Europe Chairperson started in October 2022, when I was elected by our members at the Annual General Meeting in Bucharest. I would therefore like to start this short preface by thanking and paying tribute to my predecessor Iva Holmerová for the amazing work she had overseen in her six years as our Chairperson and her invaluable contributions to Alzheimer Europe in her 14 years on our organisation's Board. I know that I have big shoes to fill and I am therefore glad that I will be able to rely on the support of my colleagues in the Alzheimer Europe Board, as well as our staff in Luxembourg.

Looking back on the activities highlighted in this Annual Report, I am aware of the amazing team work that was necessary for the many achievements which we are highlighting and celebrating in this report. My thanks therefore go to all the representatives of our national member organisations, as well as external experts who contributed to our projects, publications and meetings.

2022 was the first year that we based our activities on the six priorities of our new Strategic Plan (2021-2025) which included new strategic objectives on changing perceptions and combating stigma and raising awareness of brain health and prevention. The year also saw a gradual return to normal activities and in-person meetings after the long pause and reliance on online meetings imposed by the COVID-19 pandemic. A final important shift that occurred in 2022 was the change in funding. Whereas Alzheimer Europe had received operating grants from the European Union's health programme for more than ten years, the uncertainty about the future of health operating grants and the late call for applications made it necessary for Alzheimer Europe to identify other sources and we were delighted to sign a four-year multi-annual framework programme for core funding as an association representing people with disabilities with the Citizens, Equality, Rights and Values (CERV) programme, for our activities from 2022 to 2025.

Not surprisingly therefore, the involvement of people with dementia in our activities and meetings remained our number one strategic objective. The European Working Group of People with Dementia (EWGPWD) also marked its 10th anniversary and we celebrated the occasion with a special get together of current and previous members and a special report on the group's many achievements. The EWGPWD also authored its own guide on how to discuss and portray dementia and people

with dementia in a respectful and inclusive way and provided concrete examples of how people with dementia are affected by employment and social protection legislation, for our 2022 Yearbook. The conference symposium of the group in Bucharest was yet again one of the most popular sessions at our Annual Conference and the contributions of group members to the public involvement activities in our EU-funded research projects are too numerous to list here.

I am also particularly proud that Alzheimer Europe took the step, in 2022, to set up a European Dementia Carers Working Group, which will hopefully prove just as successful as the EWGPWD in ensuring our association duly takes into account the views, opinions and experiences of family members, care partners and supporters of people with dementia. It was great to see that 14 member organisations from 13 European countries were able to nominate members to this new group and I look forward to a closer collaboration with the group in the coming years.

Alzheimer Europe also continued to work with European and national policy makers with an interest in dementia. The European Alzheimer's Alliance with Members of the European Parliament and the European Group of Governmental Experts on Dementia are two groups which Alzheimer Europe is coordinating and which ensure that dementia is given its due priority at European and national level. It was amazing to see that we have support from Members of the European Parliament from 26 out of 27 Member States and from all political groups and that 19 countries, as well as the European Commission and World Health Organization were represented in our Governmental Expert group clearly showing that dementia truly transcends geographical and political borders.

My thanks go in particular to our colleague from the Alzheimer Europe Board, Sirpa Pietikäinen, MEP (Finland) who chairs our European Alzheimer's Alliance and who, alongside Deirdre Clune, MEP (Ireland) co-hosted and moderated our interesting lunch debates in Brussels.

On the publications front, 2022 was another busy year as we dedicated our Yearbook to employment and social protection policies of interest to people with dementia and published a guide on the respectful communication about and inclusive portrayal of dementia and people with dementia, as well as recommendations for social and health care professionals on how to better take into account sex, gender and sexuality in their important work with people living with dementia. In addition, I am truly proud of the growing number of scientific publications to which the Alzheimer Europe team has contributed. The list of scientific publications is included as Annex 2 to this report, but I would like to single out the article on "Keeping track of and recognizing the value of public involvement work in dementia research" which was authored by the public involvement team of Alzheimer Europe and published in *Frontiers in Neurology*.

Our project portfolio also continues to expand and, in 2022, Alzheimer Europe was a full partner in no less than 14 European research projects, funded by the Innovative Medicines Initiative, Horizon Europe, as well as the Luxembourg National Research Fund. Apart from providing an additional funding stream for the organisation, our participation in these important research consortia allows Alzheimer Europe to stay at the forefront of European research and ensures research projects reflect the needs, views and experiences of people living with dementia. We support these projects by helping to disseminate the progress and results to a wider audience and our communication tools (newsletter, website, social media) attract a growing number of followers interested in dementia research.

Our Annual Conferences are also an important part of our communication strategy and our Annual Conference in Bucharest constituted a true highlight for me. After two years of virtual conferences due to the COVID-19 pandemic, it was truly special to finally meet in person again. We were delighted to welcome 543 participants from 42 countries to the conference which was held under the motto "Building bridges" from 17 to 19 October. The feedback from the attendees was overwhelmingly positive and 97.83% of participants said that they would recommend our conferences to their colleagues.

Our Annual General Meeting also took place in Bucharest and it was great to meet with our members for in-person discussions and exchanges. Many thanks go to the Alzheimer Europe members of course for their confidence in me and my colleagues on the Board and their willingness to vote for me as the new Chairperson of the association. I will make sure to continue the excellent work done under Iva Holmerová. It was also great to witness how the European dementia family continues to grow as we welcomed three new full members from Austria, Estonia and Poland, as well as an additional five new provisional members from Armenia, Lithuania, North Macedonia, Serbia and Ukraine.

It is always difficult to pick your favourite moments in any given year and last year was no exception. Apart from the many highlights which I

have already mentioned, I wanted nonetheless to single out two specific new initiatives. It was the first time that Alzheimer Europe partnered with the Alzheimer Europe Foundation and our gold sponsors Biogen, Lilly and Roche to identify an outstanding initiative aimed at combating stigma and changing the perceptions around dementia and people with dementia. We had great success with our Anti-Stigma Award call, as we received applications from 52 initiatives across Europe, making our selection of the winning initiative quite a challenge. In the end, we opted to award three prizes to the top initiatives and, at the closing ceremony of our conference, presented the awards for the best anti-stigma initiatives to the "Adoption project, young adopts old" from the Alzheimer Centre Limburg in the Netherlands, followed by the "Don't forget to love me" campaign of Federazione Alzheimer Italia and the "Changing perceptions of dementia in the Punjabi community" by the UK Alzheimer's Society. They were all outstanding examples of successful initiatives challenging negative misconceptions of Alzheimer's disease.

The second initiative was our collaboration with Roche on their "What makes you, you" campaign. We worked very closely with the company to develop three short videos of members of our EWGPWD highlighting how they are able to stay active and engaged despite a diagnosis of Alzheimer's disease. I am particularly grateful to Stefan Eriksson and his daughter Janni Ahlgren from Sweden, to Bernd Heise and his wife Hilde from Germany and to Helen Rochford-Brennan from Ireland, who all shared their very personal stories of living with dementia. The three videos were launched on World Alzheimer's Day and were viewed thousands of times on the campaign website and our social media. Thanks also to Roche for a great collaboration to help create a world where people with dementia can continue to be who they are.

As I come to the end of my first Annual Report preface as Chairperson of Alzheimer Europe, I have to thank the amazing Alzheimer Europe team, as the many achievements I just highlighted would not have been possible without the great team work and collaboration between our members, the Alzheimer Europe Board and staff and the many sponsors and external experts working with us.

Alzheimer Europe's staff was led by Director Jean Georges and included Christophe Bintener, Cindy Birck, Kate Boor Ellis, Angela Bradshaw, Ana Diaz, Dianne Gove, Gwladys Guillory, Owen Miller, Stefanie Peulen and Grazia Tomasini. In 2022, they were joined by new colleagues Daphné Lamirel, Soraya Moradi-Bachiller and Cristina Pencea. I am truly in awe of the amazing work carried out by such a small, but incredibly dedicated team.

I hope that you will share my sense of pride and achievement on reading about our activities, meetings and projects in 2022.

I am counting on all of you to go further in our goals!

Maria do Rosário Zincke dos Reis
Chairperson

A few words from the Chairperson of the European Working Group of People with Dementia



Chris Roberts

Well, another year gone, far too fast! But it was perhaps a better year than the previous one, since our membership was able to resume face-to-face meetings. We met three times, once in Luxembourg (May) and twice in Brussels (June and September). This was very relevant for the group as nothing equals an in-person meeting, where bonds can be made, friendships renewed and information shared more easily. In a face-to-face meeting we can get more done, we are more effective, can support each other and can roll off others' thoughts.

A very important event also took place this year, as we had our European Working Group of People with Dementia (EWGPWD) 10 year anniversary, for which we had a report, a newsletter and an online celebration (10 November), to which all members and ex-members were invited and the three Chairs of the EWGPWD during this time, Helga, Helen, and myself co-chaired this important event. We celebrated present and past members, plus those that are no longer with us and reflected on the great achievements we have accomplished as a group, together with Alzheimer Europe.

Our working group also worked on the topic of respectful communication, in 2022, producing the "Guidelines for the ethical and inclusive communication about/portrayal, of dementia and people with dementia". These updated guidelines were developed within the group and are for the media, researchers, journalists, policy makers, and anyone who communicates about or portrays dementia and people with dementia in the public domain. They aim to promote greater reflection and increase awareness about all of these issues.

Our symposium "Building bridges, our voices, our lives" at the Alzheimer Europe Conference in Bucharest, was again a big success and very well attended, indeed the room was so full that there was not enough space for everyone that wanted to attend. The symposium was hosted and facilitated by myself as Chair and our members who spoke included Kevin, Erla, Nigel and Angela (supported by Lilo), two of whom spoke for the first time as an EWGPWD representative and all were amazing! We write our own speeches with help and feedback from our members, in our own words, and we were honoured to have a standing ovation and to get such excellent feedback.

In 2023, we will be taking part in a plenary session which again we will organise ourselves.

In October, the group started a new term for 2022-2024. We had a farewell meeting for members who had been in the group for the past term and to some who had been there for several years, including Helen, who

had been Vice-Chair and then Chair of the group, plus Stefan, Geert, Idalina, Tomaž and Danny, who had been great contributors over the years and we wish them well.

I was honoured and happy to have been re-elected as Chair for the new term and welcomed Kevin and Margaret as my Vice-Chairs. The new group has 15 members which is the largest group since the EWGPWD was set up in 2012 and it's great to see more countries putting people forward so they too can have a voice.

My thanks, as usual, go to our supporters who do so much to assist us and get us to these meetings, to Alzheimer Europe's very supportive Director Jean Georges, the Alzheimer Europe staff, especially our amazing supportive facilitators, Dianne and Ana, plus our new staff/facilitators Daphné and Soraya, the Alzheimer Europe Board and of course to the national member associations in our home countries.

Thanks!

Chris Roberts
Chairperson of the EWGPWD



Speakers at the special symposium of the European Working Group of People with Dementia, 32nd Alzheimer Europe Conference, Bucharest, 18 October 2022

Executive Summary

In 2022, Alzheimer Europe:

Provided a voice to people with dementia and their carers

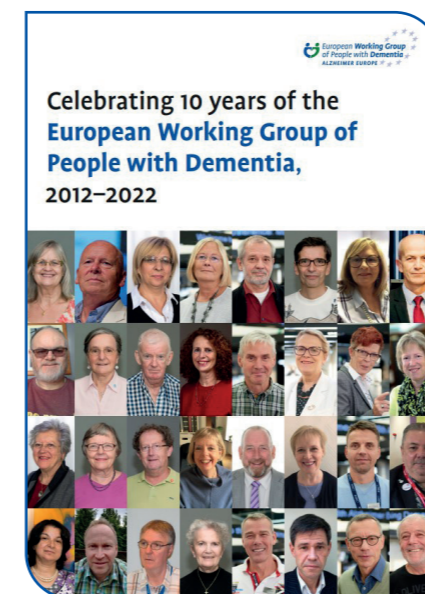
- Included the European Working Group of People with Dementia (EWGPWD) in all its activities, meetings and projects and organised three in-person and four online meetings of the group
- Organised new nominations of the EWGPWD resulting in a new group comprised of eight women and seven men from ten European countries for the period 2022-2024
- Marked the 10th anniversary of the EWGPWD by launching a report with highlights of the group's work
- Co-developed a guide for the media, researchers, journalists and policy makers on ethical and inclusive communication about dementia
- Involved the group in the 32nd Alzheimer Europe Conference in Bucharest and organised a special symposium entitled "Building bridges, our voices, our lives"
- Modified the Alzheimer Europe Statutes and Rules and Regulations to allow the setting up of the European Dementia Carers Working Group, set up the group with 14 members from 13 European countries and organised a first informal online meeting of the group

Made dementia a European priority

- Monitored EU policy developments and contributed to European Commission consultations on the European care strategy and EU disability card
- Collaborated with other European disability and health NGOs

to develop joint policy statements and contributions to EU policy discussions

- Provided the secretariat of the European Group of Governmental Experts on Dementia and organised two online meetings of the group where health ministry officials from 19 European countries participated, as well as observers from the European Commission, the OECD and the World Health Organization (WHO)
- Included 89 Members of the European Parliament from 26 of the 27 Member States of the European Union and all political groups in the European Alzheimer's Alliance and involved individual members in its European Parliament lunch debates as well as asking them for contributions to the Dementia in Europe magazine
- Focused on employment and social protection for its 2022 Yearbook and received responses from 21 member organisations which allowed the organisation to develop and publish a comparative report with the key findings, identify good practices from nine European countries, include 11 experiences of people with dementia and carers and develop recommendations aimed at national and European policy makers
- Continued its interaction with the European Medicines Agency as an accredited patient organisation and an active member of the agency's Patients and Consumers Working Party
- Had its right renewed to lodge complaints under the collective complaints procedure of the European Social Charter as an NGO with participatory status with the Council of Europe



The EWGPWD celebrated ten years in 2022, with a special publication about the group



European Group of Governmental Experts on Dementia meets online, 13 December 2022



Alzheimer's Association Academy, Brussels, 27 September 2022

- Collaborated closely with the WHO and WHO Europe, contributing to its dementia research blueprint, the position paper on brain health and joining the European Mental Health Coalition

Changed perceptions and combatted stigma

- Developed a set of guidelines for the ethical and inclusive communication about and portrayal of dementia and people with dementia together with the EWGPWD
- Published a guide for health and social care workers on “Sex, Gender and Sexuality in the Context of Dementia”
- Collaborated with the Alzheimer Europe Foundation, Biogen, Lilly and Roche to launch the 2022 Anti-Stigma Award, reviewed 52 applications and presented awards to the three best initiatives during the closing ceremony of the Alzheimer Europe Conference in Bucharest

- Collaborated with Roche on the “What Makes You, You?” initiative and involved three EWGPWD members in short videos about their life after a diagnosis of dementia, which were launched on the occasion of World Alzheimer's Day

Raised awareness of brain health and prevention

- Expanded its Clinical Trial Watch to include five Phase II and two Phase III trials investigating medicines for the prevention of Alzheimer's dementia
- Collaborated on a range of EU projects investigating ways of better identifying people at risk of developing dementia and developing prevention or brain health strategies
- Contributed to scientific publications on global estimates of people across the Alzheimer's disease continuum and on communication and risk disclosure

Strengthened the European dementia movement

- Developed a web resource with information and support for people with dementia and carers/supporters affected by the war in Ukraine and collaborated with Nezaubutni, the Ukrainian Alzheimer's association, to network with Alzheimer's associations and policy makers from neighbouring countries
- Organised two in-person and six online Alzheimer's Association Academy meetings which were attended by representatives of Alzheimer's associations from 31 European countries
- Involved the Alzheimer Europe Board in the monitoring of the association's activities and finances and organised four online meetings and one in-person meeting of the Board
- Organised the first in-person Annual General Meeting since the start of the COVID-19 pandemic, at which 33 out of 34 full member organisations were in attendance or represented
- Welcomed new full member organisations from Austria, Estonia and Poland, as well as new provisional members from Armenia, Lithuania, North Macedonia, Serbia and Ukraine



Speakers at the opening ceremony of the 32nd Alzheimer Europe Conference, Bucharest, 17 October 2022

- Elected a new Alzheimer Europe Board with Maria do Rosário Zincke dos Reis (Portugal) taking over as Chairperson of the association from Iva Holmerová (Czech Republic)
- Continued its close collaboration with INTERDEM and hosted the network's Annual General Meeting on the first day of its Annual Conference in Bucharest
- Collaborated with the European Academy of Neurology and strengthened ties with the European Association of Service Providers for Persons with Disabilities
- Coorganised a webinar on patient involvement in brain health with the European Federation of Neurological Associations (EFNA) and the Global Alliance of Mental Illness Advocacy Networks – Europe (GAMIAN-Europe)
- Partnered on the Older Adults Mental Health Week of the International Psychogeriatric Association (IPA)
- Continued as a full and active member of both the European Patients' Forum and European Disability Forum

Supported dementia research

- Actively contributed to a range of EU-funded projects by representing the views of people with dementia and their carers in the research consortia, by contributing to the ethical discussions and by supporting the communication and dissemination activities towards a non-scientific audience
- Authored and contributed to scientific publications on the value of public involvement in dementia research
- Published its monthly e-mail newsletters which were delivered to over 7,300 subscribers and covered 524 news stories of which 116 were on scientific developments
- Reached an average of 4,175 monthly visitors via its website, as well as 9,783 followers on Facebook and 13,600 followers on Twitter
- Organised its Annual Conference “Building bridges” in Bucharest, Romania which was attended by 543 participants and which included 187 oral presentations, 38 quick oral presentations and 63 poster presentations

Carried out the following project-related activities

- Continued its involvement in the following EU-funded projects:
 - AI-MIND (Artificial Intelligence for Dementia Prevention)
 - AMYPAD (Amyloid imaging to prevent Alzheimer's disease)
 - EPAD (European Prevention of Alzheimer's Dementia)
 - EPND (European Platform for Neurodegenerative Diseases)
 - EU-FINGERS (Multi-modal precision prevention toolbox for dementia in Alzheimer's disease)
 - LETHE (A personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning)
 - Neuronet (Efficiently networking European neurodegeneration research)
 - PRODEMOS (Prevention of Dementia using Mobile phone Applications)
 - RADAR-AD (Remote assessment of disease and relapse – Alzheimer's disease)

- RECOGNISED (Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and identification of patients at risk of dementia)
- VirtualBrainCloud (Personalised Recommendations for Neurodegenerative Disease)
- Started its collaboration with
 - ADIS (Early diagnosis of Alzheimer's disease by immune profiling of cytotoxic lymphocytes and recording of sleep disturbances), a three-year project funded by the Luxembourg National Research Fund in the framework of the Joint Programme for Neurodegenerative Disease Research (JPND)
 - eBRAIN-Health, a four-year project funded by Horizon Europe
 - PatternCog (Personalised ageing pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals), a three-year project funded by the Luxembourg National Research Fund in the framework of the ERA PerMed programme
- Supported the following EU projects
 - ABOARD (A personalised medicine approach for Alzheimer's disease)
 - ADAIR (From air pollution to brain pollution – novel biomarkers to unravel the link of air pollution and Alzheimer's disease)
 - DISTINCT (Dementia: Intersectoral strategy for training and innovation network for current technology)
 - MIRIAD (Multi-omics interdisciplinary research integration to address dementia diagnosis)
 - PRIME (Prevention and Remediation of Insulin Multimorbidity in Europe)
 - SPAN+ (Empowering people with dementia)
- Carried out a number of activities and projects thanks to the support of its corporate sponsors and other partners
 - Organised three European Parliament lunch debates and workshops, on “Prioritising dementia in European policies on care, disabilities and equalities” (online), “Neurological conditions and mental health in EU and World Health Organization programmes” and “The role of artificial intelligence and big data in dementia research”
 - Convened four company round table meetings bringing together representatives of industry and national Alzheimer's associations
 - Published three editions of the Dementia in Europe magazine
 - Expanded its Clinical Trials Watch and included on its website dementia-friendly information on 19 Phase II and 11 Phase III clinical trials conducted in Europe
 - Actively contributed to the FAST (Finding Alzheimer's Solutions Together) Council set up by Roche, the patient think tank of the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the GSK Health Advisory Board.

