



Annual and Financial Report 2023



Contents

1. Annual Report	3
Preface	4
<i>A few words from our Chairperson</i>	4
<i>A few words from the Chairperson of the European Working Group of People with Dementia</i>	6
<i>A few words from the Chairperson of the European Dementia Carers Working Group</i>	7
Executive Summary	8
Introduction	12
AE Core Activities	12
<i>Objective 1: Providing a voice to people with dementia and their carers</i>	12
<i>Objective 2: Making dementia a European priority</i>	15
<i>Objective 3: Changing perceptions and combating stigma</i>	17
<i>Objective 4: Raising awareness of brain health and prevention</i>	18
<i>Objective 5: Strengthening the European dementia movement</i>	19
<i>Objective 6: Supporting dementia research</i>	23
Other activities and projects	26
<i>Involvement in EU projects</i>	26
<i>Support of European research activities</i>	34
<i>Corporate affairs</i>	37
Annex 1: Meetings and conferences	43
<i>Meetings organised by Alzheimer Europe (AE) in the framework of the 2023 Operating Grant</i>	43
<i>Meetings attended by Alzheimer Europe representatives in the framework of the 2023 Operating Grant</i>	43
<i>Other meetings organised by Alzheimer Europe</i>	44
<i>EU project meetings</i>	45
<i>Other meetings</i>	46
Annex 2: Scientific publications in 2023	48
2. Financial Report	49
Preface	50
<i>A few words from our Honorary Treasurer</i>	50
Report of the Réviseur d'entreprises agréé	52
Balance sheet as of December 31, 2023	56
Profit and loss account – Year ended December 31, 2023	57
Notes to the Annual Accounts as at December 31, 2023	58
Breakdown of income	66
Our sponsors and supporters	68
3. Alzheimer Europe Board and Staff in 2023	69



Annual Report

Preface

A few words from our Chairperson



Maria do Rosário Zincke dos Reis

It is always a great privilege to write the preface for the impressive Annual Report of Alzheimer Europe and this 2023 edition is no exception. It has been another activity-packed year and we can look back on the many achievements with a great sense of pride.

One of the outstanding highlights for me was our Annual Conference in Helsinki which attracted 997 participants who attended in person and 133 delegates who participated online. It was fantastic to see so many representatives from all over Europe and to have people with dementia and carers mingle with healthcare professionals, academics, researchers, volunteers and staff of Alzheimer's associations, policy makers and industry representatives. On 11 April this year, we were informed that our conference came first in the category of "paid events" at the prestigious Evento Awards which celebrated Finland's best events, venues, speakers and companies of 2023. Not only did our conference win, but we were shortlisted amongst the three finalists in two additional categories: Charity/Social Event and Event Impact. What an amazing testimony for the uniqueness of this year's Annual Conference!

What sets our conference apart from a lot of other conferences in the Alzheimer's field is the contributions made by people living with dementia and their carers at all stages of the conference. They were involved in the planning process and preparatory stages and, in 2023, members of our European Working Group of People with Dementia (EWGPWD) planned and organised the very first plenary of the conference which was moderated by Chris Roberts, the chairperson of the group, with contributions from four members living with dementia: Kevin Quaid from Ireland, Pia Knudsen from Denmark, Věra Ryšavá from Czechia and Nigel Hullah from the UK. Their brave and frank presentations on how a diagnosis of dementia has transformed their lives and turned them from patients into advocates and co-researchers were received with a standing ovation from the audience and set the tone for the rest of the conference.

I am constantly impressed by the outstanding contributions by all the members of our European Working Group of People with Dementia who make sure that we always integrate the views and opinions of people with dementia in all our activities. Our project portfolio is constantly increasing

as well, and researchers greatly value the input and advice provided by the group through the public involvement activities, focus groups and consultations involving the group. It would be unthinkable for Alzheimer Europe to contribute to research without the active and meaningful involvement of people living with dementia. The group also published guidelines on dementia-inclusive travel and meetings and contributed to a number of scientific articles as co-authors.

Last year, we also saw our European Dementia Carers Working Group go from strength to strength. The group was only set up in 2022, but already had an impressive list of meetings and contributions in its first full year. It was great to see the group come together under the leadership of its Chairperson Sonata Mačiulskytė from Lithuania and Vice-Chairperson Trevor Salomon from the UK. The group organised a very successful and interactive session at our conference entitled "When care homes stop caring" and started contributing to a range of EU projects. I am sure that the group has as bright a future as our well established European Working Group of People with Dementia.

I am particularly grateful to the European Union's Citizens, Equality, Rights and Values (CERV) programme and its support for disability organisations which allows Alzheimer Europe to fully integrate people with dementia and their carers in our own activities and to campaign for their inclusion as citizens in society.

Another activity I particularly enjoyed was the second anti-stigma award, on which we collaborated with the Alzheimer Europe Foundation, as well as our gold sponsors Lilly and Roche. We called for initiatives promoting a positive image of dementia with a particular focus on often underrepresented or ignored populations, namely people with dementia from ethnic minorities, from the LGBTQ+ community, from economically disadvantaged

groups, as well as people with intellectual disabilities or Down syndrome. We received a great number of truly inspiring initiatives and the jury had a difficult job in selecting the three winners, which were presented during a networking dinner in the amazing setting of the Old Student House in Helsinki: Touchstone's BME (Black and Minority Ethnic) Dementia Service came first; Brighton and Hove LGBT Switchboard's initiative "Rainbow Neighbours" came second; and the third prize went to Hogeschool Windesheim for its campaign "Assess your assumptions". Worthy winners, all three!

A third highlight for me was our continuing policy work and the great interactions we have had with the members of our European Alzheimer's Alliance and the European Group of Governmental Experts on Dementia. It was fantastic to see the continued interest of Members of the European Parliament in our cause and their involvement in the three lunch debates which were organised in 2023. Similarly, the meetings of our governmental experts group were attended by health ministry officials from 16 European countries, as well as representatives from the European Commission, the Organisation for Economic Co-operation and Development (OECD) and the World Health Organization (WHO). This hopefully bodes well for our continued campaign to see dementia recognised as a European priority. We also took the opportunity of the upcoming European Parliament elections in 2024 to adopt the Helsinki Manifesto with the policy priorities of the European dementia movement on which we will be campaigning together with our national associations, over the next five years. Two key reports of Alzheimer Europe published in 2023 will support our campaigning work: The first is our 2023 Yearbook on legal capacity and supported decision making, which highlighted how some of the principles contained in the United Nations Convention for the Rights of People with Disabilities are applied unequally across Europe. The other is our European Dementia Monitor, which allowed us to compare and benchmark national policy responses to the dementia challenge and identify continuing inequalities in the access to care and treatment.

This brings me to my final highlight of 2024: the continuing and close collaboration between Alzheimer Europe and all our national member organisations. None of the previous activities and reports would have been possible without

the active contributions of our national associations who helped us collect data on national legislation and policies and support our lobbying activities at the level of the European institutions. It was fantastic to see that every single member organisation contributed statistics to our European Dementia Monitor and all but one, attended or were represented at our Annual General Meeting in Helsinki. Our public affairs meetings in Brussels were equally well attended and we learned a lot about interesting policy developments and national campaigns. Similarly, our Alzheimer's Association Academy meetings were great opportunities to share good practices between members, with 30 European countries represented at those meetings.

As every Chairperson before me, I have to pay special thanks to my colleagues on the Board. Each one of them plays an important role in monitoring the activities and finances of our association and in recommending and advising our staff on how to continue growing and expanding the association. It is a pleasure to chair the meetings of the Board which are held in a constructive and productive fashion.

Last, but in no way least, I am privileged to work with an outstanding team under the leadership of our Executive Director, Jean Georges. In 2023, we were able to welcome another new staff member to the team: Tara Klassen. With the growing team come new responsibilities which is why we instituted a new management structure with Dianne Gove as Director for Public Involvement and Ethics, Ana Diaz as Public Involvement Lead, Angela Bradshaw as Director for Research and Kate Boor-Ellis as Director for Communications and Policy. They will continue to be assisted by their colleagues Christophe Bintener, Cindy Birck, Gwladys Guillory, Daphné Lamirel, Owen Miller, Soraya Moradi-Bachiller, Cristina Pencea, Stefanie Peulen and Grazia Tomasini and are joined in 2024 by two additional colleagues, Sarah Campill and Lukas Duffner. I am looking forward to continuing our excellent collaboration in 2024, which I am certain will be another successful year.

Maria do Rosário Zincke dos Reis
Chairperson
Alzheimer Europe



Maria do Rosário Zincke dos Reis speaking at the Opening Ceremony of the 33rd Alzheimer Europe Conference, Helsinki (Finland), 16 October 2023

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



Chris Roberts

Hello to all. Another year gone already and this is probably my last Annual Report as current Chair of the European Working Group of People With Dementia (EWGPWD). It has been an honour and privilege to have had this experience and I'm very proud of the group members, current and past. Especially of the excellent work that we have achieved together during our regular meetings and the contributions to other important work, activities and projects. There truly is "Nothing about us, without all of Us"!

While I'm thanking people, I would like to give my utmost thanks to all the staff of Alzheimer Europe who do an amazing amount of work whilst supporting our group. I would also like to thank the Alzheimer's Society UK for all their support and for all they do in my country on behalf of everyone affected by dementia. A special thanks, as well, to my wife Jayne Goodrick, without whom I couldn't have achieved anything. We are a great team!

Back to the report: In general, 2023 marked a very active year for the EWGPWD. The group held regular meetings throughout the year, having four meetings online and three meetings in person. During these meetings, the members provided input on various projects, including a number of the many European research projects that Alzheimer Europe is involved in.

The group also contributed to Alzheimer Europe's position paper on Anti-amyloid therapies for Alzheimer's disease. This document is very important in the context of all the new medications being developed for Alzheimer's disease. It calls for concrete actions to ensure safe, timely and equitable access to these new medications, for all people who could benefit from treatment, in all countries.

The EWGPWD also contributed their views and testimonials to Alzheimer Europe's 2023 Yearbook, which focused on legal capacity and supported decision-making for people living with dementia.

A key piece of work that the EWGPWD focused on in 2023 was our contribution to the development of a set of guidelines on inclusive meetings and travel for people with dementia. This work is very important to us, personally, because people with dementia are being asked to join meetings about research, policy and advocacy, more and more, as we should be, so we need to be included at every step, so we can voice our thoughts and experiences to make sure we have a say in how things are done. The guidelines were developed to make sure meetings and travel plans are organised in a way that makes it easier and more accessible for people with dementia to take part, with their wellbeing and specific needs kept in mind. It also builds on previous work carried out with the EWGPWD in 2020, on inclusive meetings and travel.

The 33rd Alzheimer Europe Conference (33AEC), in Helsinki, was a very successful and inclusive conference for all, for which Alzheimer Europe won an award. Congratulations to all the Alzheimer Europe staff and to the very helpful staff at the excellent conference venue. The conference broke its previous record for the total number of attendees and was marked by the first session of its kind: a Plenary session entirely organised, chaired and presented by people with dementia. I had the honour of chairing the session, and four members of the group spoke: Kevin Quaid (Ireland), Vice-Chair of the EWGPWD, and Nigel Hullah (Wales, United Kingdom), plus two newer members of the group, Pia Knudsen (Denmark) and Věra Ryšavá (Czech Republic). Drawing from their varied personal experiences, they all spoke about Public Involvement in dementia research and advocacy at both national and European level.