Introduction

The Strategic Plan of Alzheimer Europe sets out the six main objectives of the organisation and highlights key aims and actions to be undertaken under each objective for the period covered by the plan (2021-2025).

This year's Annual Report breaks down the organisation's core activities into these six key strategic objectives. In addition, the report highlights the activities undertaken by Alzheimer Europe in support of EU projects it partnered with and presents those activities it carried out thanks to the support of its corporate sponsors and other partners.

In 2022, Alzheimer Europe received an operating grant in the framework of the European Union's Citizens, Equality, Rights and Values programme which provided the funding for a number of the organisation's following core activities.



The Alzheimer Europe team at the Annual Conference, Bucharest, 17 October 2022

Alzheimer Europe Core Activities

Objective 1: Providing a voice to people with dementia and their carers

Thanks to its European Working Group of People with Dementia (EWGPWD), Alzheimer Europe was able to ensure that the views of people with dementia were included in all of the organisation's projects, meetings and activities, as well as in European research projects and initiatives Alzheimer Europe contributed to.

In 2022, Alzheimer Europe also finalised the setting up of a European Dementia Carers Working Group.

European Working Group of People with Dementia

From January to October 2022, the EWGPWD had 14 members from 10 European countries.

- Chair: Chris Roberts (United Kingdom)
- Vice-Chairs: Bernd Heise (Germany) and Kevin Quaid (Ireland)
- Members: Idalina Aguiar (Portugal), Stefan Eriksson (Sweden), Tomaž Grižinič (Slovenia), Nigel Hullah (United Kingdom), Erla Jónsdóttir (Iceland), Petri Lampinen (Finland), Margaret McCallion (Scotland, United Kingdom), Danny McDonald (Scotland, United Kingdom), Angela Pototschnigg (Austria), Helen Rochford-Brennan (Ireland), Geert Van Laer (Belgium).

There were nominations for the new term (October 2022-October 2024) over the summer in 2022. For the nominations of the group, Alzheimer Europe introduced a requirement for a gender balance within the group,

with both genders represented by at least 40% of the membership. Since October the group had 15 members from 10 European countries, of which 8 are women and 7 are men:

- Chair: Chris Roberts (United Kingdom)
- Vice-Chairs: Margaret McCallion (Scotland, United Kingdom) and 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), Angela Pototschnigg (Austria), Real Larnou (Belgium), Stephen John McCleery (Italy), Shelagh Robinson (United Kingdom), Věra Ryšavá (Czech Republic).



European Working Group of People with Dementia meets in Luxembourg, 13 May 2022

The Chair of the EWGPWD, Chris Roberts, actively participated in the online and in-person meetings of the Board of Alzheimer Europe in 2022.

2022 marked the 10th anniversary of the creation of the group. Members of the EWGPWD therefore contributed towards the development of a special publication to celebrate 10 years of the EWGPWD. The publication was made possible thanks to a grant by the Alzheimer Europe Foundation. The publication was launched by MEP Deirdre Clune (Ireland) at a European Parliament lunch debate in Brussels on 14 June 2022. An online meeting to mark the Anniversary took place on 10 November 2022 involving members of the EWGPWD from 2012 until 2022.

In 2022, Alzheimer Europe organised three in-person meetings and four online meetings of the EWGPWD which were attended as follows:

Date	Number of participants	Countries represented
25 January	13	10
25 February	12	9
6 April	12	9
13-14 May	10	8
14-15 June	13	11
27-28 September	10	9
16 December	10	7

The topic of ethical and inclusive communication of dementia was addressed in several of the meetings of the EWGPWD throughout 2022. Based on this work, the group developed guidelines for the media, researchers, journalists, policy makers, or anyone who communicates about or portrays dementia and people with dementia in the public domain. The guidelines are aimed at provoking greater reflection and increasing awareness about these issues. In total, 20 people with dementia were involved in this work. The report containing the guidelines was published at the end of 2022 and launched in early 2023.

During the Alzheimer Europe Conference in Bucharest, the group played an active role by organising a special symposium entitled "Building bridges, our voices, our lives" which was identified as one of the conference highlights by the conference attendees. The EWGPWD chair also welcomed delegates at the opening ceremony and group member Bernd Heise provided a plenary presentation on "Adapting to the COVID-19 pandemic as a person with dementia". Other group members provided talks in parallel sessions and provided information about the EWGPWD and its activities at the group's booth in the exhibition area.

In addition, members of the group:

- played an active role during the Conference on the European Day of Persons with Disabilities (24-25 November 2022), co-organised by the European Commission and European Disability Forum,
- contributed to the guide on sex, gender and sexuality in dementia and helped identify and interview LGBTQ+ people with dementia,



European Working Group of People with Dementia meets in Brussels, 14 June 2022

- provided personal testimonials on their employment and welfare experiences for the 2022 Yearbook on employment and social protection,
- contributed personal blogs and articles for the Alzheimer Europe website, newsletter and the Dementia in Europe magazine,
- raised awareness on the importance of dementia and of public involvement in research at events organised by Dementia Jersey (21 April), the World Health Organization (18-19 May), University College Cork (2 December) and the European Federation of Pharmaceutical Industries and Associations (EFPIA) (12 December),
- contributed to the development of a training course on dementia in the framework of the STUDICODE project.

European Dementia Carers Working Group

In 2022, Alzheimer Europe modified its statutes to allow for the creation of a European Dementia Carers Working Group. The aims and nominations for the group are based on the successful model of the European Working Group of People with Dementia with candidates nominated by the national member organisations and the chair of the group joining the Alzheimer Europe Board as a full member. These statutory changes were adopted unanimously at the Annual General Meeting in Bucharest.

The nominations by national member organisations resulted in a group of 14 members from 13 European countries with 5 men and 9 women:

- Peter Banda (Slovakia), Paola Borghesi (Italy), Patrick Crosbie (Ireland), Sylva Dneboská (Czech Republic), Chris Ellermaa (Estonia), Zornitsa Karagyozyova (Bulgaria), Sonata Mačiulskytė (Lithuania), Magnús Karl Magnússon (Iceland), Maria Filomena Mira Martins Cunha (Portugal), Katarzyna Mazuruk-Russ (Poland), Barry Northedge (Scotland, United Kingdom), Trevor Salomon (United Kingdom), Liv Thorsen (Norway) and Roslynn Vella (Malta)

The group had an informal online meeting in 2022 to get to know each other and will have its first official meeting in 2023 where the group will elect its chairperson and vice-chairperson.

Objective 2: Making dementia a European priority

As in previous years, Alzheimer Europe continued to monitor and contribute to EU policy developments to ensure dementia was prioritised and included in relevant policy discussions, coordinated the European Group of Governmental Experts on Dementia and the European Alzheimer's Alliance and dedicated its 2022 Yearbook to an overview and comparison of national policies on employment and social protection.

Contributing to EU policies

Alzheimer Europe monitored policy developments at EU and national level and included 68 news stories on EU developments and 29 on national policy developments in its monthly e-mail newsletters. Alzheimer Europe also contributed to Commission consultations on the European care strategy and EU disability card and developed a guide to raise awareness amongst health and social care workers on sex, gender and sexuality in the context of dementia.



EU disability card

In addition, Alzheimer Europe collaborated with other European disability and health NGOs to develop joint policy statements and contributions to EU policy discussions.

- On 29 March, Alzheimer Europe issued a response to the call for evidence on a European Care Strategy.
- On 22 April, Alzheimer Europe contributed to a joint letter to Sandra Gallina, Director General of the Directorate-General for Health and Food Safety (SANTE) to highlight issues with the operating grant system of the EU health programme. This letter was co-signed by seven associations.
- On 12 May, Alzheimer Europe, the European Federation of Neurological Societies (EFNA) and GAMIAN Europe held an online summit to launch a joint Call for Action, highlighting the need for patient involvement to be at the heart of EU policies relating to brain health.
- On 2 September, Alzheimer Europe signed the Oslo Declaration, which called for the implementation of a range of measures intended to reduce alcohol harms. The declaration was made during the 9th European Alcohol Policy Conference Statement.
- On 8 September, Alzheimer Europe collaborated with Mental Health

Europe (MHE), the World Federation of Occupational Therapists (WFOT) and EuroHealthNet on a Joint Statement on Mental Health delivered at the 72nd session of the World Health Organization (WHO) Regional Committee for Europe.

- On 12 September, Alzheimer Europe joined 26 other organisations to support a Joint Statement on the “Regional digital health action plan for the WHO European Region (EPW flagship)” delivered at the 72nd session of the World Health Organization (WHO) Regional Committee for Europe.
- On 15 September, Alzheimer Europe was one of the organisations of the EU4Health Civil Society Alliance calling for the reintroduction of operating grants under the EU health programme.
- On 15 December, Alzheimer Europe joined with other EU NGOs within the EU4Health Civil Society Alliance to develop a Joint Position Paper “Towards meaningful engagement of health civil society organisations in EU public health policymaking”.
- On 16 December, Alzheimer Europe contributed to the consultation on the introduction of the EU Disability Card.
- As part of the 2022 operating grant activities, Alzheimer Europe also developed a guide to raise awareness amongst health and social care workers on “Sex, Gender and Sexuality in the Context of Dementia”.

European Group of Governmental Experts on Dementia

As in previous years, Alzheimer Europe provided the secretariat to the European Group of Governmental Experts on Dementia and organised two online meetings (17 June and 13 December) where national health ministry representatives updated each other on their respective strategies and initiatives to protect and support people with dementia and their caregivers during the pandemic.

The group also:

- discussed the situation in Ukraine and shared experiences on how people with dementia and carers can be supported in Ukraine, as well as amongst the refugee populations in neighbouring countries,
- received updates on important new developments at the level of the World Health Organization with regard to the Global Dementia Observatory, the new WHO dementia research blueprint and the Intersectoral Global Action Plan (IGAP) on epilepsy and other neurological conditions 2022-2030,
- discussed the European Commission's “Healthier Together” non-communicable diseases (NCD) initiative and the OECD report on long term care and end of life care,
- were informed about new national initiatives such as the three-year pilot programme in Poland aimed at improving early detection of dementia patients over 60+, a report by the German National Plan on Dementia exploring the link between COVID-19 and neurological conditions, a dementia prevention campaign in Flanders and a new concept for dementia-friendly initiatives in the Czech Republic.

In total, ministry officials from 19 countries were represented across the two meetings: Austria, Belgium (Flanders), Bulgaria, Cyprus, Czech Republic, France, Finland, Germany, Iceland, Israel, Italy, Latvia,

Luxembourg, Netherlands, Norway, Poland, Slovenia, Sweden and United Kingdom (Scotland).

In addition, representatives from Alzheimer Europe, the European Commission (DG SANTE), OECD, WHO and WHO Europe attended the meetings in an observer capacity.

European Alzheimer's Alliance

The European Alzheimer's Alliance (EAA) ended the year with 89 members, representing 26 out of 27 Member States of the European Union and all political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

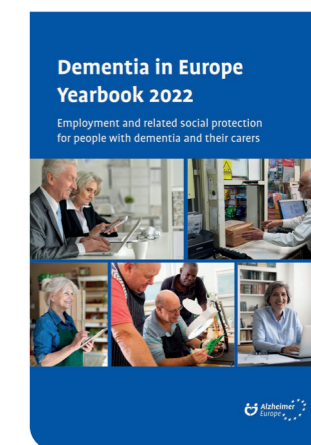


Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D).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

Members of the European Alzheimer's Alliance played an active role in Alzheimer Europe's activities by hosting three European Parliament workshops and lunch debates and by contributing to the Dementia in Europe magazine and informing Alzheimer Europe about relevant EU policy developments.

Yearbook on employment and social protection

In 2022, Alzheimer Europe focused on employment and social protection for its Yearbook. The organisation developed a survey on national employment and social protection policies, which was discussed and co-designed with national member organisations. It was trialled with a limited number of associations from Ireland, France and Scotland, UK, before being rolled out to all members. 21 organisations responded to the survey.



Thanks to the responses of national associations, Alzheimer Europe was able to identify good practices from 9 European countries in the field of employment and social protection for people with dementia and their family carers. In addition, 11 experiences of people with dementia and carers were collected, including from the members of the European Working Group of People with Dementia during 2022 (both before and after the new mandate of the group in October 2022).

On the basis of the national survey responses, Alzheimer Europe was able to develop a comparative report which included an overview of the current international and European policy context, a comparison of national dementia strategies and policies in relation to employment and social protection, an overview of legal employment protection measures and welfare benefits for people with dementia and carers. These results were published in the 2022 Yearbook which also included good practice examples, experiences of people with dementia and carers, as well as conclusions and recommendations.

The conclusion of the report contains a number of recommendations aimed at both national and European decision-makers, encouraging them to take actions to improve legislation and policies around employment and social protection, including:

- the need for greater flexibility in social support systems to allow carers to continue to work (if they wish to do so),
- the development of a social scoreboard to monitor Member States compliance with the UN Convention on the Rights of People with Disabilities,
- ensuring that information, advice and support to access benefits is available in accessible formats.

The Yearbook was published at the end of 2022 and formally launched at the beginning of 2023.

Other policy developments and issues

Alzheimer Europe continued its collaboration with the European Medicines Agency (EMA) in 2022 as an accredited patient organisation and as a full member of EMA's Patients' and Consumers' Working Party (PCWP). Alzheimer Europe participated in the online meetings of the PCWP.

At these meetings, EMA staff provided updates on:

- antimicrobial resistance (AMR) and other emerging health threats,
- availability and accessibility of medicines,
- COVID-19 vaccines, therapeutics and their safety surveillance,
- patient involvement in medicines development and regulation,
- different EMA initiatives and projects, including the ACT-EU (Accelerating Clinical Trials in the EU), DARWIN (Data Analysis and Real-World Interrogation Network) and BDSG (Big Data Steering Group)

In September 2022, the EMA also organised 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. In December 2022, the EMA together with the Heads of Medicines Agencies (HMA) convened the Big Data Stakeholder Forum, to foster collaboration and stakeholder engagement on the topic of real-world and big data for medicines regulation. Alzheimer Europe contributed to both of these events, and also participated in meetings of the Raw Data Advisory Group, providing feedback on an ongoing EMA pilot project that is assessing the value of analysing individual patient data during the evaluation of marketing authorisation applications.

A member of the European Working Group of People with Dementia also contributed to an EMA scientific advice procedure.

As an international non-governmental organisation with participatory status with the Council of Europe, Alzheimer Europe is entitled to lodge complaints under the collective complaints procedure of the European Social Charter (ESC) and had this right renewed by the Governmental Committee at its 144th meeting on 31 May 2022. This new accreditation is valid for the period from 1 July 2022 to 30 June 2026.

Finally, Alzheimer Europe also continued to engage with the World Health Organization (WHO) at both the global and European level. On 27 May, delegates at the 75th World Health Assembly approved a new intersectoral global action plan on epilepsy and other neurological disorders (including stroke, migraine, dementia and meningitis) that aims to improve access to care and treatment for people living with these conditions, while preventing new cases and promoting brain health across the life course.

The WHO also launched a position paper on brain health, setting out the importance of brain health optimisation throughout the life course. The paper highlights that 1 in 3 people will develop a neurological disorder at some point in their life, making neurological disorders the leading cause of disability and the second leading cause of death.

In October, the WHO published a dementia research blueprint, designed to provide guidance to policy-makers, funders and the research community, in an effort to make dementia research more efficient, equitable and impactful. This blueprint for dementia research summarises the current state of dementia research across six broad themes, identifying existing knowledge gaps, as well as outlining 15 strategic goals with actions and timebound milestones to address these gaps.

Alzheimer Europe also joined the pan-European Mental Health Coalition of WHO Europe and actively contributed to the work package dedicated to the mental health of older adults.

Objective 3: Changing perceptions and combating stigma

In 2022, Alzheimer Europe developed guidelines to promote inclusive language in the portrayal of dementia and people with dementia, developed a guide on sex, gender and sexuality for health and social care workers, launched the first Alzheimer Europe anti-stigma award and collaborated with Roche on the "What makes You You" campaign during World Alzheimer's Day.

Inclusive communication and portrayal of dementia

In 2022, Alzheimer Europe in tandem with the European Working Group of People with Dementia (EWGPWD) developed a new set of guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia. The guidelines, which are structured around 14 statements are targeted at the media, researchers, journalists, policy makers and anyone responsible for the portrayal of or communication about dementia in the public domain.

The guidelines are aimed at provoking greater reflection and increasing awareness about this issue. The members of the EWGPWD were keen to emphasise that they did not want to act as the "word police" and that their guidance goes beyond the choice of individual words. This is important because preferences and objections to certain words, whilst important, vary greatly, not only between different countries but also within different communities and social groups.

Rather, their goal was to offer constructive and friendly guidance to help raise awareness of the need to communicate in an ethical and inclusive manner. This means paying attention to messages and images that are communicated and used, and trying to ensure that they convey respect for people with dementia, that they are not harmful (e.g. stigmatising, insulting or degrading) and that they both reflect and promote the inclusion of people with dementia from all walks of life, including those from marginalised groups, in society.

People with dementia use language, sometimes including metaphors, to convey their personal experience of dementia at a particular moment

in time and it is important that they have the freedom to express their experience and feelings in whatever way they see fit. Words and images communicated by others, however, tend to be understood as representing or summing up the experience of all people with dementia, reducing people with dementia as a group to "sufferers" or "patients", or portraying every aspect of dementia as a devastating natural catastrophe. This is why it is important for people who do not have dementia to pay particular attention to the words and images that they use and the underlying messages that they may be conveying.

Sex, gender and sexuality in dementia

In 2022, Alzheimer Europe also developed a guide called "Sex, Gender and Sexuality in the Context of Dementia: A guide to raise awareness amongst health and social care workers".

Based on a more detailed report from 2021 on sex, gender and sexuality, a short guide was developed in 2022 to raise awareness and provide health and social care workers with recommendations on how to provide sensitive, appropriate and good quality care and support to people with dementia and their carers or supporters of different sexes, gender identities and sexual orientations.

The new guide is about the experience and wellbeing of men, women and non-binary people with dementia who are living alone or with a partner and who may or may not be sexually active. The guide draws attention to inequality, discrimination and lack of sensitivity towards their needs and wishes, both from other people and through structures and procedures within society, also towards their families, carers and in some cases health and social care workers. The guide is not limited to the experience of LGBTQ+ people but their experience is often qualitatively different to that of non-LGBTQ+ people and they encounter several issues that others do not, hence the frequent reference to this group in the guide.

Alzheimer Europe hopes that this guide will provoke reflection, contribute towards challenging assumptions and inequalities and help ensure that everyone is free from violence, discrimination and harassment irrespective of their sex, gender identity or sexual orientation.

Alzheimer Europe anti-stigma award

Alzheimer Europe, in collaboration with the Alzheimer Europe Foundation, Biogen, Lilly and Roche launched a call for applications for its anti-stigma award in June 2022, with the aim of recognising an outstanding initiative combating stigma and promoting a positive image of dementia and people living with dementia. Applications were open

to individuals and organisations established in a member country of Alzheimer Europe, for projects, campaigns, films, videos, publications or books developed and/or implemented in the past three years (2019-2022).

52 applications were received and reviewed by the Jury which was comprised of:

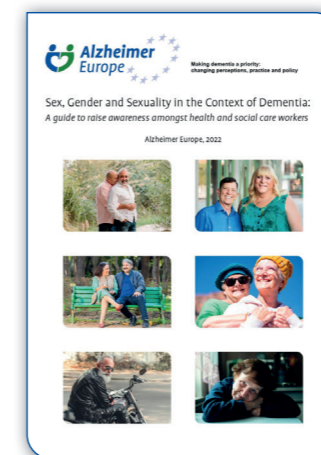
- Alzheimer Europe: Iva Holmerová and Marco Blom
- European Working Group of People with Dementia: Chris Roberts and Bernd Heise
- Alzheimer Europe Foundation: Heike von Lützu-Hohlbein (Chairperson) and Maria do Rosário Zincke dos Reis
- Biogen: Katja Buller
- Lilly: Laura Campo
- Roche: Jannice Roeser.

The three finalists were invited to present their initiatives during the Alzheimer Europe Conference in Bucharest with the winner and runners-up announced during the closing ceremony on 19 October 2022.

The "Adoptieproject: Jong adopteert Oud" (Adoption project, young adopts old) of the Alzheimer Centrum Limburg (Maastricht, Netherlands) was announced as the winner of Alzheimer Europe's new anti-stigma award. The award, together with a cash prize of EUR 5,000 was presented by Iva Holmerová, the Treasurer of the Alzheimer Europe Foundation.

The second place award, with a cash prize of EUR 3,000, was presented to the campaign "Non ti scordare di volermi bene" (Don't forget to love me), by Federazione Alzheimer Italia, while the third place, with a cash prize of EUR 1,500, went to "Changing perceptions of dementia in the Punjabi community", by Alzheimer's Society, UK.

Other promising and innovative campaigns were included on a special page on the Alzheimer Europe website: <https://www.alzheimer-europe.org/our-work/anti-stigma-award/Anti-Stigma-initiatives-2022>



Dutch "Adoptieproject" wins Alzheimer Europe's Anti-Stigma Award at Annual Conference in Bucharest, 19 October 2022

What makes You, You?

In 2022, to mark World Alzheimer's Day, Alzheimer Europe collaborated 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 aimed to help create a world where people living with diseases that affect the brain, like Alzheimer's, can live life to the fullest and stressed the importance of looking beyond a person's diagnosis and of valuing them for who they are.

Short videos (approximately three minutes each) were created, featuring three members of the EWGPWD who are living with Alzheimer's disease, together with some of their family members:

- Bernd Heise with his wife Hilde
- Helen Rochford-Brennan
- Stefan Eriksson and his daughter Janni Ahlgren



What Makes You, You campaign with Roche, launched on World Alzheimer's Day, 21 September 2022

Alzheimer Europe was delighted to have worked on this initiative in collaboration with Roche and about the impact of the videos which were seen and shared by thousands of people. The association would also like to express its gratitude to Bernd, Helen, Hilde, 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.

Objective 4: Raising awareness of brain health and prevention

In 2022, Alzheimer Europe updated its Clinical Trial Watch to include trials on dementia prevention, collaborated in a number of EU projects on brain health and prevention and supported research communication activities on these topics.

Prevention trials

In 2022, Alzheimer Europe paid particular attention to monitor databases on clinical trials to identify trials investigating drugs or other interventions for the prevention of Alzheimer's dementia or other forms of dementia. The organisation was able to identify five phase II and two phase III trials which were included on the Clinical Trial Watch section of the organisation's website.

Phase II trials				
Company	Study	Drug candidate	Population	Target
AC Immune	ABATE	ACI-24.060	Prodromal Alzheimer's disease	Amyloid-related (Immunotherapy)
Roche	Brainshuttle AD	RO7126209	Prodromal or Mild to Moderate Alzheimer's disease	Amyloid-related (Immunotherapy)
Università degli studi di Genova	FMD AD	ProlonADTM	Mild Cognitive Impairment or mild Alzheimer's disease	Low-calorie and low-protein diet
Maastricht UMC	ROMEMA	Roflumilast	MCI / Mild dementia	Anti-inflammatory
Vivoryon	VIVIAD	PQ912	Mild cognitive impairment and mild Alzheimer's disease	Amyloid-related & Inflammation (small molecule)
Phase III trials				
Company	Study	Drug candidate	Population	Target
Eisai	AHEAD 3-45	Lecanemab	At risk of developing Alzheimer's disease & Early Alzheimer's disease	Immunotherapy (passive)- amyloid-related
Hôpitaux de Toulouse	LO-MAPT	Dietary Supplement: Omega-3	Subjective memory complaints or family history of Alzheimer's disease	Neuroprotective (dietary supplement)

EU research projects on brain health

The portfolio of EU projects, which Alzheimer Europe is involved in, continues to grow and a significant number of projects are dealing with better identification of people at risk of developing dementia and development of prevention or brain health strategies:

- ABOARD
- ADIS
- AI-MIND
- eBRAIN-Health
- EU-FINGERS
- LETHE
- MIRIAD
- Pattern-Cog
- VirtualBrainCloud

More detailed information on these projects can be found in the project section below, including how Alzheimer Europe is including people at risk of developing dementia in its public involvement and communication activities on these projects.

In 2022, Alzheimer Europe also started its collaboration with the European Union Geriatric Medicine Society for the development of guidelines on physical activity and exercise in MCI and dementia.

Contributing to scientific publications on brain health

Alzheimer Europe also participated in research activities which looked at estimating the numbers of people in the at-risk stages for Alzheimer's dementia (also sometimes referred to as preclinical Alzheimer's disease) and the prodromal stages of the disease (also referred to as mild cognitive impairment). This resulted in a scientific publication "Global estimates on the number of persons across the Alzheimer's disease continuum" which was published in the journal Alzheimer's & Dementia.

The communication about risk about developing Alzheimer's dementia and of progressing from the mild cognitive impairment stage to the dementia stage and the ethical issues raised by such communication were also discussed in 2022 and the Executive Director contributed to two scientific publications on "Development and design of a diagnostic report to support communication in dementia: Co-creation with patients and care partners" and on "Ethical Frameworks for Disclosure of Alzheimer Disease Biomarkers to Research Participants: Conflicting Norms and a Nuanced Policy" which were published in the journals Alzheimer's & Dementia: Diagnosis Assessment & Disease Monitoring and Ethics & Human Research respectively.

Objective 5: Strengthening the European dementia movement

In 2022, Alzheimer Europe developed a resource hub to support people with dementia and carers from Ukraine, continued to organise its Alzheimer's Association Academy, the capacity building workshops for representatives of national Alzheimer's associations, involved its Board in the monitoring of its activities and finances, organised a successful Annual General Meeting in Bucharest and continued its collaboration with other European and international organisations.

Support of people with dementia in Ukraine

In order to support people with dementia and carers, during the ongoing war in Ukraine, Alzheimer Europe has put together a range of online resources with information and guidance. These cover national support and information in Ukraine, international support and information, as well as support in Ukraine's neighbouring countries.

Alzheimer Europe also developed closer ties with Neza-butni, the Ukrainian Alzheimer's association and organised an information exchange between the association and the national health ministry officials of the European Group of Governmental Experts, as well as with national member organisations of Alzheimer Europe to discuss support opportunities for people with dementia and carers in the Ukraine, as well as for Ukrainian refugees with dementia in other European countries.

At the Alzheimer Europe conference in Bucharest, Irina Shevchenko updated conference delegates about the work and activities of Neza-butni and the Annual General Meeting unanimously decided to welcome the association as a new provisional member of Alzheimer Europe to further strengthen the collaboration.

Alzheimer's Association Academy

In 2022, Alzheimer Europe organised two in-person and 6 online Alzheimer's Association Academy meetings on the following topics:

Date	Topics	Number of participants	Countries represented
23 March	Clinical Trials Regulation and Innovative Health Initiative	27	9
26 April	Giving a voice to people with dementia	59	20
17 May	Dementia as a disability	38	17

Date	Topics	Number of participants	Countries represented
14 June	EU and WHO developments	43	19
13 September	Intellectual disability, Down syndrome and dementia	38	15
27 September	Dementia and employment	38	17
15 November	The European Care Strategy	54	19
12 December	Public involvement in dementia research	43	20

A total of 31 European countries were represented at these capacity building workshops. Recordings of the meetings are made available to all representatives of national member organisations.

Alzheimer Europe Board and Annual General Meeting

The Alzheimer Europe Board had four online meetings (22 February, 4 April, 13 June and 5 December) as well as one in-person meeting in Brussels on 26 September. As in previous years, the Board closely monitored the activities and finances of the organisation in relation to the agreed upon Work Plan and Budget and prepared the organisation of the Annual Meeting.

For the first time since the start of the COVID-19 pandemic, the Annual General Meeting of Alzheimer Europe was an in-person meeting which took place in Bucharest on 17 October.



Annual General Meeting of Alzheimer Europe, Bucharest, 17 October 2022

33 out of 34 full members were in attendance or were represented. Alzheimer Europe celebrated its achievements in 2021 and 2022, updated members on its 2021-2022 finances and shared its plans for 2023.

The AGM also voted on new membership applications. Existing provisional member MTÜ Elu Dementsusega (Estonia) was welcomed as a full member of Alzheimer Europe, while Alzheimer Polska (Poland) and Demenz Selbsthilfe Austria (Austria) were welcomed as new full members.

Alzheimer's Care Armenia (Armenia), Demencija Lietuvoje (Lithuania), Institute for Alzheimer's disease and neuroscience (North Macedonia), O Srpskom udruženju za Alchajmerovu bolest (Serbia) and Nezabutni (Ukraine) were voted in as provisional members of Alzheimer Europe. Going forward, Alzheimer Europe will represent 41 members from 37 European countries.

The Annual General Meeting reviewed the organisation's Statutes and Rules and Regulations and approved the setting up of a European Dementia Carers Working Group which will become fully operational in 2023 and contribute to the activities of the 2023 operating grant.

All decisions at the AGM were taken unanimously.

The AGM also elected a new Board of the organisation for a new two-year mandate. The newly elected Board consists of Chairperson Maria do Rosário Zincke dos Reis (Portugal), Vice-Chair Charles Scerri (Malta), Honorary Treasurer Marco Blom (Honorary Treasurer), Honorary Secretary Mario Possenti (Italy) and members Stefanie Becker (Switzerland), René Friederici (Luxembourg), Lorène Gilly (France), Martina Mátlová (Czechia), Andy Heffernan (Ireland), Mary-Frances Morris (United Kingdom), Chris Roberts (Chair of the European Working Group of People with Dementia, United Kingdom), Katariina Suomu (Finland) and René Thyrian (Germany).

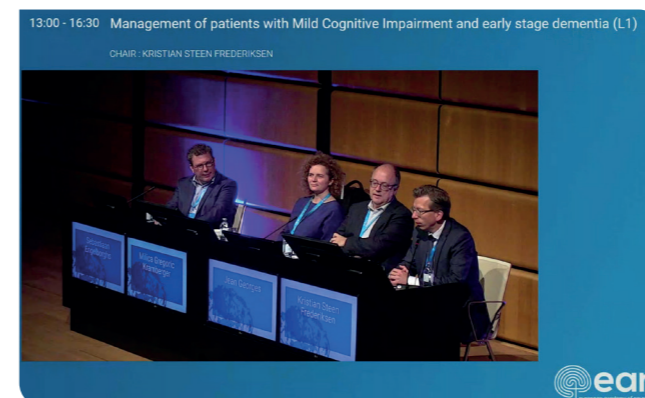
Collaboration with other organisations

Alzheimer Europe continued its close collaboration with the INTERDEM network of European researchers involved in psychosocial research in dementia. In 2022, Alzheimer Europe:

- hosted the Annual General Meeting of INTERDEM on the first day of the Annual Conference in Bucharest attended by 99 researchers, involved the INTERDEM chair Marjolein de Vugt in the opening ceremony and dedicated four parallel sessions to activities and research carried out by the group,
- supported the INTERDEM interest group on assistive technology to explore the uptake of technology among people with dementia during the COVID-19 pandemic.

Alzheimer Europe was represented at the INTERDEM Annual Meeting by Director for Projects Dianne Gove and Project Officer Ana Diaz.

In 2022, Alzheimer Europe started its contribution to a project of the European Academy of Neurology (EAN) on the burden of sleep-wake



Executive Director Jean Georges (second from right) played an active role at the European Academy of Neurology conference in Vienna, 26-28 July 2022

disorders and signed a memorandum of understanding on this collaboration. This continues the already existing collaboration between EAN and Alzheimer Europe. The Executive Director of Alzheimer Europe represented the organisation at the meetings of the Management Board of the EAN Panel for Dementia and Cognitive Disorders and played an active role at the EAN Conference in Vienna from 26 to 28 July 2022 where he presented at the in-person meeting of the Dementia Panel, co-chaired the Alzheimer Europe/EAN symposium on "Cognitive deficit and dementia: beyond neurodegenerative diseases" and provided a lecture on "Timely diagnosis in MCI and dementia: a patients' and carers' perspective" at teaching course for young neurologists on "Management of patients with mild cognitive impairment and early stage dementia".

Alzheimer Europe also strengthened its relationship with the European Association of Service providers for Persons with Disabilities (EASPD). Alzheimer Europe contributed to an EASPD knowledge café on the social impact of dementia on 27 January and signed a memorandum of understanding outlining the collaboration between the two associations in April.

On 12 May 2022, Alzheimer Europe, together with the European Federation of Neurological Alliances (EFNA) and the Global Alliance of Mental Illness Advocacy Networks - Europe (GAMIAN-Europe), organised a webinar on Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients. The three host organisations issued a call to action, highlighting the need for improved patient involvement in brain health in Europe and called on all stakeholders to develop and implement policies to ensure early and meaningful engagement and involvement of patients.

In October, Alzheimer Europe 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 was the 2nd 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.

As a full member of the European Disability Forum and European Patients' Forum, Alzheimer Europe also continued its close collaboration with both organisations.

Objective 6: Supporting dementia research

In 2022, Alzheimer Europe continued its collaboration with a growing number of EU projects (see chapter 1.5.1. below), contributed to public involvement activities of these projects, communicated about research findings via its newsletter, website and social media and organised its 32nd Annual Conference in Bucharest from 17 to 19 October 2022.

To strengthen its project team, Alzheimer Europe welcomed Daphné Lamirel and Soraya Moradi Bachiller as new project officers and Cristina Pencea as new administrative assistant. All three new staff members joined the Alzheimer Europe team on 1 June 2022.

Public involvement in dementia research

Alzheimer Europe is actively involved in a range of EU projects. In these projects, Alzheimer Europe ensures that the views of people with dementia and their carers are included through the organisation's public involvement activities and the organisation also contributes to the ethical issues raised by research projects and supports the communication activities of these projects.

The European Working Group of People with Dementia actively supported the public involvement activities of Alzheimer Europe in EU-funded research projects and provided important feedback through consultations for the following projects: AI-MIND, DISTINCT, e-BRAIN-Health, EPND, EU-FINGERS, LETHE, RADAR-AD and VirtualBrainCloud. This work was acknowledged in a scientific article "Keeping track of and recognizing the value of Public Involvement work in dementia research" which was published in the Frontiers in Neurology journal and in "Empowering interventions for people with dementia: A European survey" which was published in the Journal of Advanced Nursing.

A full list of EU projects and public involvement activities can be found in the project section below.

Research communication

For the dissemination of research findings via its newsletter, website and conference, Alzheimer Europe ensured that it did not only focus on basic and clinical science, but also involved researchers and academics with a psychosocial, care, mental health, socio-economic or health systems background. Particular attention was also paid to covering research news.

In 2022, Alzheimer Europe published 11 monthly editions of its e-newsletter, with the months of July and August being combined into one. These e-newsletters contained information on Alzheimer Europe's activities and those of its member organisations. Updates on European projects in which Alzheimer Europe is involved were also shared, as were relevant policy initiatives and developments at the national and European levels, scientific advances, human interest stories, new resources and publications, and job opportunities in the dementia field. Finally, Alzheimer

Europe also made sure to include a number of accounts written by people living with dementia, with many members of the EWGPWD contributing to this section, as well as members of national dementia working groups.

A total of 524 articles were featured in Alzheimer Europe's 2022 monthly e-newsletters (543 in 2021). They can be broken down into categories, as follows:

Subject	Number of articles (2022)	Number of articles (2021)
COVID-19 situation and situation in Ukraine	15	22
Activities and projects of Alzheimer Europe	147	151
European policy developments in the field of dementia and European Alzheimer's Alliance	69	61
National policy developments	29	29
Activities and projects of Alzheimer Europe member organisations	69	92
Scientific developments	116	119
Dementia in Society and "Living with dementia" section	35	25
New resources and publications, education and job opportunities	44	44
TOTAL	524	543

These newsletters were delivered to the following number of recipients and opened as follows:

Month	Delivered to	Opened by	Percentage
January	7,312	3,629	56.89%
February	7,257	2,402	33.10%
March	7,197	2,560	35.57%
April	7,234	2,439	33.71%
May	7,296	2,692	36.90%
June	7,302	2,354	32.24%
July-August	7,332	2,734	37.29%
September	7,304	2,566	35.13%
October	7,290	2,353	32.28%
November	7,279	2,643	36.31%
December	7,270	2,354	32.38%

In 2022, Alzheimer Europe's website had the following number of users:

Date	Users
January	4,364
February	3,358
March	3,527
April	3,373
May	3,639
June	3,775
July	3,509
August	3,865
September	4,887
October	6,363
November	5,055
December	4,389
Total	46,147
Average	4,175



Alzheimer Europe new website

The organisation also continued to develop its social media presence, on Facebook and Twitter, but also on LinkedIn and YouTube. Alzheimer Europe's Facebook page registered 9,783 followers at the end of 2022 and 2,194 followers on LinkedIn. As for Twitter, the association had reached 13,600 followers at the end of 2022.

All Alzheimer Europe team members who are involved in projects and attend Alzheimer Europe events are active Twitter users, tweeting from events where they represent the organisation. The total number of Tweets by Alzheimer Europe and its team members in 2022 was 2,117 and tweet impressions were over 1.1 million, as can be seen from the below table:

Date	Tweets	Tweet impressions
January	92	96,405
February	108	74,041
March	217	110,278
April	161	81,219
May	182	87,985
June	203	104,467
July	69	40,815
August	91	41,090
September	221	110,879
October	443	210,770
November	181	78,332
December	149	79,597
Total	2,117	1,115,878

Finally, on YouTube, Alzheimer Europe had 317 subscribers and videos of the organisation were viewed as follows:

Year	Views	Watch time (hours)	Subscribers total
2022	8,472	385.7	317

Alzheimer Europe Conference

The 32nd Alzheimer Europe Conference (#32AEC) "Building bridges" was formally opened on 17 October 2022, at the JW Marriot Hotel conference centre in Bucharest, Romania. The conference was held as a hybrid event for the first time ever, with delegates and presenters able to join either on site or online, thus making it as accessible, inclusive and interactive as possible. 543 participants from 42 countries attended the conference, which took place over three days, ending on 19 October 2022.

	2022 Bucharest	2021 Online
Academics/Researchers	228	251
Alzheimer association staff and volunteers	124	159
Health or social care professionals	74	71
Students	32	34
Industry representatives	29	38
Carers	21	12
People with dementia	20	37
Civil servants	6	10
Policy makers	5	8
Press	4	
TOTAL	543	620



Plenary 4 speaker panel at the 32nd Alzheimer Europe Conference in Bucharest, 19 October 2022

On the agenda were over 250 presenters (187 oral presentations, 38 quick oral presentations and 63 poster presentations), who shared their research, knowledge and experience in an atmosphere of collaboration and solidarity.

The keynote presentations and plenary sessions were dedicated to "Building bridges – Promoting good dementia care through pan-European collaboration", "Moving beyond the COVID-19 pandemic", "Brain health and prevention", "Building bridges across Europe through cross-border initiatives and research" and "Reprioritising dementia as a care, policy and research priority".

In addition to these plenaries and keynotes, delegates at #32AEC had a choice of 30 different parallel sessions and 6 special symposia organised by the European Working Group of People with Dementia and the sponsors of the Alzheimer Europe Conference.

In the evaluation of the Annual Conference, 97.83% of participants said that they would be happy to recommend the Alzheimer Europe Conference to a colleague.