The audience gave the EWGPWD members a standing ovation, and the feedback was extremely positive, with many attendees rating the session as a highlight of the conference. We are all very proud and we thank everyone that listened to our speeches. Some members of the EWGPWD also took part in video interviews about their experiences at the conference. The videos were shared online and were made in collaboration with the Dementia Researcher Network led by my friend, the brilliant Adam Smith.

In 2023, members of our group also participated in video interviews organised by Alzheimer Europe, in which we advocated (in our national languages) for dementia to be a European policy priority, in preparation for the EU elections taking place in June 2024. During 2024, the group will continue to be involved in campaigning activities related to these EU elections. The goal is to make sure that the new candidates elected in the European institutions prioritise dementia in all European Countries, all working together to achieve this.

Thank you very much.

Chris Roberts
Chairperson
European Working Group of People with Dementia

A few words from the Chairperson of the European Dementia Carers Working Group



Sonata Mačiulskytė

The first year of the European Dementia Carers Working Group (EDCWG) has passed in the blink of an eye. It has been a meaningful year, bringing new friends and colleagues together in this new group. This has been a milestone for each of us personally, but also for Alzheimer Europe.

We are 13 active members. All of us are or were carers. We are husbands, wives, partners, sons and daughters, all of different ages and different social, cultural, linguistic, and other backgrounds, with varied education, personal and professional experience, and genders - from North to South, from Portugal and Iceland to the East coast of the Baltic Sea. There are eight members from countries which have national dementia plans, and the other five from countries which don't. As carers, we all are often "in the shadows", supporting or sometimes, standing up for or speaking on behalf of our loved ones with dementia to defend and ensure their human and civil rights. We are not used to speaking for ourselves. After all, we are not the ones with the diagnosis of the disease, though we have our own needs, where care is concerned. Many of us were at the most active point in our professional careers when we became carers. Some of us retired early to cope with our care responsibilities. A few of us belong to a "sandwich generation", finding ourselves having both family and professional obligations as well as a deep personal responsibility to take the best care that we can of our loved ones with dementia. Providing care can be a challenge and some carers experience burden and are at a higher risk of burnout and social isolation. But the world keeps turning, and several of us have lost loved ones with dementia during this year. Despite the hardships, we have each other and I am so grateful for this group and for the support we each give and receive. I am also proud and grateful to have the opportunity, together with the rest of the group, to contribute to the work of Alzheimer Europe and ensure it duly reflects the priorities and views of carers and supporters of people with dementia.

What have we done so far? I personally think we did a lot. Much more than anybody could have expected from us. We have been involved in advisory boards of at least five projects; provided insights for Alzheimer Europe's 2023 Yearbook on legal capacity and supported decision-making, and for a position paper on risk disclosure; contributed three testimonials to the Yearbook and 12 to the Alzheimer Europe monthly newsletter; recorded two video testimonials, 10 videos in support of Alzheimer Europe's 2024 European Parliament election campaign; participated, as a group, in the 33rd Alzheimer Europe Conference in Helsinki, where we contributed to a

podcast and a panel session, held a parallel session, moderated four conference sessions, and much more! Besides all of this, we made dementia carers visible as a separate group in Alzheimer Europe and across national Alzheimer/dementia organisations, with each of our conference appearances being met with enthusiasm from national organisations wanting to establish national dementia carers working groups, while others wanted to join our EDCWG. Since then, I have learnt that some of these national organisations have launched such working groups.

The achievements during the first year are huge and all of this has made it possible for us to be invited to join the European Working Group of People With Dementia, to organise a joint Plenary session at the 34th Alzheimer Europe Conference in Geneva, in October 2024.

My personal aim was to give a voice and an opportunity to each of the EDCWG members to express themselves and to feel involved. I felt it was important to create a friendly environment to network internationally, to communicate, cooperate, support and join forces to raise dementia awareness in a diverse range of European languages. So, I am very glad to hear when my EDCWG fellows express their pleasure at being members of the group. It was an extremely enriching experience for all of us to work together with such a talented, multinational, and caring group of people and despite the challenges, we had time for socialising and lots of laughter. Being involved in different activities has allowed us to gain insight into the depth and range of work and research that is underway, giving us hope for the future, regarding diagnosis and treatment of Alzheimer's disease and other dementias.

We sincerely thank Alzheimer Europe for this extraordinary EDCWG journey together in 2023, and for the opportunity to contribute with our life experiences. Thank you, also, to our national associations for nominating us to this group.

Sonata Mačiulskytė
Chairperson
European Dementia Carers Working Group

Executive Summary

In 2023, Alzheimer Europe:

Provided a voice to people with dementia and their carers and

- involved 15 people with dementia from 11 European countries in its European Working Group of People with Dementia (EWGPWD) and organised three in-person and eight online meetings
- co-developed guidelines on dementia-inclusive travel and meetings with the group
- dedicated the first plenary of its Annual Conference to a session entitled “Transforming personal experiences into political advocacy and public involvement in dementia research”. This was planned, organised, moderated presented by members of the EWGPWD
- participated with an EWGPWD delegation in the 5th European Parliament of Persons with Disabilities and in the European Day of Persons with Disabilities
- had the first meeting of its European Dementia Carers Working Group (EDCWG) comprised of 14 members from 13 European countries and organised two in-person and four online meetings
- co-organised a session entitled “When care homes stop caring” with EDCWG members at the Annual Conference
- involved members of both groups in publications, meetings as well as through Public Involvement activities in its European dementia and brain health research projects

Made dementia a European priority and

- adopted the Helsinki Manifesto with the political priorities of the European dementia movement to campaign for the recognition of dementia as a public health and research priority at the 2024 European Parliament elections



Marjolein de Vugt, Chairperson of INTERDEM, addressing delegates at the Opening Ceremony of the 33rd Alzheimer Europe Conference, Helsinki (Finland), 16 October 2023

- monitored EU and national policy developments of interest to people with dementia and their carers
- contributed to European Commission consultations by submitting position papers and by co-developing policy statements with other European disability and health NGOs
- developed a position and issued a call for action on anti-amyloid therapies for Alzheimer’s disease (AD)
- organised a meeting of the European Group of Governmental Experts on Dementia, bringing together representatives from 16 national health ministries, as well as the European Commission, Organisation for Economic Co-operation and Development (OECD) and the World Health Organization (WHO)
- ended the year with 87 Members of the European Parliament as members of the European Alzheimer’s Alliance



Annual General Meeting of Alzheimer Europe, Helsinki (Finland), 16 October 2023

- dedicated its 2023 Yearbook to legal capacity and supported decision-making and carried out a survey in which 27 members participated and which resulted in a detailed report of national legislation on legal capacity, civil and criminal responsibility, consent to treatment and research and proxy decision-making systems,
- participated as an active member in the meetings of the Patients' and Consumers' Working Party of the European Medicines Agency
- contributed to WHO activities on dementia, long-term care and mental health

Changed perceptions and combatted stigma and

- wrote a report on how national Alzheimer's associations can contribute to the review of national disability policies by the United Nations Committee on the Rights of Persons with Disabilities to ensure that dementia is duly recognised as a disability
- launched the call for its second Anti-stigma award for initiatives and projects set up for people from minority ethnic groups, the LGBTQ+ community, people with intellectual disabilities and people from socio-economically disadvantaged groups
- presented the awards at a networking dinner during the Annual Conference in Helsinki and awarded Touchstone's BME (Black and Minority Ethnic) Dementia service with the first prize, the Brighton and Hove LGBT Switchboard's initiative "Rainbow Neighbours" with second prize and the Windesheim University of Applied Sciences campaign "Assess your assumptions" with third prize
- had its guide on ethical and inclusive communication translated into French and Italian, its practical guide on sex, gender and sexuality translated into Italian, and collaborated with NHS England to adapt its guide on intercultural care for use within the National Health Service

Raised awareness of brain health and prevention and

- included information on five phase II trials, four phase III trials and one non-drug trial on prevention conducted in Europe, in its Clinical Trials Watch
- participated in a growing number of European research projects focused on brain health, risk reduction and prevention
- developed a position on how to disclose the risk for cognitive impairment to cognitively healthy people and the risk of developing AD dementia to people with mild cognitive impairment
- contributed to scientific publications on brain health, including guidelines on physical activity and exercise and recommendations on dementia prevention in memory clinics

Strengthened the European dementia movement and

- organised three in-person and six online Alzheimer's Association Academy meetings with the participation of members from 30 European countries
- involved the AE Board in the monitoring of the association's activities and finances in relation to the agreed-upon Work Plan and budget
- organised its Annual General Meeting in Helsinki on 16 October with 33 of its 37 full member organisations present or represented
- continued its collaboration with the INTERDEM network of European researchers involved in psychosocial research and the European Academy of Neurology
- signed a memorandum of understanding with the International Psychogeriatric Association and endorsed the association's Older Adults Mental Health Awareness Week



2023 Alzheimer Europe Anti-Stigma Award winners at a special ceremony during the gala dinner of the 33rd Alzheimer Europe Conference, Helsinki (Finland), 17 October 2023

- collaborated with the European Patients' Forum and the European Disability Forum, as a full member association of both
- #### Supported dementia research and
- involved the EWGPWD and the EDCWG in the Public Involvement activities of European research projects
 - organised the first of its kind Public Involvement meeting in Luxembourg from 14 to 16 November, bringing advisory boards from six European projects together
 - launched its new online Public Involvement Pool
 - contributed to a research paper developing recommendations on actively involving people with dementia in systematic reviews
 - contributed to the communication and dissemination of research results via its established communication tools: newsletter, website and social media
 - covered 488 news stories in its 11 monthly e-mail newsletters which were sent to between 7,200 and 7,500 subscribers
 - saw a 16% increase in unique website visitors to 58,107
 - organised its 33rd Annual Conference "New opportunities in dementia care, research and policy" in Helsinki from 16 to 18 October with 1,130 participants from 48 countries of which 997 participated in-person and 133 online



EU-FINGERS, LETHE and Multi-MeMo Advisory Boards, Luxembourg, 14 November 2023



European Dementia Carers Working Group meeting prior to the 33rd Alzheimer Europe Conference, Helsinki (Finland), 15 October 2023

Carried out the following project-related activities

- Continued its involvement in a number of EU-funded projects by representing the views of people with dementia and their carers in the research consortium, by contributing to the ethical discussions and by supporting the communication and dissemination activities towards a non-scientific audience with the following projects
 - ADIS (Early Diagnosis of Alzheimer’s Disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances)
 - AI-MIND (Intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment)
 - eBRAIN-Health (Actionable Multilevel Health Data)
 - EPND (European Platform for Neurodegenerative Diseases)

- EU-FINGERS (Multi-modal precision prevention toolbox for dementia in Alzheimer’s disease)
- LETHE (A personalized prediction and intervention model for early detection and reduction of risk factors causing dementia, based on explainable AI and distributed Machine Learning)
- Pattern-Cog (Personalized aging pattern for early risk detection and prevention of cognitive impairment and dementia in cognitively healthy individuals)
- PRODEMOS (Prevention of Dementia using Mobile phone Applications)
- RADAR-AD (Development and validation of technology enabled, quantitative and sensitive measures of functional decline in people with early stage 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 (Personalized Recommendations for Neurodegenerative Disease)
- Started its collaboration with
 - Multi-MeMo (Shorter- and longer-term mechanisms of multimodal interventions to prevent dementia)
 - PREDICTOM (Prediction of Alzheimer’s disease using an AI driven screening platform)
 - PROMINENT (Precision medicine platform in neurodegenerative disease)
- 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)



European Working Group of People with Dementia, Brussels (Belgium), 6 June 2023



Alzheimer Europe hosts a European Parliament lunch debate, Brussels (Belgium), 6 June 2023

- MIRIADe (Multi-omics interdisciplinary research integration to address dementia diagnosis)
- PRIME (Prevention and Remediation of Insulin Multimorbidity in Europe)
- ReCAGE (Respectful Caring for AGitated Elderly)

Carried out a number of activities thanks to the support of its corporate sponsors and other partners and

- updated the findings of its European Dementia Monitor and compared and benchmarked the dementia responses of 37 European countries in 10 different categories
- organised three European Parliament lunch debates on behavioural and psychological symptoms in dementia, modifiable risk factors and inequalities in access to care and treatment in Europe

- published three editions of the Dementia in Europe magazine with interviews and contributions of EU and national policy makers
- included 20 phase II trials, 17 phase III trials and seven non-drug trials in the Clinical Trials Watch section of the association's website
- received funding from Gates Ventures for a project monitoring the data sharing policies of European research projects and exploring the attitudes of the general public towards and the experiences of research participants in dementia and brain health research



European Group of Governmental Experts on Dementia, Brussels (Belgium), 6 June 2023

Introduction

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

As in previous editions, the Annual Report breaks down the organisation's core activities in these six key strategic areas and highlights the activities undertaken by Alzheimer Europe in support of EU projects, as well as those carried out thanks to the support of its corporate sponsors and other partners.

AE Core Activities

In 2023, Alzheimer Europe received an operating grant from the European Union's Citizens, Equalities, Rights and Values (CERV) Health Programme which provided the funding for a number of the organisation's core activities included below.

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

Thanks to its European Working Group of People with Dementia (EWG-PWD), 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 2023, Alzheimer Europe also finalised the setting up of its European Dementia Carers Working Group.

European Working Group of People with Dementia

In 2023, the EWGPWD had the following 15 members from 11 different European organisations:

Chair:

- Chris Roberts (UK – England, Wales and Northern Ireland)

Vice-Chairs:

- Margaret McCallion (UK - Scotland)
- Kevin Quaid (Ireland).

Members:

- Bernd Heise (Germany)
- Nigel Hullah (UK – England, Wales and N. Ireland)
- Erla Jónsdóttir (Iceland)
- Marguerite Keating (Ireland)
- Lieselotte Klotz (Germany)
- Pia Knudsen (Denmark)
- Petri Lampinen (Finland)
- Réal Larnou (Belgium)
- Stephen John McCleery (Italy)
- Angela Pototschnigg (Austria)
- Shelagh Robinson (UK – England, Wales and N. Ireland)
- Věra Ryšavá (Czech Republic).

The Chair of the EWGPWD, Chris Roberts, actively participated in the online and in-person meetings of the Board of Alzheimer Europe in 2023.

Alzheimer Europe organised three in-person and eight online meetings of the EWGPWD which were attended as follows:



European Working Group of People with Dementia meeting prior to the 33rd Alzheimer Europe Conference, Helsinki (Finland), 15 October 2023

The four keynote speakers at Plenary 1 of the 33rd Alzheimer Europe Conference



Věra Ryšavá



Nigel Hullah



Kevin Quaid



Pia Knudsen

Date	Number of participants	Countries represented
15, 16 and 28 February	9	8
7 March	13	11
9 March	6	6
19 April	11	8
5 and 6 June	13	11
13 September	4	3
14 September	12	9
15 and 16 October	13	11
15 November	11	9
13 and 15 December	10	5
18 December	9	5

The topic of dementia-inclusive travel and meetings was addressed in several of the meetings of the EWGPWD in 2023. Based on this work, the group developed guidelines on this topic targeted at organisers of meetings and travel that include people with dementia. The guidelines also include some guidance for people with dementia and carers based on the feedback received from the EWGPWD. The guidelines were launched in early 2024.

During the Alzheimer Europe Conference in Helsinki, the EWGPWD played an active role by planning, moderating and speaking at the first plenary session, which was identified as one of the conference highlights by the conference attendees. The session was entitled “Transforming personal experiences into political advocacy and Public Involvement (PI) in dementia research” and was chaired by Chris Roberts, Chair of the EWGPWD. Kevin Quaid, Pia Knudsen, Věra Ryšavá and Nigel Hullah each gave a 10-minute talk, sharing their experiences and perspectives regarding PI at the national or European levels. The EWGPWD Chair also welcomed delegates at the opening ceremony together with the Finnish member, Petri Lampinen. In addition, different EWGPWD members presented 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 EWGPWD:

- actively participated in the “5th European Parliament of Persons with Disabilities” which took place on 23 May 2023 in the European Parliament in Brussels,
- shared the perspectives on being diagnosed with and living with young onset dementia (Pia Knudsen, Denmark) at the Alzheimer’s Association Academy Meeting on 4 July 2023,
- contributed to a featured research session on “Patient and public involvement in dementia research: Global perspectives” at the Alzheimer’s Association International Conference (AAIC) in Amsterdam, Netherlands in July 2023 with Chris Roberts presenting the PI work conducted by Alzheimer Europe and outlining the activities and achievements of the EWGPWD,
- attended the European Day of Persons with Disabilities in November 2023 (Kevin and Helena Quaid)
- provided personal testimonials on their experiences in the field of legal capacity and supported decision-making for the 2023 Yearbook,
- contributed personal blogs and articles for the Alzheimer Europe website, newsletter and the Dementia in Europe magazine.



Chris Roberts (left) and Petri Lampinen, at the Opening Ceremony of the 33rd Alzheimer Europe Conference, Helsinki (Finland), 16 October 2023

European Dementia Carers Working Group



Trevor Salomon (left) and Sonata Mačiulskytė

In 2022, Alzheimer Europe modified its statutes to allow for the creation of a European Dementia Carers Working Group, and the nominations by national member organisations resulted in a group of 14 members from 13 European countries with five men and nine women. They had their first in-person meeting in March 2023.

Chair:

- Sonata Mačiulskytė (Lithuania)

Vice-Chair:

- Trevor Salomon (UK - England, Wales and Northern Ireland)

Members:

- Peter Banda (Slovakia)
- Paola Borghesi (Italy)
- Patrick Crosbie (Ireland)
- Sylva Dneboská (Czech Republic)
- Chris Ellermaa (Estonia)
- Zornitsa Karagyozeva (Bulgaria)
- Magnús Karl Magnússon (Iceland)
- Maria Filomena Mira Martins Cunha (Portugal)
- Katarzyna Mazuruk-Russ (Poland)
- Barry Northedge (UK – Scotland)
- Liv Thorsen (Norway)
- Roslynn Vella (Malta)

The Chair of the EDCWG, Sonata Mačiulskytė, actively participated in the online and in-person meetings of the Board of Alzheimer Europe in 2023.

In 2023, Alzheimer Europe organised two in-person and four online meetings of the EDCWG which were attended as follows:

Date	Number of participants	Countries represented
19 January	13	12
21 and 22 March	12	12
26 July and 1 September	9	6
13 September	4	3
15 and 16 October	13	12
28 November	10	10

In 2023, the EDCWG had the following key activities:

- organised a special session entitled “When Care Homes Stop Caring” at which Trevor Salomon and Sonata Mačiulskytė presented information about the challenges linked to care homes and dementia and then facilitated a workshop discussion
- contributed to the conference as speakers, moderators and poster presenters
- provided personal testimonials on their experiences in the field of legal capacity and supported decision-making for the 2023 Yearbook
- talked about the experience of caring for his husband (Paddy Crosbie, Ireland) and the experience of a gay couple faced with dementia at an Alzheimer’s Association Academy Meeting on “Dementia and the LGBTQ+ community” on 26 April 2023
- participated in a high-level ministerial conference in the Netherlands entitled “Defeating Dementia” on 2 October
- contributed personal blogs and articles for the Alzheimer Europe website, newsletter and the Dementia in Europe magazine.



Meeting of the European Dementia Carers Working Group, Brussels (Belgium), 21 March 2023



Meeting of the European Dementia Carers Working Group, Brussels (Belgium), 21 March 2023

Objective 2: Making dementia a European priority

In 2023, Alzheimer Europe started its campaign for the 2024 European Parliament elections, 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 (EAA) and dedicated its 2023 Yearbook to an overview and comparison of national policies on legal capacity and supported decision-making.

Campaigning for change in the European Parliament elections

The 2024 European Parliament elections featured strongly in the public affairs meetings which Alzheimer Europe organised with its national member organisations. This resulted in the drafting of a document which outlined the political priorities of the European dementia movement. The Helsinki Manifesto was adopted unanimously at the Annual General Meeting of Alzheimer Europe on 16 October 2023. The Manifesto sets out the current position of dementia in Europe as well as calling for actions in four main areas: health, research, disability and social rights, and informal carers. The document, along with a public call for action and the 2024 European Dementia Pledge for candidates of the European Parliament elections, were launched at the European Parliament lunch debate of Alzheimer Europe on 5 December 2023.

Alzheimer Europe also continued to work closely with other European NGOs and co-signed Civil Society Europe's European Parliament Manifesto, calling for strengthened civil dialogue at EU level through better recognition, involvement and resourcing of civil society. The organisation also endorsed the joint campaign by the EU4Health Civil Society Alliance and supported the Manifesto issued by the European Institute of Women's Health for the European Parliament elections.

Contributing to EU policies

Alzheimer Europe monitored policy developments at the EU and national level, and included 51 news stories on EU developments and 35 on national policy developments in its monthly e-mail newsletters. Alzheimer Europe also contributed to Commission consultations on the draft Employment and Social Innovation (EaSI) strand of the European Social Fund Plus Annual Work Programme 2024, the EU disability card, the EU4Health Annual Work Programme 2024, a call for evidence on a mental health initiative, and responded to proposals on civil judicial cooperation relating to EU-wide protection for vulnerable adults. In addition, Alzheimer Europe collaborated with other European disability and health NGOs to develop joint policy statements and contributions to EU policy discussions. Alzheimer Europe and members of the European Working Group of People with Dementia (EWGPWD) actively participated in the 5th European Parliament of Persons with Disabilities which took place on 23 May 2023 in the European Parliament and in the European Day of Persons with Disabilities (November 2023).

Alzheimer Europe also approved a position on risk disclosure and issued a call for action on anti-amyloid treatments.

- On 24 January, Alzheimer Europe supported a Joint letter of patient and consumer organisations addressed to the Executive Director of the European Medicines Agency (EMA) on "The shortage of antibiotics".
- On 31 January, Alzheimer Europe submitted a response to the call for evidence on the Mental Health Initiative.
- On 18 April, Alzheimer Europe submitted a response to the European Commission's 2023 public consultation on the European Disability Card.
- On 19 May, Alzheimer Europe submitted a response to the European Commission's 2023 targeted consultation on the EU4Health Annual Work Programme 2024.
- On 29 June, Alzheimer Europe submitted a response to an invitation to comment on the draft Employment and Social Innovation (EaSI) strand of the European Social Fund Plus Annual Work Programme 2024.
- On 16 August, Alzheimer Europe submitted a response to the European Commission's proposals on civil judicial cooperation, in relation to EU-wide protection for vulnerable adults.
- On 25 September, the Alzheimer Europe Board adopted a position on risk disclosure.
- On 25 September, the Alzheimer Europe Board adopted a call for action on anti-amyloid treatments.
- On 16 October, the Annual General Meeting of Alzheimer Europe unanimously adopted the Helsinki Manifesto.