Plenary 5 speaker panel at the 32nd Alzheimer Europe Conference in Bucharest, 19 October 2022

Other activities and projects

Involvement in EU projects

Alzheimer Europe was a full partner in a number of projects funded by the European research programmes Horizon2020, Horizon Europe and the Innovative Medicines Initiative. The organisation also participated in two JPND (Joint Programme Neurodegenerative Diseases Research) projects and one ERA PerMed project funded by the Fonds National pour la recherche (FNR) in Luxembourg. In these projects, the organisation ensured that the views of people with dementia, carers and Alzheimer's associations were included, contributed to the discussion of the ethical issues raised by the projects and supported or led the dissemination activities.

In 2022, Alzheimer Europe was a full partner in the following projects:

ADIS



ADIS Kick-off meeting 14-15 July Sankt Augustin (Germany)

ADIS stands for "Early Diagnosis of Alzheimer's Disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances" and is a project funded through the JPND and Luxembourg FNR. The three-year project started on 1 July 2022.

ADIS focuses on the question of how an earlier diagnosis of Alzheimer's disease (AD) can be achieved in the future.

Two concrete objectives are to evaluate whether blood-based biomarkers derived from special types of immune cells and sleep disturbances allow us to reliably distinguish AD patients at different stages of the disease from healthy subjects; and to understand, in how far sleep disturbances might influence blood-based biomarkers.



The concrete actions will include running a clinical study with 75 participants (25 with AD, 25 with mild cognitive impairment and 25 cognitively normal participants), that will be assessed via standard questionnaires, a smart watch (worn at home), an augmented reality game (to monitor cognition) and via blood sampling.

From each of the blood samples partners will measure many different molecular markers, even on the level of individual cells. The partners will then use statistical as well as advanced computational approaches (including Artificial Intelligence) to find patterns in the data generated by the study. This will help the project evaluate whether blood-based biomarkers and sleep disturbances might allow to detect AD at an early disease stage.

Alzheimer Europe is represented by Jean Georges, Chris Bintener and Soraya Moradi-Bachiller.

In 2022, they:

- took part in the project kick-off meeting in Sankt Augustin, Germany on 14 and 15 July,
- represented Alzheimer Europe in the monthly telephone conference, contributed to the technical report,
- developed and maintained the website & social media channels,
- developed other communication materials such as a project clip,
- developed, in close collaboration with the project partner Fundació Clínic per a la Recerca Biomèdica (FCRB), the relevant documents (terms of reference, expression of interest, informative document and form to join) to be used for the identification of people interested in joining the ADIS Advisory Board,
- set up the ADIS Advisory Board, which is currently composed of 5 members from Spain and who have AD in the Mild Cognitive Impairment (MCI) stage. The European Working Group of People with Dementia will also be involved in some of the consultations organised in the context of Public Involvement,
- planned, prepared and conducted, in close collaboration with the project partner FCRB and the Confederación Española de Alzheimer (CEAFA), three informative meetings, and one social event with members of the advisory board,
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and events.

AI-MIND

The goal of AI-MIND (Intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment) is to develop novel, AI-based tools to support



AMYPAD

The "Amyloid imaging to prevent Alzheimer's disease" project aimed to improve the diagnostic workup of patients suspected to have Alzheimer's disease and their management. The consortium was led by Stichting VUmc and GE Healthcare Life Sciences. Launched in October 2016, the project aimed to improve knowledge of the natural history of Alzheimer's disease in a pre-symptomatic stage, in order to better select patients for trials. In addition, partners monitored changes in beta amyloid deposition in the brain in order to quantify the impact of novel therapies. The project came to an end in September 2022 with the end of the IMI funding.

Alzheimer Europe was represented by Jean Georges and Cindy Birck in this project. In 2022, they:

- represented Alzheimer Europe in the AMYPAD Executive Committee and its weekly telephone conference and presented regular updates on the projects' communication and dissemination activities,
- co-led the work package on ethics, communication and dissemination,
- organised and chaired the monthly communication teleconference meetings,
- coordinated the production and the regular maintenance of the communication tools (i.e. website, newsletter, Twitter, Research Gate, slide deck, YouTube, Zenodo),
- provided social media support for AMYPAD presenters at selected international and European conferences,
- contributed to the internal track of dissemination activities,
- contributed to the internal monthly report,
- followed up the AMYPAD authorship policy and publication approval policy,
- represented the AMYPAD communications team in the Neuronet communication expert community
- organised an online symposium on 1 April on biomarker disclosure and developed video interviews with research participants,
- developed the final report on dissemination activities (including impact measures) and project tools developed,
- contributed to the paper "The Amyloid Imaging for the Prevention of Alzheimer's Disease Consortium: A European collaboration with a global impact" published in the journal *Frontiers in Neurology*,
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and events,
- coordinated an article on the closure of the AMYPAD project for the *Dementia in Europe* magazine,
- attended the final General Assembly meeting on 22-23 September in Amsterdam and presented an overview of the communication and dissemination work.



AI-Mind GA - 4 May - Rome Italy

healthcare professionals in their diagnoses and offer timely interventions to patients. The researchers hope that complex, labour-intensive, costly and poorly predictive screening methods for mild cognitive impairment (MCI) will eventually be replaced by automated diagnostic screening tools, driven by artificial intelligence (AI), permitting the timely and accurate prediction of which people with MCI will eventually develop dementia.

Alzheimer Europe is represented in this project by Jean Georges, Chris Bintener, Cindy Birck, Angela Bradshaw, Ana Diaz and Dianne Gove. In 2022, they:

- attended the General Assembly Meetings on 4-5 May (Rome) and 17-18 November (Madrid) and presented the strategy for the ethical and trustworthy communication of the use of AI-based dementia risk prediction in the clinical setting and held a session on the dementia research landscape presenting various projects relevant to the AI-Mind consortium,
- represented Alzheimer Europe in the AI-Mind Executive Board Committee and its quarterly telephone conferences,
- conducted a rapid review of the literature to explore what is known about the use of AI-based dementia risk prediction for people with MCI with a focus on ethical and social issues linked to the perceived trustworthiness, use, acceptance and communication of AI-based risk prediction in the clinical setting, as well as the impact on the doctor-patient relationship,
- organised a series of interviews, focus group discussions and a short survey to help ensure that the various ethical, societal and practical issues considered reflect the views, beliefs, assumptions and priorities of people from some of the groups affected by the use of these tools (i.e. people who are at risk of dementia, have MCI or dementia or are informal carers or doctors),
- contributed to the production and maintenance of the communication tools,
- contributed to the internal newsletter,
- contributed to the development of the communication and dissemination plan,
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and events.

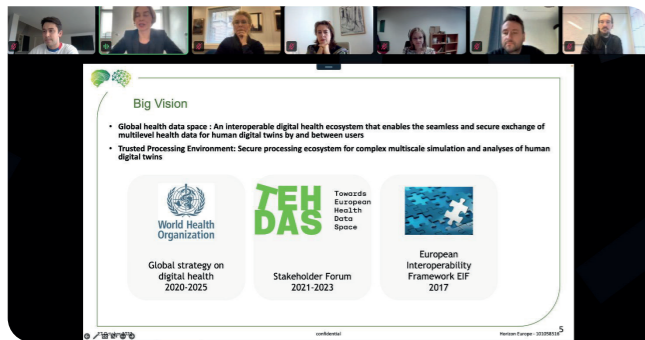


AMYPAD project final General Assembly, Amsterdam, 22 September 2022



eBRAIN-Health

eBRAIN-Health is a 4-year Horizon-Europe-funded research project, launched in July 2022 and involving 20 partners. In eBRAIN-Health, a large variety of data sources will be brought together in a GDPR-compliant research platform, to support the development of digital representations of the brain. These “digital twins” will allow researchers to conduct innovative brain research within a powerful digital platform that keeps patient data secure and confidential. In addition, digital twins have the potential to improve our understanding of brain function and disease at an individual level; improve diagnosis and risk prediction, and optimise potential therapies. Alzheimer Europe’s role in the project is to lead the public involvement and ethics activities (led by Daphné Lamirel with support from Dianne Gove) activities and to contribute to communications and outreach work (led by Ange Bradshaw).



The eBRAIN-Health project's first General Assembly meeting was held online on 27 October 2022

In 2022, they:

- attended the eBRAIN-Health kick-off meeting,
- set up the eBRAIN-Health Public and Patient Advisory Group (PPAG) consisting of 5 people from Germany, Spain and the UK ensuring some diversity, in terms of country, gender, and diagnosis/link to dementia (one person with dementia from the European Working Group of People with Dementia, as well as people with MCI, subjective memory loss and first-degree relatives of someone with dementia),
- developed a plan for public involvement activities in Year 1, with specific dates and topics for the different consultations,
- put together easy-to-understand information about the project for the members of the PPAG, as well as the consent forms to join the group,
- met with all members individually to inform them about the project and understand any specific needs they might have. All members consented to join for 1 year, with the possibility to renew their membership every year,
- undertook a scoping review on the ethical concerns linked to the development and clinical use of digital brain twins for dementia, searching databases of peer-reviewed and grey literature,
- got in touch with an expert from the eBRAINS ethics group who agreed to provide input to the review and explore publishing opportunities,
- met with representatives from the University of Vienna (a partner of the



- project) to explore additional opportunities to carry out public involvement within Work Package 2 (ethics and legal work) of the project,
- disseminated eBRAIN-Health activities via the AE newsletter and social media channels,
- contributed to the development of the eBRAIN-Health communication and dissemination plan, and public outreach strategy.

EPAD

The European Prevention of Alzheimer's dementia (EPAD) initiative was a collaborative research effort to improve the chance of successfully preventing Alzheimer's dementia and to better understand early aspects of Alzheimer's disease before dementia develops. Led by the University of Edinburgh, the project established a European-wide register of research participants. The project came to an end in September 2020 with the end of the IMI funding. An EPAD sub award was given to Alzheimer Europe in 2022 for the maintenance of the website and the support of communication activities.

Alzheimer Europe was represented by Cindy Birck in this project. In 2022, she:

- coordinated the regular maintenance of the communication and dissemination tools (i.e. website, social media channels, Research Gate),
- developed a flyer dedicated to the EPAD sample and data to be distributed at AAIC22,
- provided social media support for EPAD presenters at selected international and European conferences,
- represented EPAD in the Neuronet communication expert community,
- contributed to the paper “The European Prevention of Alzheimer's Dementia Programme: An Innovative Medicines Initiative-funded partnership to facilitate secondary prevention of Alzheimer's disease dementia” published in the journal *Frontiers in Neurology*,
- contributed to the efficient communication of the project via AE website, newsletter and events,
- coordinated an article on the EPAD samples and data for the *Dementia in Europe* magazine.



Tweet from ADDI about EPAD project's genomic data being available on the Alzheimer's Disease Workbench



EPND



EPND project's first Annual Meeting, Amsterdam, 8 December 2022

The goal of the IMI-funded “European Platform for Neurodegenerative Diseases” project is to accelerate the discovery of diagnostics and treatments for neurodegenerative diseases, by removing barriers to data and sample sharing and fostering collaboration. The consortium is led by the University of Maastricht, University of Leicester, UCB Biopharma and Gates Ventures, and includes a further 25 partners from academic institutions, pharmaceutical companies, SMEs and patient organisations. EPND is funded for a period of 5 years from November 2021. The project will create a platform that will enable the sharing of high-quality biosamples and clinical data from research cohorts on ageing and neurodegeneration, performing a series of clinical case studies that will advance research on multimodal biomarkers as well as testing and validating the EPND platform. EPND will also develop recommendations to address ethical-legal, regulatory and technical challenges in data and sample sharing and biomarker validation.

Alzheimer Europe co-led the stakeholder involvement and communication activities of the project (workpackage 6), leading a task on Public Involvement; participated in workpackages on the establishment of the technical platform (WP1), ethical and legal issues (workpackage 2) cohort interactions (workpackage 4) and sustainability (workpackage 7). Alzheimer Europe was represented by Jean Georges, Angela Bradshaw, Ana Diaz, Dianne Gove and Daphne Lamirel. In 2022, they:

- participated in the face-to-face Annual Meeting in December (Amsterdam, the Netherlands), as well as online Management Board and workpackage meetings,
- authored the EPND Communication and Dissemination Strategy, and co-authored deliverable reports from WP2 and 7,
- coordinated updates to the project's website, supporting the development and launch of the EPND Cohort Catalogue,
- coordinated the production and regular maintenance of the project's social media channels (Twitter, LinkedIn), developing newsletters, brochures and information sheets on the project,



- contributed to the efficient communication of the project via AE website, newsletter and events, including hosting a virtual booth for EPND at the 2022 AE Conference, and an article in the *Dementia in Europe* magazine,
- with the WP6 co-Lead, established the External Stakeholder Advisory Board of EPND, and launched the EPND Stakeholder Advisory Framework,
- set up a Patient Expert Group, consisting of a core group, composed of 15 people with dementia from different European countries (coordinated by AE) and a parallel group of people with Parkinson's disease and parkinsonism (coordinated by FEP), composed of 17 members from eight of the 17 Autonomous Communities of Spain,
- in close collaboration with the FEP, planned and conducted 4 virtual consultations with members of the Patient Expert Group on the topics of respectful and inclusive communication to/about and portrayal of neurodegenerative diseases, as well as facilitators and barriers to effective and ethical PI work,
- developed a comprehensive glossary for the general public, including people with neurodegenerative diseases, to promote their interest in and understanding of research into neurodegenerative diseases, which will eventually be available on the EPND website.

EU-FINGERS

The JPND and FNR-funded project, EU-FINGERS (Multi-modal precision prevention toolbox for dementia in Alzheimer's disease), kicked off in 2020 with the aim of advancing preventive strategies for risk reduction and prevention of cognitive decline and Alzheimer's dementia. An important outcome of this project will be the “Multimodal Precision Prevention Toolbox”. This Toolbox will include different tools enabling the next generation of clinical trials, to identify precision prevention strategies for Alzheimer's dementia. Precision Medicine takes into account individual characteristics, in terms of biology, lifestyle and environment, to optimise disease treatment and prevention.

Alzheimer Europe was involved in the Public Involvement (PI) activities and co-led the communication activities of the project. Alzheimer Europe was represented by Jean Georges, Cindy Birck, Ana Diaz and Dianne Gove. In 2022, they:

- participated in the general assembly meeting on 21-22 November in Stockholm,
- coordinated the production and regular maintenance of the project's communication tools (i.e. Website, Twitter, LinkedIn),
- contributed to the efficient communication of the project via AE website, newsletter and events,
- coordinated an article on brain health including views of two members of the EU-FINGERS Advisory Board,
- coordinated the activities and meetings of a project-specific Advisory Board composed of 15 members from different European countries





EU-FINGERS General Assembly meeting, Stockholm, 21 November 2022

- and who have Subjective Cognitive Decline, Mild Cognitive Impairment, dementia, are carers of a person with dementia and/or have participated in research or interventions linked to dementia prevention,
- produced reports with summaries of feedback from members of the Advisory Board,
 - presented the PI work and model at the 9th Alzheimer Symposium on August 23-25, 2022 in Kuopio, Finland.
 - Facilitated the involvement of two members of the Advisory Board in a special symposium about PI at the 9th Alzheimer Symposium on August 23-25, 2022 in Kuopio, Finland.
 - dedicated a session in one of AE's Alzheimer's Association Academy to the impact of PI in research, where the project PI activities were featured.

LETHE

LETHE (A personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on Artificial Intelligence and distributed Machine Learning) is a four-year, Horizon 2020-funded project which aims to prevent cognitive decline in older adults at an early time point using a multi-domain interventional lifestyle intervention built on a person-centred digital solution.



LETHE project consortium meeting, Ioannina (Greece), 3 October 2022



Alzheimer Europe contributed to the Public Involvement (PI) and communication and dissemination activities. Alzheimer Europe was represented by Christophe Bintener and Ana Diaz. In 2022, they:

- coordinated the activities and regular meetings of the project-specific Advisory Board composed of seven members with dementia or at a higher risk of dementia from Austria, Italy, Finland and Sweden,
- collaborated with project partners to identify topics for the Advisory Board and to develop accessible documents for the meetings,
- produced reports with summaries of feedback for each of the meetings with the members of the Advisory Board,
- conducted a short evaluation with members of the Advisory Board about their involvement,
- produced two deliverables based on the Public Involvement activities (activities report and ethical issues linked to the project)
- dedicated a session in one of AE's Alzheimer's Association Academy to the impact of PI in research, where the project PI activities were featured.
- featured the project and its Advisory Board in an article in the Dementia in Europe Magazine,
- participated in the weekly study protocol meetings,
- participated in the bi-weekly scrum meetings and collaborated with i2G for alignment in communication activities,
- supported project outreach and awareness raising activities through AE social media, newsletter and website, and participated online in the project General Assembly meeting
- provided feedback on the LETHE website and social media posts for further development.

Neuronet

Neuronet was an IMI-funded coordination and support action (CSA), which received funding in 2019 and which aimed to boost synergy and collaboration between IMI projects working on neurodegenerative diseases (NDD) such as Alzheimer's disease and Parkinson's disease. Neuronet collected and analysed information and assets from the various NDD initiatives in the IMI portfolio, aiming to identify gaps, enhance visibility and multiply the impact of the portfolio as a whole. To achieve this, Neuronet developed a Knowledge Base platform and an asset map of the portfolio, among other resources. The Neuronet consortium was led by SYNAPSE Research Management Partners and Janssen. The project concluded in July 2022.

Alzheimer Europe was represented by Jean Georges, Angela Bradshaw, Christophe Bintener, Cindy Birck, Ana Diaz and Dianne Gove. In 2022, they:

- co-led the work package on dissemination and outreach,
- contributed to work packages on projects & impact analysis, programme integration, tools & services and CSA management and sustainability and co-authored a number of project deliverables,
- authored deliverables on "Public event proceedings and videos - Year 3" &



NEURONET closing meeting, Barcelona, 1 July 2022

- "Final report on dissemination and outreach activities (including impact measures)" as well as "Final version of guidance on standards and practices for protecting data privacy"
- coordinated the production and the regular maintenance of the communication tools and channels (i.e. website, newsletter, social media channels),
 - contributed to the design development of the Knowledge Base and updated modules on publications, deliverables, tools and events,
 - coordinated and chaired meetings of the Communications Expert Community,
 - attended the fortnightly teleconference meetings of the Executive Committee and monthly work package teleconference meetings,
 - moderated the working group on patient privacy and ethics,
 - participated in the working groups on data sharing, HTA/regulatory affairs and sustainability,
 - authored a publication on "Keeping track of and recognizing the value of Public Involvement work in dementia research" and contributed to a publication on "The Innovative Medicines Initiative neurodegeneration portfolio: From individual projects to collaborative networks two publications" which were published in Frontiers in Neurology,
 - participated in the project closing meeting on 30 June and 1 July.

PatternCog

Pattern-Cog stands for "Personalised ageing pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals". Funded by ERA PerMed, the three-year project started in June 2022 and includes six partners from five European countries. The overarching goal of the project is to improve dementia prevention strategies by developing support tools for the detection of earliest signs of impending cognitive decline which would allow early and personalised multidomain interventions.

Alzheimer Europe is co-leading the work on public involvement and



Pattern-Cog online kick-off meeting, 8 June 2022

communication. Alzheimer Europe is represented in this project by Jean Georges, Cindy Birck and Soraya Moradi-Bachiller. In 2022, they:

- attended the online kick-off meeting of the project and presented the planned work,
- participated in the online Executive Board Management meetings,
- contacted partners and national Alzheimer's associations to start planning the composition of the Pattern-Cog Advisory Board (AB) and the patient and public involvement (PPI) activities,
- wrote the necessary documents needed when reaching out to candidates for the Pattern-Cog AB (i.e. Terms of Reference, Expression of Interest and Form to Join documents),
- set up a Pattern-Cog PPI-AB with the new European Dementia Carers Working Group,
- developed a corporate identity (i.e. project logo) to ensure a unified project image for all communication materials and produced templates (i.e. slides, poster, letter),
- established a communication strategy with the development of a communication and dissemination plan,
- produced the first communication tools and coordinated their regular maintenance (i.e. info email address, Twitter, LinkedIn),
- contributed to the efficient communication of the project via the Alzheimer Europe website and newsletter.