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 one in-person meeting in Brussels (6 - 7 June) 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:

- received updates on important new developments at the level of the World Health Organization (WHO), the European Commission's research programmes Horizon Europe, and the EU4 Health Programme and its focus on mental health and dementia,
- learned about the main conclusions of the Dutch High Level Meeting "Defeating Dementia",
- was informed about new national initiatives and policy developments in Austria, Belgium (Flanders), Cyprus, the Czech Republic, Germany, Iceland, Ireland, Norway, Poland, Slovenia and the United Kingdom (Scotland).

In total, ministry officials from 16 countries were represented during the two-day meeting: Austria, Belgium (Flanders), Cyprus, Czech Republic, Finland, Germany, Iceland, Ireland, Italy, Latvia, Netherlands, Norway, Poland, Slovenia, Sweden and the United Kingdom (Scotland). In addition, representatives from Alzheimer Europe, the European Commission (DG Research and Innovation and European Health and Digital Executive Agency (HaDEA)) and the WHO attended the meetings in an observer capacity.

European Alzheimer's Alliance

The EAA ended the year with 87 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 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 Papadimitoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (Renew Europe); Deirdre Clune (EPP); Ciarán Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (EPP); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Tilly Metz (Greens/EFA); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (Renew Europe); Matjaž Nemeč (S&D); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Peter Lundgren (ECR).

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

Yearbook on legal capacity and supported decision-making

In 2023, Alzheimer Europe focused on legal capacity and supported decision-making for its Yearbook. Alzheimer Europe developed a survey which was discussed and co-designed with national member organisations. It was trialled with a limited number of associations from Ireland, Portugal and Ukraine, before being rolled out to all members. 27 organisations responded to the survey.

Thanks to the responses of national associations, Alzheimer Europe was able to identify good practices from 15 European countries in the field of legal capacity and supported decision-making for people with dementia and their family carers. In addition, eight experiences of people with dementia and carers were collected, including from the members of both the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG).

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 as well as policies in relation to legal capacity and supported decision-making. These results were published in the 2023 Yearbook, which also included good practice examples, experiences of people with dementia and carers, and conclusions and recommendations for both European and national policy makers. Due to the length of the report, Alzheimer Europe opted not to print copies of the report but distributed the report in an electronic format to 7,500 people.

The conclusion of the report contains a number of recommendations aimed at both national and European decision-makers, encouraging them to take action to improve legislation and policies around legal capacity and supported decision-making, including:

- dedicating programmes of work within European Social Fund Plus (ESF+) / the Cohesion Fund of the European Commission to support the development of resources and projects which implement systems of supported decision-making for persons with disabilities
- adopting and implementing the proposed Commission Regulation on cross-border situations and the Council Decision on the Hague Convention
- reforming laws relating to substitute decision-making, moving towards a system which prioritises supported decision-making, aligning to the combined supported decision-making model contained in Alzheimer Europe's 2020 Ethics Report
- providing funding for the development of public-facing campaigns to raise awareness and understanding of powers of representation and to encourage people to make these arrangements and/or advance directives, advising people where to go and whom to approach to get more information on the process.

The Yearbook was published at the end of 2023 and formally launched at the beginning of 2024.

Other policy developments and issues

Alzheimer Europe continued its collaboration with the EMA in 2023 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:

- the reorganisation of the EMA working parties,
- medicines shortages,
- the new EU medical device regulation and in vitro diagnostics regulation,
- strategies to combat disinformation and misinformation,
- real world data initiatives,
- electronic patient information forms,
- decentralised clinical trials and
- different EMA initiatives and projects, including ACT-EU (Accelerating Clinical Trials in the EU), the European HTA Stakeholder Network and the EMA critical medicines list.

In January 2023, Alzheimer Europe joined the European Public Health Alliance and other NGOs in calling on EMA to declare antibiotics shortages a major event which would allow for a reinforced role for the EMA to address the crisis.

In March 2023, the EMA also organised a multi-stakeholder workshop with patients, healthcare professionals, academia, regulators and industry to discuss medicines shortages and withdrawals in Europe. Alzheimer Europe participated in this event.

Finally, Alzheimer Europe continued to engage with the WHO at both a global and European level. Alzheimer Europe participated in meetings of 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 2023, Alzheimer Europe developed a guide on how national Alzheimer's associations can use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) process to see dementia recognised as a disability, launched the second Alzheimer Europe anti-stigma award in collaboration with the Alzheimer Europe Foundation and its gold sponsors Lilly and Roche, and adapted as well as translated a number of previous reports on inclusive language, intercultural care and gender, sex and sexuality.

Guide on UNCRPD reporting

The UNCRPD came into effect on 3 May 2008. Under the definition of disability set out in the Convention, dementia was recognised as a disability, placing obligations on governments to ensure that people living with dementia are supported, requiring that national policies and legislation

align to the articles of the Convention and uphold the rights of individuals. However, many countries still do not recognise dementia as a disability, and therefore do not recognise the rights of people with dementia under the Convention. Alzheimer Europe is therefore keen for its member organisations to engage in the UNCRPD review process, whereby the UNCRPD Committee reviews the adherence of a country to its obligations under the Convention.

In 2023, Alzheimer Europe therefore developed a guide for national member associations on how to engage in the reporting of the UNCRPD at national level and to raise issues relevant to people with dementia and their carers. 2,000 guides were published and disseminated via the AE network of national associations.

Alzheimer Europe anti-stigma award

Alzheimer Europe, in collaboration with the Alzheimer Europe Foundation, Lilly and Roche launched a call for applications for its second anti-stigma award, 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 (2020-2023).

The 2023 call focused on initiatives and campaigns addressing the stigma experienced by people with dementia and their carers from specific groups:

- Minority ethnic groups
- LGBTQ+ community
- People with intellectual disability and/or Down syndrome
- Socio-economically disadvantaged groups.

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

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

The three finalists were invited to attend the award ceremony which took place during the networking dinner of the Alzheimer Europe Conference, held at The Old Student House in Helsinki on the evening of 17 October. The award ceremony was moderated by Kim Coppes and the awards were presented by members of the Alzheimer Europe Foundation Board.

Touchstone's BME (Black and Minority Ethnic) Dementia Service was announced as the winner of Alzheimer Europe's 2023 anti-stigma award with a cash prize of EUR 5,000. Touchstone provides health and wellbeing services to thousands of people across Yorkshire in the United Kingdom.

The second-place award, with a cash prize of EUR 3,000, was awarded to Brighton and Hove LGBT Switchboard's initiative "Rainbow Neighbours". Switchboard is a charity for LGBTQ people looking for a sense of community, support or information.

The third place, with a cash prize of EUR 1,500, was scooped up by Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for its campaign "Assess your assumptions".

Adapting and translating previous reports

In 2022, Alzheimer Europe, in tandem with the European Working Group of People with Dementia (EWGPWD), had developed a new set of guide-

lines for the ethical and inclusive communication about/portrayal of dementia and people with dementia. The guidelines, which are targeted at the media, researchers, journalists, policy makers and anyone responsible for the portrayal of or communication about dementia in the public domain, were officially launched in 2023. These guidelines were also translated and published in French by France Alzheimer and in Italian by Federazione Alzheimer Italia.

In 2023, NHS England collaborated with Alzheimer Europe to adapt the organisation's guide on intercultural dementia which the association had published in 2020. The launch of the new report coincided with Dementia Action Week from 15 to 23 May with the hope that the report will improve care for people from an ethnic minority background who are living with dementia.

Finally, an Italian version of Alzheimer Europe's guide to help raise awareness of issues around sex, gender and sexuality in dementia was translated and published by Federazione Alzheimer Italia.

Objective 4: Raising awareness of brain health and prevention

In 2023, Alzheimer Europe updated its Clinical Trials 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.

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
Imperial College London	MET-FINGER	/	At risk of developing Alzheimer's dementia	Multidomain intervention
Maastricht UMC	ROMEMA	Roflumilast	MCI / Mild dementia	Anti-inflammatory

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
Washington University School of Medicine	DIAN-TU & DIAN-TU-001	Lecanemab, E2814, solanezumab, gantenerumab	Early onset Alzheimer's disease	Amyloid or Tau-related (Immunotherapy)
Hôpitaux de Toulouse	LO-MAPT	Dietary Supplement: Omega-3	Subjective memory complaints or family history of Alzheimer's disease	Neuroprotective (dietary supplement)

Phase III trials			
Company	Study	Population	Target
Alzheimercentrum Amsterdam	FINGER-NL	At risk for cognitive decline	Multi-domain lifestyle intervention

Prevention trials

In 2023, 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 trials, four phase III trials and one non-drug trial which were included on the Clinical Trials Watch section of the organisation's website.

EU research projects on brain health

The portfolio of EU projects in which Alzheimer Europe is involved continues to grow, and the following projects are focused on improving the identification of people at risk of developing dementia as well as the development of prevention or brain health strategies:

- ABOARD
- ADIS
- AI-MIND
- eBRAIN-Health
- EU-FINGERS
- LETHE
- MIRIADÉ
- Multi-MeMo
- Pattern-Cog
- VirtualBrainCloud

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

Position paper on risk disclosure

Although dementia risk prediction is happening in research and may be happening in clinical practice in the near future, very little focus has been placed on the disclosure of such risk. To address this lack of focus on risk disclosure, Alzheimer Europe developed general and specific recommendations in collaboration with its national members and the European Dementia Carers Working Group.

These recommendations were structured as follows:

- General recommendations when disclosing risk for cognitive impairment to cognitively healthy people, or disclosing risk for Alzheimer's disease (AD) dementia to people with Mild Cognitive Impairment (MCI) due to AD.
- Specific recommendations when disclosing risk for cognitive impairment to cognitively healthy people.
- Specific recommendations when disclosing the risk for AD dementia to people with a diagnosis of MCI due to AD. The recommendations are aimed at both clinicians and researchers, as the risk disclosure may happen during someone's participation in research or as part of a person's proactive search for their risk status in a clinical practice.

The position statement calling for open, honest, empathetic and compassionate disclosure of dementia risk in both research and clinical practice was published on 30 November 2023.

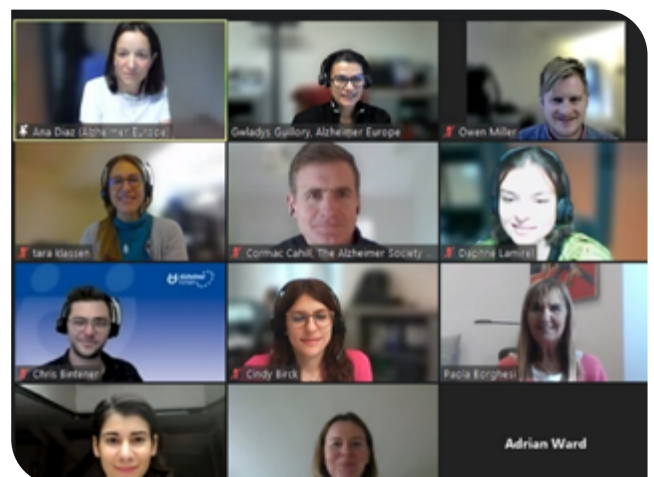
Contributing to scientific publications on brain health

In 2023, Alzheimer Europe also continued its collaboration with the European Union Geriatric Medicine Society and other scientific organisations. This collaboration resulted in the development of guidelines on physical activity and exercise in MCI and dementia, which was published in the journal *European Geriatric Medicine*.

Alzheimer Europe also joined a task force of European experts to discuss how brain health services could be further developed and promoted. This resulted in a scientific paper "Dementia prevention in memory clinics: recommendations from the European task force for brain health services", which was published in the journal *Lancet Regional Health - Europe*.

Objective 5: Strengthening the European dementia movement

In 2023, Alzheimer Europe 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 Helsinki and continued its collaboration with other European and international organisations.



Online Alzheimer's Association Academy on legal capacity and decision-making, 13 November 2023

Alzheimer's Association Academy

In 2023, Alzheimer Europe organised three in-person and six online Alzheimer's Association Academy meetings which were attended as follows (see tabel on next page).

Date	Topic	Format	Number of participants	Countries represented
24 January	Artificial intelligence in dementia research	Online	46	16
28 February	Understanding clinical trials	Online	33	9
22 March	National policy and campaigning activities	In-person in Brussels	29	21
26 April	Dementia and the LGBTQ+ community	Online	39	11
6 June	European Parliament elections and European Dementia Manifesto European Parliament elections and European Dementia Manifesto Advent of anti-amyloid treatments for Alzheimer's disease in Europe Risk prediction, brain health and prevention Impact of COVID-19 on Alzheimer's associations The United Nations Convention on the Rights of People with Disabilities	In-person in Brussels	27	20
4 July	Providing services and support for people with young onset dementia	Online	43	12
13 November	Legal capacity and decision making	Online	36	9
5-6 December	Public Affairs Meeting Helsinki Manifesto Advent of anti-amyloid treatments for Alzheimer's disease in Europe European Dementia Monitor Brain health in national Alzheimer's associations	In-person in Brussels	35	21
11 December	Continence care	Online	35	7



Alzheimer Europe Public Affairs meeting with members, Brussels (Belgium), 5 December 2023



INTERDEM Annual Meeting, Helsinki (Finland), 15 October 2023

A total of 30 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 two online meetings (20 February and 25 September) as well as three in-person meetings in Brussels on 20-21 March, 5 June and 4 December. 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 General Meeting (AGM).

The AGM of Alzheimer Europe was also held in-person and took place in Helsinki on 16 October prior to the organisation’s Annual Conference. Of Alzheimer Europe’s 37 full member organisations, 33 (or 89.19%) were present or represented at the Annual General Meeting. 27 associations (72.97%) were present and six associations (16.22%) were represented by proxy.

Online Alzheimer’s Association Academy on “Providing services and support for people with young onset dementia”, 4 July 2023



Annual General Meeting of Alzheimer Europe, Helsinki (Finland), 16 October 2023

During the AGM, the “Helsinki Manifesto” with the political priorities of the European dementia movement was adopted. The Alzheimer Europe AGM also celebrated the organisation’s achievements in 2022, its 2022-2023 finances and shared its plans for 2024 with meeting participants and observers. Both the Chairperson of the European Working Group of People with Dementia, Chris Roberts (UK – England, Wales and Northern Ireland) and the Chairperson of the European Dementia Carers Working Group, Sonata Mačiulskytė (Lithuania) then addressed the attendees of the meeting and following their speeches, the meeting closed with the AGM unanimously adopting Alzheimer Europe’s 2024 Work Plan and Budget.

Collaboration with other organisations

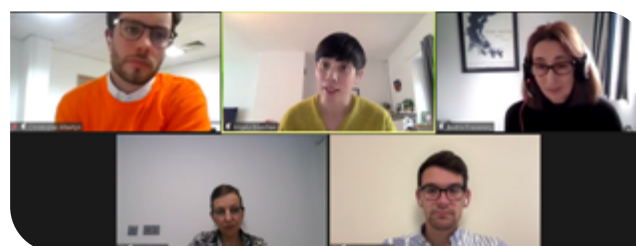
Alzheimer Europe continued its close collaboration with the INTERDEM network of European researchers involved in psychosocial research in dementia. In 2023, Alzheimer Europe:

- Hosted the Annual General Meeting of INTERDEM on 15 and 16 October prior to the Annual Conference in Helsinki attended by 99 researchers, involved the INTERDEM Chairperson Marjolein de Vugt in the opening ceremony and dedicated four parallel sessions to activities and research carried out by the group,
- collaborated with the INTERDEM Academy to launch 10 bursaries for early stage researchers from underrepresented countries and organised a special session for “Dementia Researchers of the Future” which was chaired by INTERDEM Academy Chair Fania Dassen and the Alzheimer Europe Foundation Treasurer Iva Holmerová,
- contributed to the INTERDEM interest group on prevention and risk reduction.

In 2023, Alzheimer Europe continued its contribution to a project of the European Academy of Neurology (EAN) on the burden of sleep-wake disorders and updated the memorandum of understanding on this collaboration. 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. Alzheimer Europe also joined the Brain Health Mission which is coordinated by EAN.

In October, Alzheimer Europe again endorsed the Older Adults Mental Health Awareness Week, organised by the International Psychogeriatric Association (IPA) from 1-10 October with the United Nations’ International Day of Older Persons kicking off the event on 1 October, and the WHO World Mental Health Day concluding the Awareness week on 10 October. Alzheimer Europe also signed a memorandum of understanding with IPA formalising the partnership between the two organisations.

Finally, as a full member of the European Disability Forum and European Patients’ Forum, Alzheimer Europe continued its close collaboration with both organisations.



Online Alzheimer’s Association Academy on “Understanding clinical trials”, 28 February 2023

Objective 6: Supporting dementia research

In 2023, Alzheimer Europe continued its collaboration with a growing number of EU projects (see chapter 1.5.1. below), contributed to Public Involvement (PI) activities of these projects, communicated about research findings via its newsletter, website and social media and organised its 33rd Annual Conference in Helsinki from 16 to 18 October 2023.

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 PI activities as well as contributing to the ethical issues raised by research projects and supporting the communication activities of these projects.

The European Working Group of People with Dementia (EWGPWD) and the newly created European Dementia Carers Working Group (EDCWG) actively supported the PI activities of Alzheimer Europe in EU-funded research projects, and provided important feedback through consultations for the following projects: ADIS, AI-MIND, DISTINCT, e-BRAIN-Health, EPND, EU-FINGERS, LETHE, Multi-MeMo, Pattern-Cog, RADAR-AD and VirtualBrain-Cloud. This work was acknowledged in a scientific article "Keeping track of and recognising the value of PI work in dementia research" which was published in the *Frontiers in Neurology* journal. A full list of EU projects and PI activities can be found in the project section below.

From 14 and 16 November, Alzheimer Europe brought together six European research projects for an unprecedented series of consultations focusing on PI in dementia and brain health research. A total of 44 members from the advisory boards of the ADIS, eBRAIN-Health, EPND, EU-FINGERS, LETHE and Multi-MeMo met in Luxembourg in the first collaborative meeting of this type and scale, uniting projects working on different aspects of dementia research, funded through the three largest research and innovation programmes in Europe: The Joint Programme on Neurodegenerative Diseases (JPNND), the Innovative Health Initiative (IHI) and Horizon Europe.

In 2023, Alzheimer Europe launched its new online PI Pool and invited individuals affected by and interested in dementia and brain health to join the new platform. By joining the PI pool, members will have the opportunity to provide input on different aspects of ongoing European research initiatives.

Finally, Alzheimer Europe collaborated with the DECIDE-SR project to help create a framework for the active involvement of people living with dementia in systematic reviews. The findings were published in a paper "Participatory development of a framework to actively involve people living with dementia and those from their social network, and healthcare professionals in conducting a systematic review: the DECIDE-SR protocol" in the *BioMed Central (BMC)* journal.

Research communication

For the dissemination of research findings via its newsletter, website and conference, Alzheimer Europe ensured that it not only focused 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.

As in previous years, 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 included 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 488 articles were featured in Alzheimer Europe's 2023 monthly e-newsletters (524 in 2022). They can be broken down into categories, as follows:

Subject	Number of articles (2023)	Number of articles (2022)
COVID-19 situation and Ukraine		15
Activities and projects of Alzheimer Europe	165	147
European policy developments in the field of dementia and European Alzheimer's Alliance	51	69
National policy developments	35	29
Activities and projects of Alzheimer Europe member organisations	85	69
Scientific developments	88	116
Dementia in Society and "Living with dementia" section	34	35
New resources and publications, education and job opportunities	30	44
TOTAL	488	524

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

Month	Delivered to	Opened by	Percentage
January	7,252	2,659	36.67%
February	7,262	2,515	34.63%
March	7,278	2,667	36.64%
April	7,279	2,575	35.38%
May	7,504	2,774	36.97%
June	7,512	2,637	35.10%
July-August	7,515	2,833	37.70%
September	7,518	2,838	37.75%
October	7,530	2,898	38.49%
November	7,500	2,704	36.05%
December	7,441	2,564	34.46%

In 2023, Alzheimer Europe's website saw an increase of 16% in visitors and had the following number of users:

Month	Users (2023)	Users (2022)
January	4,757	4,364
February	5,150	3,358
March	6,300	3,527
April	4,600	3,373
May	4,800	3,639
June	5,100	3,775
July	5,300	3,509
August	3,700	3,865
September	4,400	4,887
October	6,300	6,363
November	4,400	5,055
December	3,300	4,389
Total:	58,107	50,104
Average:	4,842	4,175

The organisation also continued to develop its social media presence on Facebook and Twitter as well as on LinkedIn and YouTube. Alzheimer Europe's Facebook page registered 10,043 followers at the end of 2023 (9,783 at the end of 2022) and 3,603 followers on LinkedIn (2,194 at the end of 2022). As for X, formerly known as Twitter, the association had reached 14,200 followers at the end of 2023 (13,600 at the end of 2022).

Unfortunately, due to a number of restrictions imposed by X, it was no longer possible to accurately measure the number of tweets of Alzheimer

Europe and its staff members or the number of impressions generated by these tweets.

Finally, on YouTube, Alzheimer Europe had 355 subscribers (317 in 2022) and videos of the organisation were viewed as follows:

Year	Views	Watch time (hours)	Subscribers total
2022	8,472	385.7	317
2023	7,941	329	355

In 2023, the Executive Director of Alzheimer Europe was invited to co-edit an e-book on "Impacts of public-private collaborative research on Alzheimer's disease: the case of the Innovative Medicines Initiative (IMI)". The e-book was published by Frontiers in Neurology, and Jean Georges co-edited the book together with Elisabetta Vaudano from the Innovative Health Initiative (IHI), Monica Ensinì from the Health and Digital Executive Agency of the European Commission, Martin Hofmann-Apitius from Fraunhofer Institute for Algorithm and Scientific Computing and Daniel Lo from the National Center for Advancing Translational Sciences. A total of 11 research papers on past and ongoing IMI and IHI projects were included in the collection, including six projects with involvement from Alzheimer Europe (AMYPAD, EPAD, EPND, Neuronet, PROMINENT and RADAR-AD). Among the contributing authors of these papers were Alzheimer Europe staff members: Cindy Birck, Angela Bradshaw, Ana Diaz, Jean Georges, Dianne Gove, Daphné Lamirel and Soraya Moradi-Bachiller.

Alzheimer Europe Conference

The 33rd Alzheimer Europe Conference (#33AEC) "New opportunities in dementia care, research and policy" took place at the Messukeskus in Helsinki, Finland from 16 to 18 October 2023. The conference was held as a hybrid event. In total, 1130 participants were registered from 48 countries of which 997 attended in person and 133 online.