PRODEMOS

The PRODEMOS (Prevention of Dementia using Mobile phone Applications) project kicked off in January 2018. This project aims to make an evidence-based dementia prevention strategy using mobile Health accessible to those at increased risk of dementia who are usually not reached by preventive medicine. The project targets socio-economically deprived populations in the EU and a population at risk of dementia in China. The final aim is to implement the mHealth platform in a culturally appropriate form in a range of health care settings. Originally scheduled to be a





PRODEMOS project General Assembly, Luxembourg, 20 September 2022

60-month project, beginning 1 January 2018 and ending December 2022, the PRODEMOS project has been extended by 6 months to come to an end in June 2023.

Alzheimer Europe supports the communication and dissemination activities and is represented by Jean Georges and Cindy Birck. In 2022, they:

- organised and attended the general assembly meeting held on 19-20 September in Luxembourg,
- participated in the monthly telephone conferences of the PRODEMOS WP leads,
- developed regular news items for the PRODEMOS mHealth platform,
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and events.

RADAR-AD

The RADAR-AD (Remote Assessment of Disease and Release – Alzheimer’s disease) project funded by the Innovative Medicines Initiative started in 2019. The ultimate goal of the project is the development and validation of technology-enabled, quantitative and sensitive measures of functional decline in people with early-stage Alzheimer’s disease.

Alzheimer Europe’s role in the project was to lead and support the patient and public involvement activities of the project. The organisation was represented by Ana Diaz, Dianne Gove and Jean Georges in this project. In 2022, they:

- attended the online General Assembly on 10 and 11 March and the in-person Consortium meeting on 28 and 29 September in Amsterdam,
- facilitated the involvement of a member of the Patient Advisory Board at the RADAR-AD General Assembly and Consortium meeting,
- coordinated the participation of a member of Patient Advisory Board in a workshop organized by EFPIA on “Patient involvement: establishing patient relevance and the importance of the patient voice”,
- attended the online Steering Committee meetings of the project,
- dedicated a session in one of AE’s Alzheimer’s Association Academy to the impact of PI in research, where the Patient Advisory Board activities were featured,
- organised and facilitated online and in-person consultations with members of the RADAR-AD Patient Advisory Group on a range of topics related to the RADAR-AD studies and the Qualification Advice Briefing Book,
- contributed to the project publications management team,
- supported project outreach and awareness raising activities through AE social media, newsletter and website.



RADAR-AD project consortium

RECOGNISED

The RECOGNISED project (Retinal and cognitive dysfunction in type 2 diabetes: unraveling the common pathways and identification of patients at risk of dementia) started in January 2020 and is funded by Horizon 2020 for a 4-year period. RECOGNISED will apply innovative approaches to identify the molecular mechanisms involved in the high prevalence of cognitive impairment and dementia in the T2D population. It will use this knowledge to characterise clinical phenotypes based on retinal functional and structural characteristics and serum biomarkers in order to stratify the risk and severity of cognitive decline.

Alzheimer Europe contributed to the dissemination and exploitation (WP8) and communication activities (WP9) workpackages. Alzheimer Europe was represented by Angela Bradshaw. In 2022, she:

- participated in General Assembly meetings and regular workpackage meetings,
- attended meetings of the Dissemination and Exploitation Board (DEB),
- contributed to the implementation of the RECOGNISED communication plan, including drafting of news items and lay summaries for scientific publications,
- contributed to the production and maintenance of the communication tools (website, leaflet, twitter), and development of the RECOGNISED newsletter,
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and events, including an article in the Dementia in Europe magazine.



Retinal scanning used in RECOGNISED

VirtualBrainCloud



Petra Ritter presents VirtualBrainCloud at Alzheimer Europe lunch debate, Brussels, 27 September 2022

The VirtualBrainCloud project was launched in December 2018 and will conclude in May 2023. TVB_Cloud is developing and validating a decision support system that provides access to high quality multi-disciplinary data for clinical practice. The result will be a cloud-based brain simulation platform to support personalised diagnostics and treatments for neurodegenerative diseases (NDD). The software will be tailored to the individual, bridging multiple scales to identify key mechanisms that predict NDD progression. The interdisciplinary VirtualBrainCloud consortium will also develop robust solutions for legal and ethical matters.

Alzheimer Europe contributed to the ethical and legal (workpackage 2), software integration, visualisation and interaction (workpackage 6) and communication and dissemination (workpackage 9) activities of VirtualBrainCloud. Alzheimer Europe was represented by Jean Georges, Angela Bradshaw, Ana Diaz and Dianne Gove. In 2022, they:

- participated in quarterly General Assembly meetings and regular workpackage meetings, co-authoring project deliverables,
- organised a European Parliament lunch workshop in Brussels on “The role of artificial intelligence and big data in dementia research”, hosted by Sirpa Pietikäinen, MEP (Finland), during which the project leader, Petra Ritter, delivered a presentation,
- co-hosted a virtual booth at the 32nd Alzheimer Europe conference in Bucharest,
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and social media,
- organised a face-to-face consultation with members of the European Working Group of People with Dementia (EWGPWD) on the development and testing of a rehabilitation gaming system being developed by VirtualBrainCloud partner, Eodyne,
- produced reports with summaries of feedback from the EWGPWD.



Support of European Research Activities

In addition to the projects described above where Alzheimer Europe is a full partner, the organisation also supported a number of other European research projects.

ABOARD



Junior researchers of ABOARD visited PGGM (a not-for-profit cooperative pension fund service provider), 11 July 2022

ABOARD, short for "A personalized medicine approach for Alzheimer's disease", is a public-private project which aims to prepare for a future in which Alzheimer's disease is stopped before dementia has started. ABOARD, coordinated by Wiesje van der Flier, scientific director of the Alzheimer Centre Amsterdam, aims to achieve this by improving diagnostic markers, developing personalised risk scores and by focusing on prevention through increased awareness of dementia and brain health. To lower the number of individuals with dementia, ABOARD focuses on the alzheimer-stages before dementia onset.

ABOARD-representatives from healthcare, health insurance, digital health, pharma, big data, education and patient organisations met for two project meetings in Utrecht on 28 April and 17 November 2022.

The project counts Alzheimer Europe among its more than 30 partners and Alzheimer Europe Director Jean Georges, who is a member of the project's Advisory Board, participated in the November meeting.

ADAIR

The ADAIR project aims to provide crucial mechanistic insight about the effects of air pollutants on the brain in humans and discover biomarkers for air pollution and Alzheimer's disease (AD) risk prediction.

ADAIR is a JPND-funded project and addresses a major societal challenge with wide health-related, environmental, economic, scientific, social, and political impact. Lowering the incidence of AD attributable



ADAIR consortium at kick-off meeting in Prague, 16 January 2020

to air pollution and contribution to the mitigation of climate change, are closely linked. The ultimate goal is to develop strategies for early identification of people at risk of AD, and to discover novel targets for preventive strategies in AD.

Alzheimer Europe is represented by Jean Georges and Ana Diaz in this project. In 2022, they:

- participated in some online events of the project (General Assembly and webinars).

DISTINCT



Simone Felding from DISTINCT presents at Alzheimer Europe's online Alzheimer's Association Academy, 12 December 2022

DISTINCT (Dementia: Intersectoral Strategy for Training and Innovation Network for Current Technology) is an EU-funded Marie Skłodowska-Curie Innovative Training Network which received continued funding in 2020. Coordinated by the University of Nottingham, the network brings together 13 research organisations which host 15 early-stage researchers who are focusing on improving the usability of technology in dementia care.

Alzheimer Europe and its European Working Group of People with Dementia were involved in this project and the organisation was represented by Dianne Gove and Ana Diaz in this project. In 2022, they:

- supported the secondment of two early-stage researchers from DZNE,
- facilitated the active involvement and participation of the two early-stage researchers in in-person meetings of the EWGPWD

- planned, supported the preparation and participated in one consultation with the EWGPWD, involving 5 ESRs from the project
- dedicated a session in one of AE's Alzheimer's Association Academy on the impact of PI in research, where the project was featured,
- featured the early stage researchers of the project in a special symposium at the Annual Conference in Bucharest,
- participated in online supervisory and management meetings of the project.

MIRIAD



Miriade Annual Meeting, Netherlands, September 2022

MIRIAD (Multi-omics Interdisciplinary Research Integration to Address Dementia diagnosis) is another EU funded Marie Skłodowska-Curie Innovative Training Network which received continued funding in 2020. The project aims to generate a novel generation of scientists able to accelerate fluid biomarker development for dementias.

Alzheimer Europe's role in the project was to support the dissemination and communication activities and provide secondments to two early-stage researchers during the course of the project. The organisation was represented by Jean Georges, Ana Diaz, Dianne Gove, Angela Bradshaw and Chris Bintener in this project. In 2022, they:

- provided support to one of the Early Stage Researchers in the project regarding possible research opportunities,
- supported the dissemination of the activities of the project,
- attended the General Assembly with other project partners.

PRIME

The PRIME (Prevention and Remediation of Insulin Multimorbidity in Europe) project brings together a multidisciplinary team to (1) extend our understanding of insulin multimorbidity across the lifespan, (2) understand the causal mechanisms linking somatic and mental insulin-related illnesses, (3) develop tools for early diagnosis, improved clinical care, and prevention of insulin-related lifespan multimorbidity. PRIME aims to bring this new knowledge to society, based on e.g. repurposing medication and lifestyle interventions (diet/exercise monitored by mHealth



PRIME project General Assembly meeting, Barcelona, 6 September 2022

assessment), identifying and validating novel drug targets, developing and testing candidate biomarkers, and by improving existing medical guidelines and policy. Furthermore, educational approaches to inform clinicians, patients and the general public will be developed.

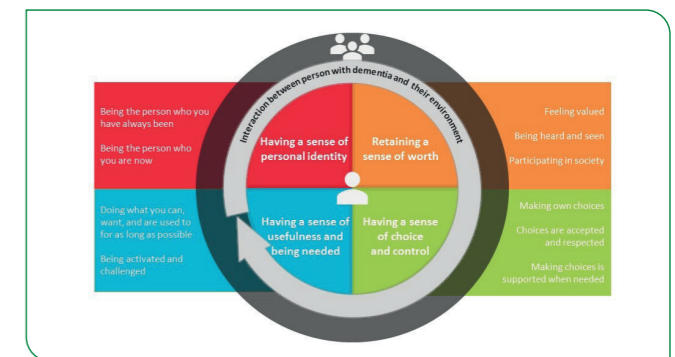
Alzheimer Europe contributed to the policy outreach and dissemination activities of PRIME. Alzheimer Europe was represented by Angela Bradshaw. In 2022, she:

- participated in the general assembly meeting, webinars and other PRIME events,
- contributed to the work of the Scientific and Ethical Advisory Board (SEAB), Internal Innovation Board (IIB) and Dissemination Team,
- organised an elevator pitch workshop and moderated a World Café session for early-career researchers and PRIME consortium members at a general assembly meeting in Barcelona.

SPAN+

The SPAN+ project, which is led by Radboud University Medical Centre, aims to develop an effective empowerment intervention for people with dementia at home and in care homes. Alzheimer Europe was represented by Dianne Gove, Ana Diaz and Jean Georges in this project. In 2022, they:

- co-authored an article on empowering interventions for people living with dementia in Europe.



SPAN+ figure



Corporate Affairs

European Parliament lunch debates and workshops

Alzheimer Europe held three European Parliament lunch debates and workshops in 2022:

- On 22 March 2022, an online workshop was held on “Prioritising dementia in European policies on care, disabilities and equalities” hosted by Sirpa Pietikäinen, MEP (Finland).
- On 14 June 2022, a lunch debate was held in Brussels on “Neurological conditions and mental health in EU and World Health Organization (WHO) Europe programmes” hosted by Deirdre Clune, MEP (Ireland).
- On 27 September 2022, a lunch debate was held in Brussels on “The role of artificial intelligence and big data in dementia research” hosted by Sirpa Pietikäinen, MEP (Finland).

Amongst the speakers were:

- Alejandro Moledo, Head of Policy, European Disability Forum
- Andrzej Rys, Director at DG SANTE, European Commission
- Astrid Dentler, Member of the Cabinet of European Commission Vice-President Dubravka Šuica
- Catherine Berens, Deputy Head of Unit, DG Research and Innovation, European Commission
- Gözde Susuzlu-Briggs, DataSavesLives Coordinator, European Patients’ Forum
- Immaculada Placencia Porrero, Senior Expert at DG Employment, European Commission
- Jesper Kjær, Director of the Data Analytics Center at the Danish Medicines Agency



Sirpa Pietikäinen MEP opens Alzheimer Europe lunch debate, Brussels, 27 September 2022

- Joke Jaarsma, President, European Federation of Neurological Associations (EFNA)
- Ledia Lazeri, Regional Advisor, WHO Europe
- Marianne Takki, Team Leader at DG SANTE, European Commission
- Petra Ritter, Project Coordinator of VirtualBrainCloud; Berlin Institute of Health at Charité University Hospital
- Tilly Metz, MEP (Luxembourg)

All three events were well-attended, with representatives from the European Parliament and Commission, people with dementia and their carers, Alzheimer Europe member associations, national government officials and the organisation’s sponsors.



Alzheimer Europe lunch debate, Brussels, 14 June 2022

Dementia in Europe magazine

In 2022, Alzheimer Europe published three issues of the Dementia in Europe magazine, which covered Alzheimer Europe’s activities, such as the lunch debates and Annual Conference or the organisation’s EU projects, as well as developments at a European and national level which had relevance for dementia policy. The first edition of the 2022 magazine continued in a digital-only format, but from June 2022, Alzheimer Europe restarted publishing and distributing printed copies of its magazines.

Over the three editions of the magazine, the organisation was pleased to have interviews and contributions from a number of European and national policy-makers, including:

- Artur Furtado, Deputy Head of Unit at DG SANTE, European Commission
- Hilde Vautmans, MEP (Belgium)
- Irena Joveva, MEP (Slovenia)
- Ivan Štefanec, MEP (Slovakia)
- Milan Brglez, MEP (Slovenia)
- Pierre Meulien, outgoing Executive Director, Innovative Health Initiative
- Rodrigo Cataldi, Mental health Officer at World Health Organization (WHO)
- Sara Cerdas, MEP (Portugal)
- Seán Kelly, MEP (Ireland)
- Sirpa Pietikäinen, MEP (Finland)
- Tomáš Zdechovský, MEP (Czech Republic)
- Wouter Beke, Flemish Minister for Health (Belgium)

The 2022 issues included articles on a range of other relevant policy and research initiatives:

- AMYPAD as a European collaboration on the impact of amyloid imaging
- Brain health in EU projects EU-FINGERS and LETHE
- Collaboration between EPAD and ADDI on data sharing
- Cost of Alzheimer’s disease in Portugal
- COVID-19 impact on people with dementia and carers
- Davos Alzheimer’s Collaborative
- Dementia dogs in Bulgaria and Scotland
- Dementia in French elections
- Dementia-friendly urban design
- EPND for the discovery of biomarkers for neurodegenerative diseases
- European Care Strategy
- European Commission “Healthier Together” initiative
- France’s driving ban for people with dementia
- Genetic risk factors for dementia
- Impact of the Innovative Health Initiative on neurodegenerative research

DEMENTIA IN EUROPE
THE ALZHEIMER EUROPE MAGAZINE

Issue 40
October 2022

Sirpa Pietikäinen MEP and Milan Brglez MEP
make progress on European care policy

Deirdre Clune MEP
hosts first in-person Alzheimer Europe lunch debate for two years

Pierre Meulien
reflects on his leading public private research in Europe

Iva Holmenová
reflects on her time as Chairperson of Alzheimer Europe

- Impact of Ukraine war on people with dementia
- Lack of new EMA-approved medicines for Alzheimer’s disease
- Multi-domain interventions for risk reduction
- Neuronet decision tool for engagement with regulatory and health technology assessment bodies
- Nutrition in dementia
- Responsible health data sharing
- UN Disability Rights Committee evaluation of European Union
- VirtualBrainCloud and AI-based brain simulations
- WHO knowledge exchange platform and involvement of people with dementia
- WHO pan-European Mental Health Coalition
- WHO research blueprint
- World Dementia Council on international commitments on dementia

Clinical Trials Watch

In 2022, Alzheimer Europe continued with the development of its Clinical Trial Watch which provides accessible and up-to-date information on clinical trials that are investigating interventions for Alzheimer's disease and other types of dementia. As in previous years, Alzheimer Europe focused on phase II and III clinical trials that were:

- Recruiting participants and
- Conducted in at least one European country.

At the end of 2022, the following 19 phase II and 11 phase III clinical trials recruiting participants in Europe were included on the AE website:



Alzheimer Europe Project Officer Cindy Birck presents the Clinical Trials Watch at an online Company Round Table meeting, 6 December 2022

Phase II trials				
Company	Study	Drug candidate	Population	Target
AC Immune	ABATE	ACI-24.060	Prodromal Alzheimer's disease	Amyloid-related (Immunotherapy)
Janssen	AUTONOMY	JNJ-63733657	Early Alzheimer's disease	Tau (Immunotherapy)
Roche	Brainshuttle AD	RO7126209	Prodromal or Mild to Moderate Alzheimer's disease	Amyloid-related (Immunotherapy)
Cognition Therapeutics	COG022	CT1812	Mild to moderate Alzheimer's disease	Amyloid-related (small molecule)
UCL	DESPIAD	CPHPC	Mild Alzheimer's disease	Anti-amyloid therapy (drug - Elimination SAP)
Denali Therapeutics	DNL593	DNL593	Frontotemporal Dementia	Other
Novartis	Explain-AD	Canakinumab	Mild Cognitive Impairment or Mild Alzheimer's Disease	Anti-IL-1 antibody
Norwegian University of Science and Technology	ExPlas	ExPlas	Early Alzheimer's Disease	Plasma transfusion
WAVE Life Sciences	FOCUS-C9	WVE-004	Frontotemporal Dementia	DNA/RNA-based
Centre Hospitalier St Anne	IL-AD2	IL-2 (PROLEUKIN®)	Early Alzheimer's Disease	Immunotherapy
Alector	INVOKE-2	AL002	Early Alzheimer's disease	Inflammation (Immunotherapy)
Medesis	NANOLI-AD	NanoLithium® NPO3	Mild to severe Alzheimer's disease	Neuroprotection (small molecule)
Università degli studi di Genova	FMD AD	ProlonADTM	Mild Cognitive Impairment or mild Alzheimer's disease	Low-calorie and low-protein diet
The Israeli Medical Center for Alzheimer's	NAVE-Sci-001	SCI-110	Alzheimer's disease and agitation	Other Neurotransmitters (Small Molecule)
New Amsterdam Pharma	TA-8995 AD-1	Obicetrapib	Early Alzheimer's disease	Cholesterol ester transfer protein (CETP) inhibitor (small molecule)
reMyND	REMAD-02	REM0046127	Mild to moderate Alzheimer's disease	Synaptic Plasticity/Neuroprotection
Maastricht UMC	ROMEMA	Roflumilast	MCI / Mild dementia	Anti-inflammatory
Transposon Therapeutics	TPN-101	TPN-101	Frontotemporal Dementia	Inflammation (Small molecule)
Vivoryon	VIVIAD	PQ912	Mild cognitive impairment and mild Alzheimer's disease	Amyloid-related & Inflammation (small molecule)

Phase III trials				
Company	Study	Drug candidate	Population	Target
Otsuka	17-AVP-786-305	AVP-786	Dementia of the Alzheimer's type	Small Molecule (Neurotransmitter based)
Otsuka	20-AVP-786-306	AVP-786	Dementia of the Alzheimer's type	Small Molecule (Neurotransmitter based)
Otsuka	20-AVP-786-307	AVP-786	Dementia of the Alzheimer's type	Small Molecule (Neurotransmitter based)
Eisai	AHEAD 3-45	Lecanemab	At risk of developing Alzheimer's disease & Early Alzheimer's disease	Immunotherapy (passive)- amyloid-related
Alzheon	APOLLOE4	ALZ-801	Early Alzheimer's disease	Small molecule- amyloid-related
Centre regional hospitalier de Lille	CAFCA	Caffeine	Alzheimer's disease at beginning to moderate stages	/
Assistance publique – Hôpitaux de Paris	CHOLINE-2	Donepezil	Early onset AD	Small Molecule - Cholinergic System
Novo nordisk	EVOKE & EVOKE PLUS	Semaglutide	Early Alzheimer's disease	(to improve insulin signaling in the brain)
Alector	INFRONT-3	AL001	Frontotemporal dementia	Sortilin (Immunotherapy)
Hôpitaux de Toulouse	LO-MAPT	Dietary Supplement: Omega-3	Subjective memory complaints or family history of Alzheimer's disease	Neuroprotective (dietary supplement)
Imperial College London	NorAD	Guanfacine	Mild to moderate Alzheimer's disease	Neurotransmitter based (noreadraline)

Other corporate activities

Alzheimer Europe was also an active member of the FAST (Finding Alzheimer's Solutions Together) Council set up by Roche which brought together representatives of a number of European and international Alzheimer's associations to discuss topics of common interest, such as the prioritisation of dementia at a global and national level, inclusivity in clinical trials or the communication of safety and efficacy of anti-amyloid treatments. The collaboration resulted in the development of a report "Integrating the perspectives of people living with Alzheimer's disease and their study partners into clinical trial development" which was formally launched during the Alzheimer Europe conference in Bucharest.

Alzheimer Europe also collaborated with Roche on the "What makes you, you?" campaign around World Alzheimer's Day. More details on the campaign are included in chapter 1.4.3.4. above.

Finally, Alzheimer Europe participated in meetings of the Patient think-tank of the European Federation of Pharmaceutical Industries and Associations and of the GSK Health Advisory Board.

Annex 1: Meetings and conferences

Meetings organised by Alzheimer Europe (AE) in the framework of the 2022 Operating Grant

Date	Meeting	Venue
25 January	European Working Group of People with Dementia	Online
1 February	AE Executive	Online
22 February	AE Board	Online
4 April	AE Board	Online
6 April	European Working Group of People with Dementia	Online
26 April	Alzheimer's Association Academy on "Giving a voice to people with dementia in national Alzheimer's associations"	Online
13 - 14 May	European Working Group of People with Dementia	Luxembourg, Luxembourg
17 May	Alzheimer's Association Academy meeting on "Dementia as a disability".	Online
30 May	"International Tea & Blether" meeting hosted by the Scottish Dementia Working Group and European Working Group of People with Dementia	Online
13 June	AE Board	Brussels, Belgium
14 - 15 June	European Working Group of People with Dementia	Brussels, Belgium
5 September	AE Membership Committee	Online
13 September	Alzheimer's Association Academy Intellectual disability, Down Syndrome and Dementia	Online
26 September	AE Board	Brussels, Belgium
27 September	Alzheimer's Association Academy Employment and dementia	Brussels, Belgium
27 - 28 September	European Working Group of People with Dementia	Brussels, Belgium
17 October	AE Annual General Meeting	Bucharest, Romania
10 November	European Working Group of People with Dementia	Online
15 November	Alzheimer's Association Academy meeting on the European Care Strategy	Online
5 December	AE Board	Online
12 December	Alzheimer's Association Academy on "Public involvement in dementia research"	Online
16 December	European Working Group of People with Dementia (Christmas gathering)	Online

Other meetings organised by Alzheimer Europe

Date	Meeting	Venue
22 March	European Parliament workshop "Prioritising dementia in European policies on care, disabilities and equalities"	Online
23 March	Company round table meeting	Online
14 June	European Parliament lunch debate on "Neurological conditions and mental health in EU and WHO Europe programmes"	Brussels, Belgium
14 June	Company round table meeting	Brussels, Belgium
17 June	Meeting of the European Group of Governmental Experts on Dementia	Online
27 September	Company round table meeting	Brussels, Belgium

Date	Meeting	Venue
27 September	European Parliament lunch debate on "The role of artificial intelligence and big data in dementia research"	Brussels, Belgium
17 - 19 October	32 nd Annual Conference "Building bridges"	Bucharest, Romania
6 December	Company round table meeting	Online
13 December	Meeting of the European Group of Governmental Experts on Dementia	Online

Meetings attended by Alzheimer Europe representatives

EU project meetings

Date	Meeting	Venue
13 January	RADAR-AD Steering Committee meeting	Online
19 January	AI-Mind Executive Board meeting	Online
20 January	RADAR-AD qualification advice meeting	Online
24 January	Webinar on obesity & mental health for the PRIME project	Online
24 January	EPAD communications meeting	Online
25 January	PRODEMOS WP leads meeting	Online
27 January	Period 2 review meeting for the VirtualBrainCloud project	Online
27 January	EPND Management Board meeting	Online
27 January	MinD network meeting	Online
28 January	EPND communications meeting with ADDI	Online
1 February	Neuronet Communication Expert meeting	Online
1 February	Gate Ventures meeting to discuss a project proposal	Online
3 February	EPND communications meeting with ADDI	Online
3 - 4 February	General Assembly meeting of the PRIME project	Online
9 February	EPAD communications meeting with ADDI	Online
11 February	Meeting with ADDI for the EPND project	Online
17 February	First periodic review meeting of the LETHE project	Online
22 February	Meeting with Eodyne for the TVB_Cloud project	Online
23 February	LETHE Advisory Board meeting	Online
25 February	Consultation with the EWGPWD for the AI-MIND project	Online
1 March	Neuronet working group meeting on data sharing	Online
1 March	EU-FINGERS Advisory Board meeting	Online
10 - 11 March	RADAR-AD annual meeting	Online
14 March	ADAIr virtual seminar	Online
15 March	PRIME project meeting	Online
22 March	PRODEMOS WP leads meeting	Online
22 March	Neuronet Communication Expert meeting	Online
23 March	EPND sustainability workshop	Online
24 March	Neuronet working group meeting on ethics and patient privacy	Online
29 March	Meeting with Eodyne for the VirtualBrainCloud project	Online
30 March	Neuronet Scientific Coordination Board meeting	Online
31 March	MIRIADE Supervisory Board	Online

Date	Meeting	Venue
1 April	AMYPAD project symposium "Perspectives on biomarker testing for AD in people without dementia"	Online
4 April	EPND project meeting on stakeholder involvement	Online
6 April	EU-FINGERS and LETHE projects' joint educational event	Online
7 April	RADAR-AD Patient Advisory Board meeting	Online
7 April	Meeting with Eodyne for the TVB_Cloud project	Online
12 April	Consultation for the AI-MIND project	Online
15 April	EPND project meeting on cohort onboarding	Online
20 April	Pattern-cog Executive Management Board	Online
20 April	AI-Mind Executive Board Meeting	Online
21 April	PRIME project meeting	Online
22 April	Gates Ventures meeting on data sharing	Online
2 May	RADAR-AD Steering Committee meeting	Online
4 - 5 May	AI-Mind General Assembly Meeting	Rome, Italy
11 May	LETHE Advisory Board meeting	Online
11 May	RECAGE project meeting	Online
13 May	LETHE project meeting	Online
16 May	Human Brain Project training session on brain data governance	Online
16 May	Kick-off meeting of the TIMING project	Copenhagen, Denmark
17 May	DISTINCT Supervisory Board meeting	Online
17 May	Presentation on the advocacy and public involvement activities of Alzheimer Europe, at the DISTINCT Summer School	Online
25 May	Neuronet Regulatory and HTA Working Group meeting	Online
30 May	General Assembly meeting of the ADAIR project	Online
30 May	General Assembly meeting of the VirtualBrainCloud project	Online
7 June	AMYPAD sustainability workshop	London, UK
8 June	Online Pattern-Cog kick-off meeting	Online
9 June	IDEA-FAST project monthly forum	Online
28 June	MinD project network meeting	Online
1 July	Neuronet closing meeting	Barcelona, Spain
11 July	Kick-off meeting for the eBRAIN-Health project	Online
14-15 July	ADIS project kick-off meeting	Sankt Augustin, Germany
25 August	EPND Project Management Team meeting	Online
29 August	Pattern-Cog Executive Management Board meeting	Online
6 - 8 September	General Assembly meeting of the PRIME project	Barcelona, Spain
8 September	Lethe Advisory Board meeting	Online
12 September	RECOGNISED General Assembly meeting	Online
15 - 21 September	Joint Lethe and EU-FINGERS Advisory Boards meeting	Online
19 - 20 September	Annual General Meeting of PRODEMOS	Luxembourg, Luxembourg
22 - 23 September	AMYPAD General Assembly Meeting	Amsterdam, Netherlands
29 September	RADAR-AD Consortium Meeting	Amsterdam, Netherlands
29 September	Sustainability workshop for the EPND project	Monheim am Rhein, Germany
3 - 4 October	3 rd LETHE project consortium meeting	Online

Date	Meeting	Venue
11 October	World Wide Fingers Network Meeting	Online
27 October	General Assembly meeting of the eBRAIN-Health project	Online
28 October	PRIME project webinar on the long QT syndrome	Online
7 - 10 November	EU-FINGERS Advisory Board meetings	Online
9 November	EPND project meeting	Online
17 November	Fall meeting of the ABOARD project	Online
17 - 18 November	AI-MIND General Assembly Meeting	Madrid, Spain
21 - 22 November	EU-FINGERS General Assembly Meeting	Stockholm, Sweden
29 November	Online consultation with the EWGPWD for the EPND project	Online
8 - 9 December	EPND project consortium meeting	Amsterdam, Netherlands and online
21 December	Joint LETHE and EU-FINGERS Christmas Advisory Boards online gathering	Online

Other meetings

Date	Meeting	Venue
12 January	EMA raw data advisory group	Online
17 January	INTERDEM task force meeting on prevention	Online
17 January	Meeting with the European Association for Service Providers for People with Disabilities	Online
19 January	Biogen Patient Advisory Group meeting	Online
20 January	Meeting of the EU4Health Civil Society Alliance	Online
20 January	Information meeting of DG SANTE on operating grants under the health programme	Online
21 January	Meeting with the European Public Health Alliance	Online
24 January	Financial Times webinar on supporting Pharma Innovation in Europe, jointly organised with EFPIA	Online
25 January	European network of Social Authorities webinar on "Quality of life: post Covid challenges and opportunities for seniors, professionals and persons with disabilities"	Online
26 January	INTERDEM task force on technology and Covid	Online
26 January	Launch of the Innovative Health Initiative	Online
26 January	Meeting with Biogen and Roche	Online
26 January	Innovative Health Initiative & Neuronet project meeting	Online
27 January	Brain Health meeting "How European research can join forces"	Online
27 January	European Association of Service providers for Persons with Disabilities knowledge café	Online
27 January	Demo at the European Convention Center Luxembourg	Online
27 January	Management Board of the Dementia Panel of the European Academy of Neurology	Online
27 January	Brain Health meeting "How European research can join forces"	Online
28 January	Meeting with Lufthansa Group	Online
28 January	Meetings with suppliers for the 32 nd Alzheimer Europe Conference	Online
2 February	Task force on dementia friendly design	Online
3 February	EU Commission webinar on its NCD initiative "Healthier Together"	Online
4 February	Meeting with Lilly	Online
8 February	Meeting with the EFPIA AD team	Online
8 February	Meeting with Nutricia	Online

Date	Meeting	Venue
9 February	Meeting with the European Federation of Neurological Associations	Online
10 February	European Disability Forum's European Non-Governmental Organisations meeting	Online
10 February	Meeting with Orion Pharma	Online
15-16 February	WHO-Europe regional technical consultation on the implementation of the European Framework for Action on Mental Health 2021-2025	Online
16 February	Convention Center Dublin, Ireland visit	Dublin, Ireland
17 February	Meeting with Biogen	Online
21 February	PatientView webinar "Timely diagnosis of Alzheimer's disease: the common challenges in primary care"	Online
21 February	STUDICODE meeting	Online
23 February	DataSavesLives core group meeting	Online
23 February	Meeting with Roche	Online
24 February	Meeting with EFPIA	Online
24 February	ImmiDem webinar and debriefing meeting	Online
25 February	Biogen Advisory Meeting	Online
25 February	WHO Europe's NSA engagement sessions on the role of communities in the COVID-19 response	Online
28 February	PAVE (Project Alzheimer's Value Europe) meeting	Online
2 March	Call with the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe	Online
2 - 3 March	Joint meeting of the EMA Patient's Consumer's Working Party (PCWP) Healthcare Professional's WP (HCPWP)	Online
8, 15, 25 and 30 March	Meeting with the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe on patient involvement in brain research	Online
9 March	EFPIA Patient Think Tank on the Innovative Health Initiative	Online
10 March	DataSavesLives webinar	Online
14 March	Meeting with Roche and the EFPIA Alzheimer's Platform	Online
14 - 15 March	BIAForum	Brussels, Belgium
15 March	Launch of the WHO framework on long-term care	Online
16 - 18 March	AD/PD Conference	Barcelona, Spain
17 March	Meeting with representatives from Biogen, Lilly, Novo Nordisk, Prothena and Roche	Barcelona, Spain
18 March	EMA Raw Data Advisory Group meeting	Online
18 March	Symposium "Where does our hope come from in Alzheimer's disease" at the AD/PD Conference	Barcelona, Spain
21 March	Meeting with Paola Barbarino and Chris Smith from Alzheimer's Disease International	Online
24 - 25 March	World Artificial Intelligence Network (JAIN) Challenge competition for prototypes and products	Online
28 March	Online information session for networks supported by the CERV programme	Online
28 March	Astellas symposium on multimorbidities	Online
30 March	INTERDEM Task Force meeting about the use of technology during COVID	Online
30 March	Briefing session on Development and implementation of dementia plans and strategies	Online
4 April	WHO Europe briefing for Non-State Actors, on activities in Ukraine	Online
6 April	Meeting of the European Commission's High Level Group on the future of social protection	Online
7 April	European Parliament meeting on Communications Aspects for Civil Society Organisations	Online

Date	Meeting	Venue
8 April	Meeting with Essity to discuss ongoing work on continence care	Online
12 April	Discussion on Request for Proposal Process organised by Conferli	Online
14 April	European Disability Forum webinar on the war in Ukraine and the coordination of needs for people with disabilities	Online
19 April	Meeting with representatives of the Davos Alzheimer's Collaborative	Online
19 April	On 19 April, Jean and Owen attended a mMbrain health Call to Action	Online
22 - 23 April	Web Video Hackathon	Online
23 April	Annual General Meeting of the European Patients' Forum	Online
25 April	Round table discussion on sustainable destinations and events organised by Business Events Luxembourg	Online
26 April	Webinar on how to disseminate successfully EU-funded project results - Expert Insights organised by EMDESK in cooperation with Europa Media Trainings	Online
26 April	MIND network meeting	Online
26 April	Future of Science Communication Conference 2.0	Brussels, Belgium
27 April	Communications Strategy meeting for Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients	Online
28 April	Joint Programme - Neurodegenerative Disease Research / JPCo-fund2 Midterm Symposium for Supported Projects	Brussels, Belgium
28 - 29 April	Meeting of the European Alzheimer's Disease Consortium	Online
29 April	Interviews with clinicians for the AI-MIND project	Online
29 April	Meeting of the European Medicines' Agency's Advisory Group on Raw Data	Online
3 May	OECD/EBrains meeting "Towards the new European Brain Initiative Delivering on the promise of actionable brain health data"	Online
3 May	Management group meeting of the dementia panel of the European Academy of Neurology	Online
4 - 5 May	Meeting of the WHO Pan-European Mental Health Coalition and contributed to the work package discussion on mental health of older adults	Online
9 -12 May	AG Leventis Foundation conference on prevention on Alzheimer's disease & cognitive decline with diet lifestyle starting	Nicosia, Cyprus
9 - 10 May	Finding Alzheimer's Solution Together (FAST) Council meeting	Online
12 May	Symposium "Patient involvement in brain health: safeguarding the future of brain health for patients" together with the European Federation of Neurological Associations (EFNA) and GAMIAN Europe	Online
12 May	Advisory board meeting organised by TauRx	Online
12 May	DARE (Disability Advocacy Research in Europe) meeting	Online
13 May	Meeting with LuMind IDSC Foundation to discuss collaboration on dementia and intellectual disabilities	Online
16 May	European Commission civil society dialogue on access to essential services	Online
17 May	Suisse Convention Bureau	Luxembourg, Luxembourg
17 May	Webinar on healthcare systems preparedness, by the Davos Alzheimer's Collaborative	Online
18 May	Ethics Committee of the Luxembourg Alzheimer's Association meeting	Online
18 - 19 May	WHO Informal Consultation with People Living with Noncommunicable Diseases and Mental Health Conditions in the European Region	Online
19 May	DG MOVE online "Consequences of road traffic offenses and medical fitness" consultation on the revision of EU Directive on driving licences	Online
20 May	Meeting et with representatives of the Marriott Hotel to discuss the preparations of the 32 nd Alzheimer Europe Conference	Bucharest, Romania

Date	Meeting	Venue
20 May	Webinar about the Patient's Perspective, organised by the European Centre for Clinical Research Training	Online
25 May	World Health Assembly side event launching Alzheimer Disease International's Plan to Impact report	Online
31 May	European Academy of Neurology (EAN) Brain Health Summit	Online
1 June	Policy squad of the Finding Alzheimer's Solution Together (FAST) Council	Online
1 June	Online meeting of the EU4Health Civil Society Alliance	Online
1 - 2 June	EMA Patient's and Consumer's Working Party meeting	Online
3 June	DG SANTE meeting on the Healthier Together NCD initiative	Online
8 June	Council Meeting of Alzheimer's Disease International	London, UK
9 June	Meeting of European Disability Forum's European Non-Governmental Organisations group	Online
9 June	Meeting with representatives of the Women's Brain Project	London, UK
9 - 10 June	Annual Conference of Alzheimer's Disease International presentation on Alzheimer Europe's "Public involvement activities in dementia research"	London, UK
9 - 10 June	Meeting with representatives of Lilly, Prothena and TauRx	London, UK
10 June	Webinar on the rules and procedures of the Innovative Health Initiative	Online
14 June	HI networking and brokerage event	Brussels, Belgium
15 June	ADDI and Scotland meeting	Online
17 June	Launch of the WHO's World Mental Health Report	Online
22 June	Launch of the DG SANTE's Healthier Together NCD initiative	Online
23 June	Webinar on the IHI neurodegenerative diseases call topic	Online
23 - 25 June	ICCA Destination Marketing European Business Workshop	Bordeaux, France
24 June	DataSavesLives session at the European Patients' Forum Congress	Brussels, Belgium
25 June	Dementia and Cognitive Disorders Panel of the European Academy of Neurology	Vienna, Austria
25-26 June	25 th European Disability Forum (EDF) General Assembly	Athens, Greece
26 - 28 June	Congress of the European Academy of Neurology	Vienna, Austria
27 June	Interdem taskforce meeting on the use of technology by people with dementia during the pandemic	Online
27 June	Meeting of the European Medicines Agency Advisory Group on Raw Data	Online
28 June	Meeting of the Dementia Toolkit Initiative	Online
28 June	Meeting of the MEP Interest Group on Accessible Healthcare, focused on the forthcoming Pharmaceutical Strategy	Online
5 July	BBMRI-ERIC Stakeholder Forum	Online
8 July	Online stakeholder event hosted by the European Commission on the EU4Health programme	Online
11 July	Health Advisory Board of GSK	Online
14 July	Meeting with a representative of the US National Task Group on ID & Dementia Practices	Online
15 July	Joint meeting of the EMA Patient's Consumer's Working Party (PCWP) and FDA Patient Engagement Collaborative	Online
2 August	Online meeting with Flavia Topan from the European Patients' Forum	Online
8 August	Introductory call with UCB	Online
9 August	Meeting with Clarinex	Online
11 August	Online meeting with Roche	Online
14 August	Online launch of the WHO's position paper on brain health	Online