	2023 Helsinki	2022 Bucharest
Academics/Researchers	404	228
AE staff & volunteers	217	124
Health or social care professionals	214	74
Students	96	32
Industry representatives	68	29
Carers	41	21
People with dementia	52	20
Civil servants	21	6
Policy makers	7	5
Press	10	4
Total:	1130	543



Speakers and moderators at the Opening Ceremony of the 33rd Alzheimer Europe Conference, Helsinki (Finland), 16 October 2023

As in previous years, the conference was formally opened by the Chairpersons of Alzheimer Europe, the host association, Muistiliitto, the Alzheimer's Society of Finland and of INTERDEM. Kaisa Juuso, the Minister of Social Affairs and Health participated in person whereas Helena Dalli, EU Commissioner for Equality and Stella Kyriakides, EU Commissioner for Health and Food Safety sent a recorded welcome message to the attendees.

On the agenda were over 450 presenters (210 oral presentations, 90 quick oral presentations and 260 poster presentations), who shared their research, knowledge and experience in an atmosphere of collaboration and solidarity.

The plenary sessions were dedicated to "From personal experiences to political advocacy" (organised and moderated by the European Working Group of People with Dementia), Brain Health and Prevention, Intersectionality, New Opportunities in dementia care, and a Research and Policy round table on "dementia as a public health and research priority".

In addition to these plenaries, delegates at #33AEC had a choice of 48 different parallel sessions and six special symposia organised by the sponsors of the Alzheimer Europe Conference.

As in previous years, the Alzheimer Europe Foundation provided bursaries for people with dementia to attend the conference and supported

the costs of the meetings of the European Working Group of People with Dementia and the European Dementia Carers Working Group, which took place prior to the Conference. In 2023, the Alzheimer Europe Foundation also partnered with the INTERDEM Academy to provide bursaries for early stage researchers from underrepresented countries to attend the conference.

In the evaluation of the Annual Conference, 93.79% of participants said that they would be happy to recommend the Alzheimer Europe Conference to a colleague.



Members of the European Working Group of People with Dementia at ADIS and EPND project consultations, Luxembourg, 15 November 2023

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 Horizon 2020, Horizon Europe, the Innovative Health Initiative (IHI) and the Innovative Medicines Initiative (IMI). 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 2023, Alzheimer Europe was a full partner in the following projects:

ADIS



ADIS General Assembly meeting, Tel Aviv (Israel), 31 January 2023

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 would allow us to reliably distinguish AD patients at different stages of the disease from healthy subjects; and to understand the extent to which sleep disturbances might influence blood-based biomarkers.



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

From each of the blood samples, researchers will measure different molecular markers, including measurement at the cellular level. They 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 researchers evaluate whether measuring blood-based biomarkers and sleep disturbances would be instrumental in detecting AD at an early disease stage.

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

In 2023, they:

- took part in two General Assembly meetings; one in Tel Aviv, Israel from 31 January to 1 February and the other online on 11 July
- represented Alzheimer Europe in the monthly telephone conference calls
- contributed to the technical report
- developed and maintained the website & social media channels
- developed other communication materials such as an extended project clip and interviews with early-career researchers
- planned, prepared and conducted, in close collaboration with the project partner FCRB and Confederación Española de Alzheimer (CEAFA), four online meetings (three with the ADIS Advisory Board and one with Alzheimer Europe European Working Group of People with Dementia, EWGPWD), two in-person meetings (one with the ADIS Advisory Board and one with the EWGPWD), and one online end-of-the-year social event with the ADIS 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





AI-Mind General Assembly meeting, Helsinki (Finland), 19 October 2023

healthcare professionals in timely diagnosis and interventions for 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 Chris Bintener, Cindy Birck, Angela Bradshaw, Ana Diaz and Dianne Gove.

In 2023, they:

- attended the General Assembly Meetings on 16-17 March (Zurich) and 19-20 October (Helsinki) and organised an ethics workshop on the topic of “Bias & discrimination in the use of AI-based technologies in dementia prediction”,
- represented Alzheimer Europe in the AI-Mind Executive Board Committee and its quarterly telephone conferences,
- contributed to the production and maintenance of the communication tools,
- contributed to the internal newsletter,
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and events,
- organised an AI-Mind symposium at the 33rd Alzheimer Europe conference in Helsinki,
- contributed to an Alzheimer’s Association Academy on the topic of Artificial Intelligence.

eBRAIN-Health

eBRAIN-Health is a four-year Horizon Europe funded research project which was launched in July 2022 and involves 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 (PI) and ethics activities (led by Daphné Lamirel with support from Dianne Gove) and to contribute to communications and outreach work (led by Ange Bradshaw).



eBRAIN-Health Advisory Board, Luxembourg, 15 November 2023

In 2023, they:

- attended virtual project meetings, including a general assembly and technical coordination meetings,
- developed an ethical framework deliverable, outlining ethical concerns related to eBRAIN-Health and recommendations for project partners, and drawing from the findings of a scoping review and PI consultations,
- developed, in partnership with the University of Vienna, a policy brief deliverable on the topic of the EU Artificial Intelligence Act, outlining key ethical concerns and feedback from the advisory group,
- co-presented policy brief findings and PI feedback in a parallel session at the Alzheimer Europe conference,
- planned and conducted six online consultations (five with the eBRAIN-Health Public and Patient Advisory Group and one with the EWGPWD) on topics spanning the ethics of AI and digital brain twins and the communication of eBRAIN-Health to the public,
- organised one in-person meeting with the Advisory Group in Luxembourg focused on testing and gathering feedback on the usability of a cognitive training app and virtual reality tools developed as part of the project,
- disseminated eBRAIN-Health activities via the Alzheimer Europe newsletter and social media channels,
- contributed to the development of the eBRAIN-Health communication and dissemination plan, and public outreach strategy.

EPND



EPND was well-represented at the Alzheimer's Association International Conference in Amsterdam (Netherlands), 16 July 2023

The goal of the Innovative Medicines Initiative (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 five years from November 2021. The project will create a platform that will enable the sharing of high-quality bio-samples 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, leading a task on PI and participated in work packages on the establishment of the technical platform, ethical and legal issues, cohort interactions and sustainability.

Alzheimer Europe was represented by Angela Bradshaw, Ana Diaz, Dianne Gove and Daphné Lamirel.

In 2023, they:

- participated in the in-person Annual Meeting, as well as monthly Management Board and work package meetings,
- in close collaboration with the FEP (Spanish Parkinson's Federation), planned and conducted two virtual consultations and one in-person consultation with members of the EWGPWD on the topics of facilitators and barriers to effective and ethical PI work, and data sharing and consent,

- 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,
- collected feedback from the EWGPWD and EDCWG on the glossary,
- contributed extensively to a deliverable on tools for stakeholder engagement, outlining the feedback from PI consultations held with the EWGPWD and the Parkinson's group, and providing a comprehensive overview of the principles and importance of Public Involvement in the context of EPND,
- convened a meeting of the External Stakeholder Advisory Board, providing pre-reading materials, co-organising the agenda and format of the meeting, presenting the stakeholder engagement strategy of the project, and organising reporting and feedback on the meeting,
- coordinated the project's social media channels (Twitter/X, LinkedIn) and updates to the project's website, creating new content, publishing newsletters, brochures and information sheets on the project,
- organised the communication strategy and public launch of the EPND Catalogue, a searchable database allowing researchers to identify studies of interest for data and sample sharing
- organised the first public-facing webinar of the project on tools and resources to support biomarker discovery and development,
- contributed to the efficient communication of the project via the AE website, newsletter and events, including hosting a lunch symposium on data sharing at the 2023 AE Conference and an article in the Dementia in Europe magazine on the EPND Catalogue.

EU-FINGERS



EU-FINGERS was well-represented at the 33rd Alzheimer Europe Conference in Helsinki (Finland), October 2023

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 enable the next generation of clinical trial

researchers 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 PI activities and co-led the communication activities of the project. Alzheimer Europe was represented by Cindy Birck, Ana Diaz and Dianne Gove.

In 2023, they:

- coordinated the regular maintenance of the project's communication tools (i.e. website, Twitter, LinkedIn),
- produced several video interviews with members of the EU-FINGERS Advisory Board and researchers,
- contributed to the efficient communication of the project via the AE website, newsletter and events,
- organised an EU-FINGERS symposium at the 33rd Alzheimer Europe conference,
- coordinated the production of an EU-FINGERS supplement launched at the 33rd Alzheimer Europe conference,
- coordinated the activities and meetings of a project-specific Advisory Board composed of 15 members from different European countries 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 2023 Alzheimer's Association International Conference (AAIC) in Amsterdam, Netherlands,
- facilitated the involvement of a member of the Advisory Board in a special symposium about PI at the 2023 Alzheimer's Association International Conference (AAIC) in Amsterdam, Netherlands,
- organised a first in-person event in Luxembourg with members of the EU-FINGERS Advisory Board.

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 using a multi-domain lifestyle intervention built on a person-centred digital solution.

Alzheimer Europe contributed to the PI as well as communication and dissemination activities. Alzheimer Europe was represented by Christophe Bintener and Ana Diaz.



LETHE consortium meeting, Bologna (Italy), 5 June 2023

In 2023, they:

- collaborated with project partners to identify topics for the Advisory Board and to develop accessible documents for the meetings
- coordinated the regular online meetings of the project-specific Advisory Board which is composed of seven members with dementia or at a higher risk of dementia from Austria, Italy, Finland and Sweden
- organised an in-person event in Luxembourg with members of the LETHE Advisory Board
- 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 PI activities (activities report and ethical issues linked to the project)
- dedicated a session of Alzheimer Europe's Alzheimer's Association Academies 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 and The Lisbon Council for alignment in communication and dissemination 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.



Multi-MeMo



Online kick-off meeting for Multi-MeMo project, 30 May 2023

Multi-MeMo stands for “Shorter- and longer-term mechanisms of multimodal interventions to prevent dementia”. Funded by JPND, the project aligns experimental molecular, cellular, and animal models with a very strong array of unique multi-national multimodal human trials which have already demonstrated multi-year cognitive and functional benefits across the entire continuum from at-risk to prodromal disease stages. This will allow comprehensive in-depth analysis of multiple relevant molecular and cellular mechanisms that cannot be clarified from human trials alone, as well as to rapidly validate the identified mechanisms for clinical relevance using successful long-term (up to 11 years) human trial data and samples.

Alzheimer Europe is co-leading the work on PI and communication. Alzheimer Europe is represented in this project by Cindy Birck and Ana Diaz.

In 2023, they:

- took part in the online kick-off meeting on 30 May
- developed the project’s visual identity (logo), and main communication tools including the launch of the project’s website
- coordinated the production and regular maintenance of the project’s social media channels (Twitter & LinkedIn)
- featured Multi-MeMo in an article in the Dementia in Europe Magazine
- contributed to the efficient communication of the project via the Alzheimer Europe website and newsletter
- developed materials for setting up the Advisory Board
- participated in an in-person PI event in Luxembourg with members of the EU-FINGERS and LETHE Advisory Boards.



Pattern-Cog

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 the earliest signs of impending cognitive decline which would allow early and personalised multidomain interventions.

Alzheimer Europe is co-leading the work on PI and communication. Alzheimer Europe is represented in this project by Cindy Birck and Soraya Moradi-Bachiller.



Pattern-Cog holds its first General Assembly Meeting, Helsinki (Finland), 19 October 2023

In 2023, they:

- took part in the project General Assembly meeting in Helsinki, Finland on 19 October
- participated in the online Executive Board Management meetings
- planned, prepared and conducted three consultations with the Pattern-Cog Advisory Board (two online and one in-person)
- launched the project’s website, newsletter and flyer
- coordinated the regular maintenance of the project’s communication tools (i.e. website, Twitter & LinkedIn)
- contributed to the efficient communication of the project via the Alzheimer Europe website and newsletter.