Date	Meeting	Venue
18 August	Meeting with EFPIA to discuss the EU pharmaceutical strategy	Online
23 - 25 August	9 th Kuopio Alzheimer Symposium and 3 rd Nordic Memory Clinic Conference	Kuopio, Finland
24 August	Exchange with Korian Foundation	Online
28 August	Meeting with Slovak member organisation about the Alzheimer Europe Conference	Online
31 August	Meeting of the EMA Advisory Group on Raw Data	Online
5 - 6 September	Site inspection for the 32 Alzheimer Europe Conference	Online
6 September	Meeting of AIM on the subject of the European Care Strategy	Online
7 September	Multistakeholder Forum organised by Lilly	Munich, Germany
9 September	Meeting with the EFPIA AD Platform	Online
11 September	Meeting with a delegation of the European Federation of Neurological Associations	Luxembourg, Luxembourg
14 September	Information meeting with TauRx	Online
14 September	Meeting with Producer Estephania Bonnett Alonso from film production company Playlab Films	Online
15 September	Meeting with a representative of AC Immune	Online
15 September	Meeting of the Alzheimer Europe Anti-Stigma Award Committee	Online
21 September	Ethics Committee of the Luxembourg Alzheimer's Association	Online
21 - 22 September	EMA multi-stakeholder workshop and meetings of the Patients' and Consumers' Working Party	Amsterdam, Netherlands
28 September	Llaunch of the European Commission's Together for Rights campaign	Online
29 September	European Commission stakeholder meeting on Cross Border Protection of Vulnerable Adults	Online
30 September	Interdem taskforce on primary prevention Webinar	Online
30 September	Meeting with the European Disability Forum	Online
3 - 5 October	2022 Patient Engagement Open Forum	Barcelona, Spain
4 October	Launch of the World Health Organization (WHO)'s blueprint for dementia research	Online
6 October	European NGOs' meeting organised by the European Disability Forum	Online
10 October	Training on financial sustainability of the European Disability Forum	Online
10 October	Meeting with the Executive Director of the European Federation of Neurological Associations (EFNA)	Online
10 - 11 October	DataSavesLives Bootcamp	Prague, Czech Republic
11 October	Meeting of the About Me Global Steering Committee	Online
12 October	"Defeating Alzheimer Conference" of the Dutch Ministry of Health	Online
13 October	Belgian "Ligue Nationale Alzheimer Liga" (LINAL) paid a visit to the Alzheimer Europe offices	Luxembourg, Luxembourg
13 October	Digital Health Society roundtable on a social compact for data sharing	Online
17 October	INTERDEM's Annual Meeting	Bucharest, Romania
20 October	Meeting of the EU4Health Civil Society Alliance	Online
24 - 25 October	FAST Council (Finding Alzheimer's Solutions Together) meeting	Online
28 October	Meeting with a representative of the Translational Biomarker Group at the Luxembourg Institute of Health	Strassen, Luxembourg
2 November	Meeting with a representative of the Luxembourg Institute of Health	Online
6 - 9 November	61 st ICCA congress	Krakow, Poland
7 November	Meeting with a representative of Essity	Online
8 November	Training of the European Disability Forum on public funding	Online
8 November	Meeting with representatives of the European Alzheimer's Disease Consortium	Online

Date	Meeting	Venue
8 November	Preparatory meeting for the EMA Big Data Steering Group Big Data Forum	Online
10 November	Meeting with representatives of Amoneta, Biogen and Novo Nordisk	Online
11 November	Meeting between members of the EU4Health Civil Society Alliance and DG SANTE representatives on the future of operating grants	Online
15 November	Annual European Medicines Agency (EMA) Patients' and Consumers' Working Party meeting for all eligible member organisations	Online
16 November	14 th International Dementia Conference	Dublin, Ireland
17 November	Food and Drug Administration (FDA) webinar on amyloid-PET brain imaging for Alzheimer's Disease	Online
18 November	Age Platform Europe Annual Conference	Online
22 November	Meeting of the DataSavesLives Core Group	Online
22 - 23 November	European Commission's conference on "Health Security in the EU"	Online
23 - 24 November	Conference of the pan-European Mental Health Coalition of the World Health Organization – European Region	Online
24 - 25 November	European Day of Persons with Disabilities conference 2022, organised by the European Commission and the European Disability Forum	Brussels, Belgium
29 November to 2 December	Clinical Trials in Alzheimer's Disease (CTAD) Conference	San Francisco, USA
29 November to 2 December	Meetings with Alzheon, Alzheimer's Research UK, Prothena, Roche and TauRx	San Francisco, USA
1 December	European Medicines Agency (EMA) /HMA Big Data Stakeholder Forum	Online
2 December	Public and Patient Involvement in Dementia Research: a European and Irish perspective seminar	Online
5 December	INTERDEM Academy Café - Exploring best practices to support early career dementia researchers	Online
6 December	Workshop on the UNCRPD organised by the European Disability Forum	Online
8 December	Patient Think Tank organised by EFPIA	Online
12 December	Meeting with Grifols	Online
12 December	EFPIA breakout session Patient engagement: establishing patient relevance and the importance of the patient voice	Online
13 December	Webinar on healthcare systems preparedness organised by the Davos Alzheimer's Collaborative	Online
14 December	Meeting with Icometrix	Online
14 December	Meeting with PRInnovation	Online
15 December	Meeting of PAVE (Project Alzheimer's Value in Europe)	Online
15 December	Seminar of the Communauté mixte de recherche DIMA (on dementia and Down's Syndrome)	Online
16 December	Extraordinary meeting of the EMA Patient's Consumer's Working Party (PCWP) Healthcare Professional's WP (HCPWP)	Online

Annex 2: Scientific publications in 2022

In 2022, Alzheimer Europe staff contributed to the following scientific publications:

Alzheimer Europe (2022). *Dementia in Europe Yearbook 2021: Dementia-inclusive Communities and initiatives across Europe*. ISBN 978-2-919811-02-1, Luxembourg, Alzheimer Europe

Alzheimer Europe (2022). *Dementia in Europe Yearbook 2022: Employment and related social protection for people with dementia and their carers*. ISBN 978-2-919811-05-2, Luxembourg, Alzheimer Europe

Bunnik EM, Smedinga M, Milne R, **Georges J**, Richard E, Schermer MHN. (2022). Ethical Frameworks for Disclosure of Alzheimer Disease Biomarkers to Research Participants: Conflicting Norms and a Nuanced Policy. *Ethics & Human Research*. 44(6):2-13. DOI: 10.1002/eahr.500146

Colij L, Farrar G, Vallez Garcia D, Bader I, Shekari M (.../...) **Birck C, Georges J** et al. (2022). The Amyloid Imaging for the Prevention of Alzheimer's Disease Consortium: A European collaboration with global impact. *Frontiers in Neurology*. DOI: 10.3389/fneur.2022.1063598

Festari C, Massa F, Cotta Ramusino M, Gandolfo F, Nicolosi V (.../...) **Georges J** et al. (2022). European consensus for the diagnosis of MCI and mild dementia: Preparatory phase. *Alzheimer's & Dementia*. DOI: 10.1002/alz.12798

Georges J, Diaz-Ponce A, Lamirel D, Moradi-Bachiller S and Gove D (2022). Keeping track of and recognizing the value of Public Involvement work in dementia research. *Frontiers in Neurology*. 11;13:1031831 DOI: 10.3389/fneur.2022.1031831

Gustavsson A, Norton N, Fast T, Frölich L, **Georges J** et al. (2022). Global estimates on the number of persons across the Alzheimer's disease continuum. *Alzheimer's & Dementia*. DOI: 10.1002/alz.12694

Jessen F, **Georges J**, Wortmann M, Benham-Hermetz S. (2022). What Matters to Patients with Alzheimer's Disease and Their Care Partners? Implications for Understanding the Value of Future Interventions. *The Journal Of Prevention of Alzheimer's Disease*. 9(3): 550-555. DOI: 10.14283/jpad.2022.22

O'Rourke D, Coll-Adrós N, Bradshaw A, Killin L, Pradier L, **Georges J** et al. (2022). The Innovative Medicines Initiative neurodegeneration portfolio: From individual projects to collaborative networks. *Frontiers in Neurology*. 2;13:994301. DOI: 10.3389/fneur.2022.994301

Saunders S, Gregory S, Clement MHS, **Birck C**, Geyten S van der, Ritchie CW. (2022). The European Prevention of Alzheimer's Dementia Programme: An Innovative Medicines Initiative-funded partnership to facilitate secondary prevention of Alzheimer's disease dementia. *Frontiers in Neurology*. 13:1051543 DOI: 10.3389/fneur.2022.1051543

van Corven CTM, Bielderma A, **Diaz Ponce A, Gove D, Georges J**, Graff MJL et al. (2022). Empowering interventions for people living with dementia: A European survey. *Journal of Advanced Nursing*. 78(12):4104-12. DOI: 10.1111/jan.15385

van Gils AM, Visser LNC, Hendriksen HMA, **Georges J** et al. (2022). Development and design of a diagnostic report to support communication in dementia: Co-creation with patients and care partners. *Alzheimer's & Dementia: Diagnosis Assessment & Disease Monitoring*. 14(1). DOI: 10.1002/dad2.12333

Preface to the financial accounts



Marco Blom

After two years impacted by the COVID-19 pandemic, I am happy to report that, for my third year as Honorary Treasurer of Alzheimer Europe, our income and expenditure levels have returned to pre-pandemic levels. As can be seen from the below graph, our income had fallen by over half a million in 2020 and 2021, but thankfully, we had been able to reduce our expenditure by similar margins, as we had to cut down on in-person meetings and travel. On the positive front, we were able to conclude both years with small operating surpluses despite the negative impact of the pandemic.

Evolution of income and expenditure

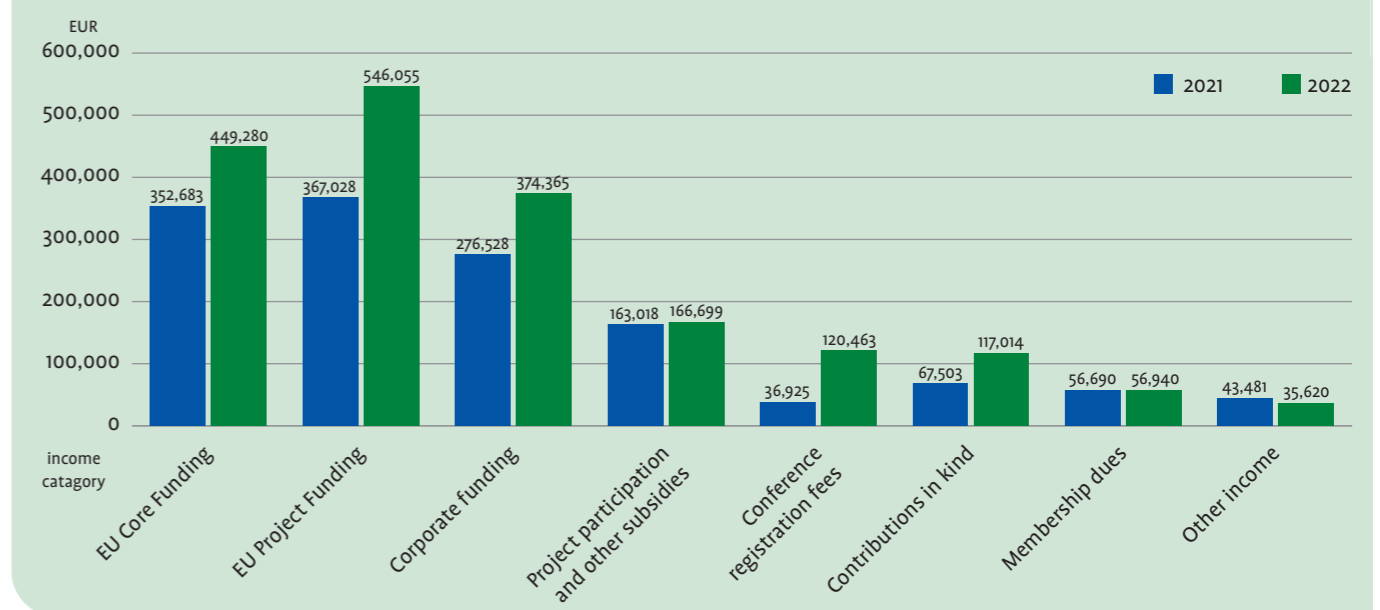


After a cautious two years, we were able to expand our activities again in 2022, thanks to a number of positive developments:

- After having received operating grants from the European health programme for the preceding ten years, Alzheimer Europe was able to sign a new framework agreement with the European Commission for its core funding as an organisation representing the interests of people with disabilities, under the Citizens, Equality, Rights and Values (CERV) programme.
- Alzheimer Europe was able to further expand its funding from European projects funded by EU programmes (Horizon Europe or Innovative Medicines Initiatives) and the Luxembourg National Research Fund (Joint Programme for Neurodegenerative Disease Research (JPND) or ERA PerMed).
- After two years of virtual conferences, Alzheimer Europe resumed the organisation of in-person Annual Conferences and was delighted to welcome 543 participants at its 32nd Conference in Bucharest, Romania.

As can be seen from the below graph, almost all income categories exceeded the 2021 levels by a healthy margin:

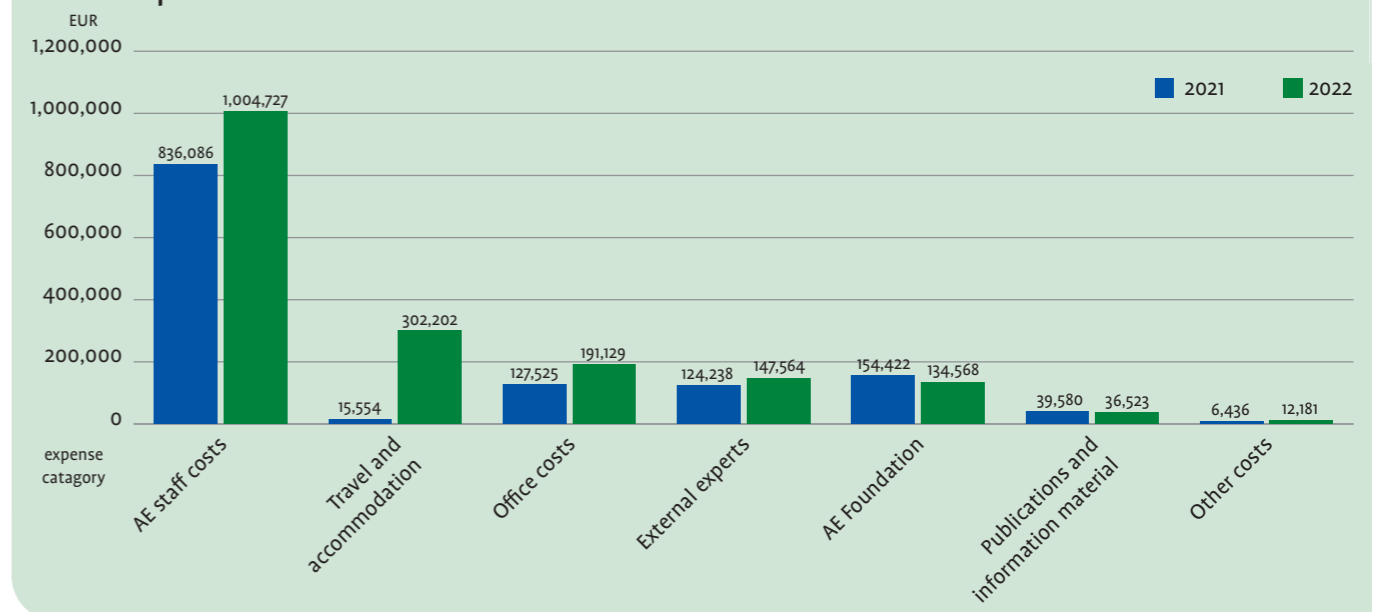
Total income in 2021 and 2022



Due to these positive developments, it was possible for Alzheimer Europe to expand the staff team involved in EU projects and in 2022, we welcomed three new colleagues: Daphné Lamirel, Soraya Moradi-Bachiller and Cristina Pencea. At the same time, from the second quarter of 2022 onwards, Alzheimer Europe restarted its in-person meetings, including the Annual Conference in Bucharest. 2022 also saw a return of printed and mailed publications, rather than the online-only publications of the preceding two years.

The evolution of expenditure between 2022 and 2023 can be seen in the below graph:

Total expenditure in 2021 and 2022



Like the previous years, the Alzheimer Europe Board monitored the income and expenditure of the association very closely throughout the year and I am truly delighted to report that we were again able to provide a grant of EUR 135K to the Alzheimer Europe Foundation, as well as close the year yet again with a small operating surplus (EUR 37,542).

Thanks to these positive results, the reserves of Alzheimer Europe and those of our Foundation have increased from EUR 533K to 570K and from EUR 609K to 708K respectively. These combined reserves now represent close to a year of annual running costs, a comfortable position to find ourselves in, should we confront any financial difficulties in the future.

In her preface, Maria do Rosário Zincke dos Reis, our newly-elected Chairperson highlighted the teamwork necessary for the many positive outcomes, results and achievements on the front of our activities. Our positive financial results and optimistic outlook are similarly a result of the support provided by the many programmes, organisations, foundations and companies which supported Alzheimer Europe in 2022. All our partners and sponsors are duly acknowledged later in this report,

but, as in previous years, I wish to single out the very generous and unrestricted grant of EUR 88K provided by Fondation Alzheimer of Luxembourg and the invaluable support we received from the European disability programme for our core activities.

Let me end this short preface by thanking Stefanie Peulen and Jean Georges, our Finance Officer and Executive Director, who updated my Board colleagues and me on a regular basis about the financial situation of Alzheimer Europe and who ensured that we were able to end the year with a surplus. It is reassuring to see that Alzheimer Europe was able to return to its pre-pandemic levels of income and I hope that we will be able to further grow both our activities and our funding in the coming years.

Marco Blom
Honorary Treasurer

Financial Report

Report of the Réviseur d'entreprises agréé



ALZHEIMER EUROPE
Association sans but lucratif

R.C.S. Luxembourg F 2773

14, rue Dicks
L-1417 LUXEMBOURG

Report of the Réviseur d'entreprises agréé
and
annual accounts as at December 31, 2022



To the Board of Directors of
ALZHEIMER EUROPE
 14, rue Dicks
 L-1417 LUXEMBOURG

REPORT OF THE REVISEUR D'ENTREPRISES AGREE

Opinion

We have audited the annual accounts of ALZHEIMER EUROPE (the « Association »), which comprise the balance sheet as at December 31, 2022, and profit and loss account for the year then ended, and notes to the annual accounts, including a summary of significant accounting policies.

In our opinion, the accompanying annual accounts give a true and fair view of the financial position of the Association as at December 31, 2022, and of the results of its operations for the year then ended in accordance with Luxembourg legal and regulatory requirements relating to the preparation and presentation of the annual accounts.

Basis for opinion

We conducted our audit in accordance with the Law of the 23 July 2016 on the audit profession (Law of 23 July 2016) and with International Standards on Auditing (ISAs) as adopted for Luxembourg by the "Commission de Surveillance du Secteur Financier" (CSSF). Our responsibilities under the Law of 23 July 2016 and ISAs as adopted for Luxembourg by the CSSF are further described in the « Responsibilities of "réviseur d'entreprises agréé" for the Audit of the Annual Accounts» section of our report. We are also independent of the Association in accordance with the International Code Ethics for Professional Accountants, including International Independence Standards, issued by the International Ethics Standards Board for Accountants (IESBA Code) as adopted for Luxembourg by the CSSF together with the ethical requirements that are relevant to our audit of the annual accounts, and have fulfilled our other ethical responsibilities under those ethical requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.



Responsibilities of the Board of Directors of Those Charged with Governance for the annual accounts

The Board of Directors is responsible for the preparation and fair presentation of these annual accounts in accordance with Luxembourg legal and regulatory requirements relating to the preparation and presentation of the annual accounts, and for such internal control as the Board of Directors determines is necessary to enable the preparation of annual accounts that are free from material misstatement, whether due to fraud or error.

In preparing the annual accounts, the Board of Directors is responsible for assessing the Association's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Board of Directors either intends to liquidate the Association or to cease operations, or has no realistic alternative but to do so.

Responsibilities of the « Réviseur d'Entreprises Agréé » for the Audit of the annual accounts

Our objectives are to obtain reasonable assurance about whether the annual accounts as a whole are free from material misstatement, whether due to fraud or error, and to issue a report of "réviseur d'entreprises agréé" that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Law dated 23 July 2016 and with ISAs as adopted for Luxembourg by the CSSF will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these annual accounts.

As part of an audit in accordance with the Law dated 23 July 2016, and with ISAs as adopted for Luxembourg by the CSSF, we exercise professional judgement and maintain professional skepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the annual accounts whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Association's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Board of Directors.



- Conclude on the appropriateness of Board of Directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Association's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our report of "réviseur d'entreprises agréé" to the related disclosures in the annual accounts or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our report of "réviseur d'entreprises agréé". However, future events or conditions may cause the Association to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the annual accounts, including the disclosures, and whether the annual accounts represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Luxembourg, February 20th 2023

FOR AUDITEURS ASSOCIÉS, Cabinet de révision agréé
30, boulevard Joseph II
L-1840 Luxembourg

Philippe SLENDZAK
Partner

Appendix:

- Annual accounts as at December 31st, 2022

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Balance sheet as of December 31, 2022

	Notes	2022 (Euro)	2021 (Euro)
ASSETS			
C. Fixed assets	3.1	44,613.17	52,108.08
I. Intangible fixed assets	4	23,849.99	39,749.99
II. Tangible fixed assets	5	20,763.18	12,358.09
D. Current assets		1,720,097.75	1,227,376.70
II. Debtors	3.2, 6	410,886.31	258,707.17
a) becoming due and payable within one year		410,886.31	258,707.17
IV. Cash at bank and in hand		1,309,211.44	968,669.53
E. Prepayments and accruals	3.3, 7	39,694.63	94,925.83
		1,804,405.55	1,374,410.61
LIABILITIES			
A. Capital and reserves		570,052.59	532,510.82
V. Profit or loss brought forward		532,510.82	472,495.64
VI. Profit or loss for the financial year		37,541.77	60,015.18
B. Provisions	3.4, 8	45,009.00	34,953.84
C. Creditors	3.5, 9	1,023,363.96	608,018.56
a) becoming due and payable within one year		1,023,363.96	608,018.56
D. Deferred income	3.6, 10	165,980.00	198,927.39
		1,804,405.55	1,374,410.61

The accompanying notes are an integral part of these annual accounts.

ALZHEIMER EUROPE
Association sans but lucratif
RCS Luxembourg F2773

Profit and loss account
Year ended December 31, 2022

	Notes	2022 (Euro)	2021 (Euro)
4. Other operating income	3.7, 11	1,866,107.20	1,363,855.81
5. Raw materials and consumables and other external expenses	12	-654,027.62	-291,681.55
b) Other external expenses		-654,027.62	-291,681.55
6. Staff costs	13, 14	-1,004,727.26	-836,085.71
a) Wages and salaries		-888,505.36	-735,585.66
b) Social security costs			
i) relating to pensions		-71,862.22	-60,483.62
ii) other social security costs		-44,359.68	-40,016.43
7. Value adjustments		-28,770.85	-16,747.57
a) in respect of formation expenses and of tangible and intangible fixed assets		-28,770.85	-16,747.57
8. Other operating expenses	15	-141,068.79	-158,693.85
11. Other interest receivable and similar income			
b) other interest and similar income		328.19	0.00
14. Interest payable and similar expenses			
b) other interest and similar expenses		-299.10	-631.95
		37,541.77	60,015.18

The accompanying notes are an integral part of these annual accounts.

ALZHEIMER EUROPE
Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2022

NOTE 1. GENERAL

Alzheimer Europe ("the association") was established on 2 March 1992 and is organised under the laws of Luxembourg as a non profit association subject to the law of 21 April 1928, amended by the law of 4 March 1994 for an unlimited period. It is registered with Trade and Company Register of Luxembourg with the number F2773.

The registered office is established in the municipality of Luxembourg, Luxembourg. The financial year runs from 1 January to 31 December of each year.

Alzheimer Europe is a voluntary organisation whose purpose is to enhance the dignity, respect and self-determination of the person with dementia and his/her family and other supporters throughout the course of the disease and to improve the quality of life, the care and treatment of people with dementia, their families and their carers through collaboration amongst its members.

The membership of Alzheimer Europe consists of national organisations of and for people with dementia, their families and their carers. The association shall be non-political and without religious or philosophical affiliation.

NOTE 2. BASIS OF PREPARATION

The annual accounts have been prepared in accordance with generally accepted accounting principles and with the laws and regulations in force in the Grand-Duchy of Luxembourg.

The association has voluntarily adopted the accounting policies of the amended law of 19 December 2002.

NOTE 3. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

3.0. Comparability of financial years

Certain items in the annual accounts as at 31 December 2022 have been reclassified. For comparability purposes, the financial statements for the year 2021 have been reclassified in the same way. These restatements had no impact on the result for the year.

3.1. Fixed assets

Fixed assets are valued at purchase price including the expenses incidental thereto. They are depreciated using the straight line method over their estimated useful lives:

Software and similar rights:	3 years
Furniture:	5 years
Computer equipment:	3 years
Other fixtures:	5 years

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2022**3.2. Debtors**

Debtors are recorded at nominal value. They will be subject to value adjustments when the estimated realisable value is lower than the nominal value. These value adjustments are reversed if the reasons for which the value adjustments were made have ceased to apply.

3.3. Prepayments and accruals

Prepayments represent expenditure incurred during the financial year or earlier but relating to a subsequent financial year. Accruals will be made for income that has been earned, but not yet received or invoiced.

3.4. Provisions

Provisions will be set up if losses or debts are likely or certain to be occurred, but uncertain as to their amount or the date on which they will arise.

3.5. Creditors

Creditors are recorded at their reimbursement value.

3.6. Deferred income

Deferred income represents amounts received or invoiced during the financial year or earlier, that will be booked to income in a subsequent financial year. The underlying transactions may have already been recognised in the profit and loss account with the unused portion being transferred to a future period (deferred funding), or may fully relate to a subsequent period when they will be booked to income (funding received on account).

3.7. Co-financing in kind

Goods or services obtained at reduced rates or for free are recorded at the fair market value of the item received. Expertise from member organisations is valued at a standard daily rate. In-kind contributions are booked in a separate revenue account. The expense side of the transaction is recorded in its functional expense account.

3.8. Foreign currency translation

The association maintains its books, records and bank accounts in EUR. Transactions expressed in currencies other than EUR are translated at the exchange rate applied by the bank at the time of the payment. If this rate is not known at the time the accounts are established, the monetary assets and liabilities in foreign currency and the underlying revenues and expenses are valued at the exchange rate prevailing at the Balance Sheet date, and exchange gains or losses will be recorded in the Profit and Loss account at the moment of their realisation.

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2022**NOTE 4. INTANGIBLE FIXED ASSETS**

The movements for the year are as follows:

	Software and similar rights (EUR)	Total (EUR)
Gross book value – opening balance	51,302.12	51,302.12
Additions for the year	0.00	0.00
Gross book value – closing balance	51,302.12	51,302.12
Accumulated value adjustments – opening balance	11,552.13	11,552.13
Allocations for the year	15,900.00	15,900.00
Accumulated value adjustments – closing balance	27,452.13	27,452.13
Net book value – closing balance	23,849.99	23,849.99
Net book value – opening balance	39,749.99	39,749.99

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2022**NOTE 5. TANGIBLE FIXED ASSETS**

The movements for the year are as follows:

	Furniture (EUR)	Computer equipment (EUR)	Other fixtures (EUR)	Total (EUR)
Gross book value – opening balance	24,588.40	50,094.90	20,110.02	94,793.32
Additions for the year	11,517.48	7,933.49	1,824.97	21,275.94
Gross book value – closing balance	36,105.88	58,028.39	21,934.99	116,069.26
Accumulated value adjustments – opening balance	21,899.66	40,425.55	20,110.02	82,435.23
Allocations for the year	3,252.16	9,253.70	364.99	12,870.85
Accumulated value adjustments – closing balance	25,151.82	49,679.25	20,475.01	95,306.08
Net book value – closing balance	10,954.06	8,349.14	1,459.98	20,763.18
Net book value – opening balance	2,688.74	9,669.35	0.00	12,358.09

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2022**NOTE 6. DEBTORS**

Debtors consist of:

	2022 (Euro)	2021 (Euro)
Accruals for EU and other public funding	296,056.82	123,654.57
Other receivables	<u>114,829.49</u>	<u>135,052.60</u>
	410,886.31	258,707.17

NOTE 7. PREPAYMENTS AND ACCRUALS

Prepayments and accruals can be broken down as follows:

	2022 (Euro)	2021 (Euro)
Prepayments	11,818.07	86,537.58
Other accruals	<u>27,876.56</u>	<u>8,388.25</u>
	39,694.63	94,925.83

NOTE 8. PROVISIONS

Provisions are composed of:

	2022 (Euro)	2021 (Euro)
Provision for untaken holidays	31,719.74	24,814.60
Audit provision	9,149.50	8,775.00
Other debts	<u>4,139.76</u>	<u>1,364.24</u>
	45,009.00	34,953.84

NOTE 9. CREDITORS

The amounts due and payable for creditors are as follows:

	2022 (Euro)	2021 (Euro)
EU and other public funding received on account	823,406.97	361,421.79
Trade creditors	150,948.42	205,687.780
Social security debts	25,445.70	21,929.86
Tax debts	22,616.31	18,979.13
Other creditors	<u>946.56</u>	<u>0.00</u>
	1,023,363.96	608,018.568

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2022**NOTE 10. DEFERRED INCOME**

Deferred income consists of:

	2022 (Euro)	2021 (Euro)
Corporate funding received on account	141,500.00	165,000.00
Project participation and other funding received on account	7,000.00	4,794.06
Deferred funding	<u>17,480.00</u>	<u>29,133.33</u>
	165,980.00	198,927.39

NOTE 11. OTHER OPERATING INCOME

Other operating income is composed of:

	2022 (Euro)	2021 (Euro)
EU and other public funding	995,334.50	719,711.00
Corporate funding (*)	374,365.49	276,527.92
Project participation and other subsidies	173,698.55	163,017.51
AE Conference registration fees	120,462.50	36,925.00
Co-financing in kind	117,013.69	67,503.03
Membership fees and contributions	56,940.00	56,690.00
Donations	19,194.91	5,359.01
Deferred income	11,653.33	38,107.34
Other operating income	4,444.23	15.00
Project participation received on account	<u>-7,000.00</u>	<u>0.00</u>
	1,866,107.20	1,363,855.81

(*) Corporate funding is accepted by Alzheimer Europe in line with its internal rules and regulations to ensure the independence of the association. All funders and amounts are acknowledged in full transparency on the Alzheimer Europe website and in the annual reports. Main sponsors (over 10,000 Euro) were:

	2022 (Euro)	2021 (Euro)
Hoffmann-La Roche	82,950.00	70,300.00
Biogen	80,691.09	61,935.00
Lilly	65,000.00	20,000.00
TauRx	25,275.50	30,000.00
Eisai	25,000.00	20,000.00
Grifols	25,000.00	12,203.06
NovoNordisk	12,838.90	750.00
AbbVie	12,500.00	15,000.00
GE Healthcare	12,500.00	10,000.00
Danone/Nutricia	12,500.00	7,500.00
Other sponsors	<u>20,110.00</u>	<u>28,839.86</u>
	374,365.49	276,527.92

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Notes to the annual accounts as at December 31, 2022**NOTE 12. OTHER EXTERNAL EXPENSES**

Other external expenses are composed of:

	2022 (Euro)	2021 (Euro)
Accommodation expenses	218,919.00	12,118.60
External experts	147,563.62	124,237.67
Travel expenses	83,283.46	3,435.20
Office rent and associated costs	51,241.09	46,892.50
Equipment and Leasing	49,721.00	31,098.49
Communication costs	49,050.87	26,030.62
Publication and Information material	36,522.80	39,580.38
Office stationery and related costs	6,174.34	2,978.37
Membership fees	3,850.00	3,870.00
Recruitment costs	3,001.05	0.00
Bank charges	2,749.67	1,307.35
Other costs	<u>1,950.72</u>	<u>132.37</u>
	654,027.62	291,681.55

NOTE 13. STAFF

The association employed an average of 12 persons on a full time equivalent basis during the financial year (2021: 10), one Executive Director and 11 employees.

NOTE 14. REMUNERATION OF THE BOARD OF DIRECTORS

No compensation was paid to members of the Board of Directors in respect of their functions within the association in the period under review. Moreover, no advances or loans have been granted to the members of the Board.

NOTE 15. OTHER OPERATING EXPENSES

Other operating expenses can be broken down as follows:

	2022 (Euro)	2021 (Euro)
Grant to Alzheimer Europe Foundation	134,567.97	154,421.66
Software licenses	6,170.82	3,777.19
Other expenses	<u>330.00</u>	<u>495.00</u>
	141,068.79	158,693.85

NOTE 16. OFF-BALANCE SHEET COMMITMENTS

As at December 31, 2022, the association had a rental guarantee of EUR 16.200 granted to the owner of the offices used by the association.

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Notes to the annual accounts as at December 31, 2022**NOTE 17. AUDIT FEES**

Audit fees for the year under review amounted to EUR 9,149.50 (2021: EUR 8,775).

NOTE 18. RELATED-PARTY TRANSACTIONS

The following significant transactions with related parties have been entered into during the year under review:

	2022 (Euro)	2021 (Euro)
Grant to Alzheimer Europe Foundation	134,567.97	154,421.66
Grant from Fondation Alzheimer	87,000.00	87,000.00

Breakdown of income

Funding source	Core funding received (2022)	As % of AE core income (2022)	Project funding received (2022)	As % of AE Project income (2022)	Total funding received (2022)	As % of AE total income (2022)	As % of AE total income (2021)
Hoffmann-LaRoche		0.00%	84,909	7.59%	84,909	4.55%	5.15%
Biogen		0.00%	80,691	7.21%	80,691	4.32%	4.54%
Lilly		0.00%	65,000	5.81%	65,000	3.48%	1.47%
TaurX		0.00%	25,276	2.26%	25,276	1.35%	2.20%
Eisai		0.00%	25,000	2.23%	25,000	1.34%	1.47%
Grifols		0.00%	25,000	2.23%	25,000	1.34%	0.89%
Novo Nordisk		0.00%	12,839	1.15%	12,839	0.69%	0.05%
Abbvie		0.00%	12,500	1.12%	12,500	0.67%	1.10%
GE Healthcare		0.00%	12,500	1.12%	12,500	0.67%	0.73%
Orion		0.00%	5,000	0.45%	5,000	0.27%	0.00%
Various donors	1,783	0.24%		0.00%	1,783	0.10%	0.00%
GlaxoSmithKline		0.00%	360	0.03%	360	0.02%	0.06%
Janssen		0.00%		0.00%	-	0.00%	0.73%
Sub-total Pharmaceutical funding	1,783	0.24%	349,075	31.20%	350,858	18.80%	18.41%
HOYNG ROKH MONEGIER	13,000	1.74%		0.00%	13,000	0.70%	0.00%
Nutricia		0.00%	12,500	1.12%	12,500	0.67%	0.55%
Essity		0.00%	10,000	0.89%	10,000	0.54%	0.73%
Newsweaver	4,636	0.62%		0.00%	4,636	0.25%	0.34%
Microsoft	1,746	0.23%		0.00%	1,746	0.09%	0.00%
Sanador		0.00%	1,000	0.09%	1,000	0.05%	0.00%
OptiChronix		0.00%		0.00%	-	0.00%	0.33%
Fujirebio		0.00%		0.00%	-	0.00%	0.26%
Sub-total: Other corporate sources	19,382	2.59%	23,500	2.10%	42,882	2.30%	2.21%
Total Corporate funding	21,165	2.83%	372,575	33.30%	393,740	21.10%	20.62%
European Commission	449,280	60.10%	416,006	37.18%	865,286	46.36%	48.41%
Luxembourg National Research Fund (FNR)		0.00%	130,049	11.62%	130,049	6.97%	4.36%
Irish Ministry for Agriculture, Food and Marine	2,000	0.27%		0.00%	2,000	0.11%	0.15%
Total Public funding	451,280	60.37%	546,055	48.80%	997,335	53.44%	52.92%
Fondation Alzheimer, Luxembourg	87,000	11.64%		0.00%	87,000	4.66%	6.38%
Time donated by experts	60,300	8.07%		0.00%	60,300	3.23%	1.11%
University of Nottingham - DISTINCT		0.00%	35,000	3.13%	35,000	1.88%	0.37%

BREAKDOWN OF INCOME

Funding source	Core funding received (2022)	As % of AE core income (2022)	Project funding received (2022)	As % of AE Project income (2022)	Total funding received (2022)	As % of AE total income (2022)	As % of AE total income (2021)
Deferred income	11,653	1.56%		0.00%	11,653	0.62%	2.79%
DZNE		0.00%	10,000	0.89%	10,000	0.54%	0.09%
Alzheimer Europe Foundation	8,093	1.08%		0.00%	8,093	0.43%	0.11%
PAVE		0.00%	7,500	0.67%	7,500	0.40%	0.00%
DAC		0.00%	6,250	0.56%	6,250	0.33%	0.00%
bPRIDE		0.00%	5,500	0.49%	5,500	0.29%	0.00%
University of Edinburgh - EPAD		0.00%	4,794	0.43%	4,794	0.26%	0.95%
EBC/EFPIA		0.00%	4,792	0.43%	4,792	0.26%	0.00%
Various organisations		0.00%	3,451	0.31%	3,451	0.18%	0.00%
Concenctris- PRIME		0.00%	3,000	0.27%	3,000	0.16%	0.22%
University of Eastern Finland - ADAIR		0.00%	2,500	0.22%	2,500	0.13%	0.37%
VUMC - MIRIADe		0.00%	1,061	0.09%	1,061	0.06%	0.27%
Ferb Onlus RECage		0.00%	1,500	0.13%	1,500	0.08%	0.09%
Danish Dementia Research Centre-TIMING		0.00%	1,500	0.13%	1,500	0.08%	0.00%
Aridhia - EPAD		0.00%		0.00%	-	0.00%	1.68%
ADDI		0.00%		0.00%	-	0.00%	0.73%
SPAN+		0.00%		0.00%	-	0.00%	0.50%
Global Coalition on Ageing		0.00%		0.00%	-	0.00%	0.18%
University of Vechta		0.00%		0.00%	-	0.00%	0.01%
Income received on account		0.00%	7,000	-0.63%	7,000	-0.38%	0.00%
Total Foundations and organisations	167,046	22.35%	79,848	7.14%	246,894	13.23%	15.86%
Individuals (conference fees, donations, publication sales)	2,435	0.33%	120,463	10.77%	122,898	6.58%	2.95%
Total: Individuals	2,435	0.33%	120,463	10.77%	122,898	6.58%	2.95%
AE member organisations	105,240	14.08%		0.00%	105,240	5.64%	7.65%
Total: Member organisations	105,240	14.08%	0	0%	105,240	5.64%	7.65%
Bank interest and similar	328	0.04%		0.00%	328	0.02%	0.00%
Total: Bank interest and similar	328	0.04%	0	0.00%	328	0.02%	0.00%
Total Income	747,494	100%	1,118,941	100%	1,866,435	100%	100%

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