PREDICTOM



PREDICTOM kick-off meeting, Stavanger (Norway), 15-16 November 2023

The PREDICTOM (Prediction of Alzheimer's disease using an AI driven screening platform) project, funded through IHI, saw its official start on 1 November 2023.

The goal of the PREDICTOM project is to develop a screening platform capable of identifying people at risk of dementia, before the first symptoms appear. Crucially, patients would be able to start the screening process from the comfort of their own homes. They could collect samples of bodily fluids, and use digital technologies to gather results (e.g. smartphone-based eye tracking and cognitive tests).

Samples will be sent to the PREDICTOM partners' laboratories, and then to the PREDICTOM platform for processing of the data. Algorithms based on artificial intelligence would then assess the person's risk of developing dementia and their prognosis. In this way, the platform will facilitate the early diagnosis of a wider range of people, enabling earlier intervention and hopefully slowing progress of the disease.

Alzheimer Europe is leading the work on PI and social and ethical implications. Alzheimer Europe is represented in this project by Dianne Gove, Ana Díaz and Soraya Moradi-Bachiller.

In 2023, they:

- contributed to the project press-release
- conducted several consultations with an Advisory Board composed of lay people (e.g. older people with an interest in brain health and carers of people with dementia).



PRODEMOS



PRODEMOS General Assembly, Amsterdam (Netherlands), 2 June 2023

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 healthcare settings. Originally scheduled to be a 60-month project, beginning 1 January 2018 and ending December 2022, the PRODEMOS project was extended by six months and came to an end in June 2023.

Alzheimer Europe supported the communication and dissemination activities and was represented by Jean Georges and Cindy Birck.

In 2023, they:

- took part in the final General Assembly Meeting in Amsterdam, Netherlands, on 2 June
- 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
- contributed to scientific publications
- featured PRODEMOS in an article in the Dementia in Europe Magazine.

PROMINENT

PROMINENT is a collaborative pan-European public-private partnership funded through the Innovative Health Initiative (IHI) for five years that started in June 2023. PROMINENT will create a digital platform for precision medicine to improve the diagnosis and treatment of neurodegenerative disease and co-morbidities. The overriding objective is to assist clinicians with individualised decision support in the evaluation of patients with suspected cognitive impairment.

Alzheimer Europe is leading the work on PI, stakeholder mapping and engagement as well as on communication and dissemination. Alzheimer Europe is represented in this project by Dianne Gove, Angela Bradshaw, Daphné Lamirel and Christophe Bintener.

In 2023, they:

- took part in the project General Assembly meeting in Stockholm, Sweden on 9 and 10 November
- represented Alzheimer Europe in the monthly WP1 telephone conference
- organised and moderated quarterly WP5 calls
- developed and maintained the project website, brand identity & social media channels as well as coordinated press release about the launch of the project
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and events
- set up the PROMINENT PI Board, involving people with dementia, people with MCI and carers of people with dementia from different countries in Europe
- organised the selection and appointment of the External Ethics Advisor and developed a report on the process, including the Memorandum of Understanding and the Non-Disclosure Agreement
- developed a Terms of Reference document for the PI Board and the planned PI activities for the project
- completed project deliverables, including a communication and dissemination strategy, and a report on a stakeholder mapping exercise, with identification of tools and initial roadmap for stakeholder engagement.



PROMINENT Consortium Meeting, Stockholm (Sweden), 10 November 2023



RADAR-AD



RADAR-AD final consortium meeting and public event, Amsterdam (Netherlands), 15 May 2023

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 AD.

Alzheimer Europe’s role in the project was to lead and support the PI activities of the project. The organisation was represented by Ana Diaz, Dianne Gove and Jean Georges in this project.

In 2023, they:

- organised and facilitated online and in-person consultations with members of the RADAR-AD Patient Advisory Group
- participated together with members of the Patient Advisory Board in the Final Public Event of the project in Amsterdam on 16 May
- contributed to a video clip about PI in RADAR AD and coordinated the participation of members of the Patient Advisory Board in the video clip
- co-authored two publications in peer-reviewed journals on the topics of ethical challenges of using remote monitoring technologies in research and the challenges and opportunities of using digital endpoints in research
- contributed to the project publications management team
- supported project outreach and awareness raising activities through AE social media, newsletter and website.



RECOGNISED

The RECOGNISED project (Retinal and cognitive dysfunction in type 2 diabetes: unravelling 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, exploitation and communication activities. Alzheimer Europe was represented by Angela Bradshaw.



RECOGNISED 4th Annual General Assembly, Barcelona (Spain), 18 September 2023

In 2023, she:

- participated in General Assembly meetings and regular work package meetings
- attended meetings of the Dissemination and Exploitation Board
- 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.



VirtualBrainCloud



The Virtual Brain Cloud consortium meeting, Barcelona (Spain)

The VirtualBrainCloud project was launched in December 2018 and concluded in May 2023. VirtualBrainCloud 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 ethical and legal questions, software integration, visualisation and interaction and communication and dissemination activities of VirtualBrainCloud.

Alzheimer Europe was represented by Angela Bradshaw, Ana Diaz and Dianne Gove.

In 2023, they:

- participated in quarterly General Assembly meetings and regular work package meetings
- contributed to the efficient communication of the project via the Alzheimer Europe website, newsletter and social media
- organised an in-person consultation with members of the European Dementia Carers Working Group (EDCWG) on trust and trustworthiness in Artificial Intelligence and data sharing
- building on feedback from the EDCWG, analysed the ethical challenges raised by the VirtualBrainCloud project, making recommendations for future development of the platform; publishing these reflections in a deliverable report co-authored with the University of Vienna.

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.

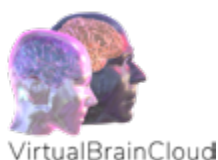
ABOARD

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 AD 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 disease-stages before dementia onset.

The project counts Alzheimer Europe among its more than 30 partners and Alzheimer Europe’s Executive Director Jean Georges is a member of the project’s Advisory Board. In 2023, Alzheimer Europe continued to support the communication activities of the project and hosted a workshop on research participation organised by ABOARD researchers at its Annual Conference in Helsinki.



ABOARD project “Midterm Meeting”, Amsterdam (Netherlands), 29 November 2023



ADAIR



ADAIR was well-represented at the 33rd Alzheimer Europe Conference in Helsinki (Finland), October 2023

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 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 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.

Jean Georges and Ana Diaz attended a number of meetings organised by the project. In 2023, Alzheimer Europe hosted a session of the ADAIR project at its Annual Conference and invited the Principal Investigator, Katja Kanninen from the University of Eastern Finland, to present the key aims and findings of the project at a lunch debate in the European Parliament on modifiable risk factors and as a plenary speaker at the Annual Conference in Helsinki.

DISTINCT

DISTINCT (Dementia: Intersectoral Strategy for Training and Innovation Network for Current Technology) is an EU-funded Marie Skłodowska-Curie Innovative Training Network which finished its work in 2023. Coordinated by the University of Nottingham, the network brought together 13 research organisations that hosted 15 early-stage researchers. Their focus was 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. A number of early-stage researchers of the project presented their findings at the Annual Conference in Helsinki.



INDUCT-DISTINCT update Best Practice Guidance on Human Interaction with Technology in Dementia

MIRIADE



Final MIRIADE training week, September 2023

MIRIADE (Multi-omics Interdisciplinary Research Integration to Address Dementia diagnosis) is another EU funded Marie Skłodowska-Curie Innovative Training Network which received continued funding in 2023. The project aims to generate a novel generation of scientists able to accelerate fluid biomarker development for dementias.

In 2023, Alzheimer Europe's role in the project was to support some of the dissemination and communication activities of the project.

RECAge



Sara Fascendini presents RECAge at Alzheimer Europe lunch debate, Brussels (Belgium), March 2023

Alzheimer Europe also collaborated with the RECAge (“Respectful caring for agitated elderly) project. This project, funded by the European Union’s Horizon 2020 programme aimed to understand the impact of special care units (SCU-B) for persons with dementia and behavioural and psychological symptoms. The mission of these SCU-Bs is to improve the patient’s behaviour, so as to allow, where possible, their return home.

Alzheimer Europe supported the organisation of the final consensus conference in Brussels on 21 and 22 February and Iva Holmerová, the former Chair of Alzheimer Europe, moderated the meeting of the Board evaluating the results of the project. In addition, Alzheimer Europe invited a representative of the project to contribute to the March lunch debate on modifiable risk factors and invited the project coordinators to organise a special session at the Annual Conference in Helsinki.

PRIME



PRIME project general assembly meeting, Budapest (Hungary), 10 May 2023

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 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 2023, she:

- participated in the in-person general assembly meeting, webinars and other PRIME events,
- contributed to the work of the Scientific and Ethical Advisory Board, Internal Innovation Board and Dissemination Team,
- with collaborators at the International Diabetes Federation-Europe, coordinated and delivered a presentation on engagement of researchers with patient organisations, patients and the general public.



Corporate affairs



The European Dementia Monitor 2023 was launched at our lunch debate in Brussels (Belgium), 5 December 2023

European Dementia Monitor

In 2023, Alzheimer Europe updated the findings of its European Dementia Monitor. The objective is to provide a benchmark of national dementia policies in order to compare and rate the responses of European countries to the dementia challenge. The survey covered all Member States of the European Union (with the exception of Latvia), as well as Armenia, Iceland, Israel, Jersey, North Macedonia, Norway, Serbia, Switzerland, Turkey, the United Kingdom (both England and Scotland) and Ukraine.

The European Dementia Monitor compares countries on 10 different categories:

- The availability of care services
 - The affordability of care services
 - The reimbursement of medicines and other medical interventions
 - The availability of clinical trials
 - The involvement of the country in European dementia research initiatives
 - The recognition of dementia as a policy and research priority
 - The development of dementia-friendly initiatives
 - The recognition of legal rights
 - The ratification of International and European human rights treaties
 - Care and employment rights
- According to the findings of the European Dementia Monitor, no country excelled in all 10 categories and there were significant differences between European countries. Some of the key findings were:
 - Luxembourg scored highest on care availability with most services rated as sufficiently available, whereas Norway scored highest on care affordability as it ensured that these services were accessible and affordable for people with dementia and their carers. On both care availability and care affordability, Bulgaria ranked last.
 - On the availability and reimbursement of medical interventions, Sweden scored highest as all included medical interventions (with the exception of Fortasyn Connect) were covered by the national reimbursement system. Armenia ranked last in this category as none of the medical interventions were reimbursed.
 - As Europe is waiting for the authorisation by the European Medicines Agency of new anti-amyloid treatments for Alzheimer's disease (AD), only Greece, Ireland, Slovakia, Sweden and the United Kingdom (England) had set up a working group or strategy to prepare for the introduction of these new treatments.
 - France scored highest in the category of clinical trials as the only country where it was possible for people with dementia to take part in eight of the 10 phase III clinical trials which were studied for the report. The Netherlands, Spain and the United Kingdom came second, with seven clinical trials active in these countries. Armenia, Lithuania, Luxembourg, Malta and North Macedonia were on the other end of the scale, with no clinical trials available for people with dementia in those countries.

- France, Germany and the Netherlands were the countries that were the most active in European dementia research collaborations scoring 100% in that category, whereas Armenia, Cyprus, Greece, Iceland, Lithuania, Malta, North Macedonia, Serbia and Ukraine were not involved in the Joint Programme for Neurodegenerative Diseases Research (JPND) or any of the calls for European research collaboration.
- For recognition of dementia as a national policy and research priority, the United Kingdom (Scotland) came first with full marks whereas North Macedonia, Serbia and Ukraine did not score any points in this category.
- The United Kingdom (England and Scotland) had the most dementia-inclusive initiatives and communities, but Luxembourg, North Macedonia, Portugal and Serbia did not score any points in this category.
- Regarding the protection of the legal rights of people with dementia, a growing number of countries complied with Alzheimer Europe's five recommendations in this field (Austria, Croatia, Czech Republic, Denmark, France, Germany, Iceland, Ireland, Israel, Italy, Jersey, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden and the United Kingdom (England)). However, Bulgaria, North Macedonia, Poland and Romania scored no points in this category.
- In relation to International and European Human Rights Conventions, there has been progress since earlier editions of the Monitor (2017 and 2020), with an increasing number of countries (Cyprus, Czech Republic, Estonia, Finland, France, Greece and Portugal) having signed and ratified all of the treaties. Israel was the country with the least number of conventions signed and ratified.
- The Czech Republic, the Netherlands and the United Kingdom (Scotland) were the three countries where all care and employment rights were recognised, whereas Armenia, Cyprus and Ukraine came last in this category with none of these rights recognised in legislation.
- The European Dementia Monitor was published in December 2023 and the findings were presented at a European Parliament lunch debate on 5 December 2023.

European Parliament lunch debates

Alzheimer Europe held three European Parliament lunch debates in 2023:

- On 21 March, Sirpa Pietikäinen, MEP (Finland) hosted a lunch debate entitled "Dealing with behavioural and psychological symptoms in dementia carer".
- On 6 June, the lunch debate hosted by Milan Brglez, MEP (Slovenia) was dedicated to "The role of modifiable risk factors for the prevention of dementia".
- The third lunch debate on 5 December was hosted by Deirdre Clune, MEP (Ireland) on the topic of "Inequalities in access to dementia care and treatment in Europe".
- Amongst the speakers were:
 - Sube Banerjee, Professor of Dementia, University of Plymouth, United Kingdom
 - Abida Durrani, Coordinator for International Affairs on dementia, long-term care and ageing, Ministry of Health, Welfare and Sport, Netherlands



Alzheimer Europe hosts a European Parliament lunch debate, Brussels (Belgium), 5 December 2023



Alzheimer Europe hosts a European Parliament lunch debate, Brussels (Belgium), 21 March 2023

- Sara Fascendini, Director, Alzheimer Medical Centre, Fondazione Europea Ricerca Biomedica, Italy
- Jean Georges, Executive Director, Alzheimer Europe
- Jacqueline Hoogendam, Coordinator for International Affairs on dementia, long-term care and ageing, Ministry of Health, Welfare and Sport, Netherlands
- Katja Kanninen, Professor at the Faculty of Health Sciences, University of Eastern Finland, Finland
- Øyvind Kirkevold, Assistant Research Director, Norwegian National Advisory Unit on Ageing and Health, Norway
- Gill Livingston, Professor of Psychiatry of Older People, University College London, United Kingdom
- Sonata Mačiulskytė, Chairperson, European Dementia Carers Working Group, Lithuania
- Owen Miller, Policy Officer, Alzheimer Europe
- Chris Roberts, Chairperson, European Working Group of People with Dementia, United Kingdom
- Tom C. Russ, Consultant Psychiatrist, University of Edinburgh, United Kingdom
- Jan Steyaert, Scientific Officer, Flemish Centre of Expertise on Dementia, Belgium
- Anca Toma, Executive Director, European Patients' Forum



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.

Dementia in Europe magazine



Dementia in Europe magazine issue 43 October 2023 - EU-Fingers supplement

In 2023, 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. All editions were printed and mailed, as well as distributed in PDF format.

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:

- Philippe Close, Mayor of Brussels, Belgium
- Áine Flynn, Director of the Decision Support Service, Ireland
- Frank Golden, person with dementia and author of "The Irish Job"
- Katarina Ivanković-Knežević, Director, Social Rights and Inclusion, European Commission
- Florence Lassarade, French Senator
- Borut Pahor, Former President of Slovenia



Milan Brglez MEP hosting our European parliament lunch debate, Brussels (Belgium), 6 June 2023

- Nicolas Schmit, Commissioner for Jobs and Social Rights
- Andreas Stein, Head of Unit for Civil Justice, European Commission
- Maree Todd, Minister for Social Care, Mental Wellbeing and Sport, Scotland, United Kingdom
- Olivia Wigzell, Director General of the Swedish National Board of Health and Welfare
- The 2023 issues included articles on a range of other relevant policy and research initiatives:
- Alzheimer Europe Campaign “What makes you, you?” for World Alzheimer’s Day
- Anti-Stigma initiatives
- Armenian National Dementia Plan
- Artificial intelligence in EU research projects (ADIS, eBRAIN-Health and Pattern-Cog)
- Brain Health Services
- Caring for people with dementia in the Ukraine
- Continence care
- Dementia Choirs
- Dementia-friendly cities
- Disease-modifying treatments for AD
- Dual heritage families and dementia
- EPND Cohort Catalogue

- European Care Strategy
- European Day of Persons with Disabilities
- French Assembly working group on AD
- Global Ageing Network
- Ireland’s assisted decision-making act
- LGBTQ+ community and dementia
- OECD report on end-of-life care
- Portuguese Museums for inclusion in dementia
- Protection of vulnerable adults
- Scotland’s fourth national strategy
- Sleep disorders and dementia
- Slovenian Dementia Strategy
- VirtualBrainCloud project
- WHO iSupport Network
- WHO Pan-European Mental Health Coalition

A special supplement dedicated to the findings of the EU-FINGERS project was published together with issue 43 of the magazine in October.



Sirpa Pietikäinen MEP hosting our European Parliament lunch debate, Brussels (Belgium), 21 March 2023

Clinical Trials Watch

In 2023, Alzheimer Europe continued with the development of its Clinical Trials Watch which provides accessible and up-to-date information on clinical trials that are investigating interventions for AD 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.

In 2023, Alzheimer Europe expanded its Clinical Trials Watch by also including information on non-drug trials.

By the end of 2023, the following 20 phase II trials, 17 phase III clinical trials and seven non-drug trials recruiting participants in Europe were included on the AE website:

Phase II trials				
Company	Study	Drug candidate	Population	Target
AC Immune	ABATE	ACI-24.060	Prodromal Alzheimer's disease	Amyloid-related (Immunotherapy)
Abbie	ABBV-552	ABBV-552	Mild Alzheimer's disease	Small molecule (other)
Treeway B.V.	ASURE	TW001	Mild Alzheimer's disease	Small molecule (other)
Roche	Brainshuttle AD	RO7126209	Prodromal or Mild to Moderate Alzheimer's disease	Amyloid-related (Immunotherapy)
Biogen	CELIA	BIIB080	Mild cognitive impairment or mild dementia due to Alzheimer's disease	Antisense oligonucleotide (ASO)
UCL	DESPIAD	CPHPC	Mild Alzheimer's disease	Anti-amyloid therapy (drug - Elimination SAP)
Denali Therapeutics	DNL593	DNL593	Frontotemporal Dementia	Other
Eisai	E2814-G000-103	E2814	Mild to Moderate Cognitive Impairment Due to Dominantly Inherited Alzheimer's Disease	Tau (Immunotherapy)
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
GemVax & Kael	GV1001	GV1001	Mild to moderate Alzheimer's disease	Immunotherapy (other)
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® NP03	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
Imperial College London	MET-FINGER	/	At risk of developing Alzheimer's dementia	Multidomain intervention
The Israeli Medical Center for Alzheimer's	NAVE-Sci-001	SCI-110	Alzheimer's disease and agitation	Other Neurotransmitters (Small Molecule)
University of Dublin, Trinity College	NITEGSON	/	Amnesic Mild Cognitive Impairment	Electrical stimulation
reMyND	REMAD-02	REM0046127	Mild to moderate Alzheimer's disease	Synaptic Plasticity/Neuroprotection
Maastricht UMC	ROMEMA	Roflumilast	MCI / Mild dementia	Anti-inflammatory

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)
Karuna Therapeutics	ADEPT-1	KarXT	Psychosis associated with AD dementia	Cholinergic System (small molecule)
Eisai	AHEAD 3-45	Lecanemab	At risk of developing Alzheimer's disease & Early Alzheimer's disease	Immunotherapy (passive)- 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
Washington University School of Medicine	DIAN-TU & DIAN-TU-001	Lecanemab, E2814, solanezumab, gantenerumab	Early onset Alzheimer's disease	Amyloid or Tau-related (Immunotherapy)
Biogen	ENVISION	Aducanumab	Early Alzheimer's disease	Amyloid-related (Immunotherapy)
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)
Suven Life Sciences Limited	Masupirdine	Masupirdine	Agitation in people with dementia	Small Molecule (other Neurotransmitter)
Fondation pour l'accueil et l'hébergement des personnes âgées	MedCanDem	Cannabis Sativa Oil	Severe dementia	/
Imperial College London	NorAD	Guanfacine	Mild to moderate Alzheimer's disease	Neurotransmitter based (noredraline)
Novo Nordisk	Semaglutide	Semaglutide	MCI or mild dementia	Other
Eli Lilly	TRAILBLAZER-ALZ6	Donanemab	Early Alzheimer's disease	Amyloid related (immunotherapy)
Non-drug trials				
Company	Study	Population	Target	
University of Bergen	ALMUTH	Mild (early) Alzheimer's disease or Mild Cognitive Impairment	Neurocognitive music therapy	
University of Bern	Cognitive training	Early Alzheimer's disease	Computerised cognitive training	
Roche	EAPP	At risk of developing Alzheimer's dementia or family history of Alzheimer's disease	Clinical performance study for the Elecsys® Amyloid Plasma Panel	
Alzheimercentrum Amsterdam	FINGER-NL	At risk for cognitive decline	Multi-domain lifestyle intervention	
Kuopio University Hospital	Gamma tACS	Dementia with Lewy Bodies, Alzheimer's disease, Frontotemporal dementia	Brain Stimulation	
University of West Attica	Mental Imagery	Early dementia	Mental Imagery	
Haukeland University Hospital	N-DOSE-AD	Early Alzheimer's disease	Dietary supplement	

Other corporate activities

In 2023, Alzheimer Europe received funding from Gates Ventures for a project to monitor the data sharing policies and practices in European dementia research projects, to identify synergies and promote collaboration between projects, to explore views of the general public on research expectations and attitudes towards data sharing and to better understand the experiences of research participants involved in dementia research. The project will be launched more fully in 2024, but a symposium on data sharing in dementia research was organised during the Alzheimer Europe Conference in Helsinki.

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.

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 2023 Operating Grant

Date	Meeting	Venue
28 January	European Working Group of People with Dementia	online
19 January	Introductory meeting of European Dementia Carers Working Group	online
24 January	Alzheimer's Association Academy on "Artificial Intelligence in dementia research"	online
15 February	European Working Group of People with Dementia	online
20 February	Alzheimer Europe Board	online
28 February	Alzheimer's Association Academy on "Understanding clinical trials"	online
7 March	European Working Group of People with Dementia	online
20-21 March	Alzheimer Europe Board	Brussels, Belgium
21 March	European Dementia Carers Working Group	Brussels, Belgium
22 March	Public affairs meeting	Brussels, Belgium
26 April	Alzheimer's Association Academy on "The LGBTQ+ community and dementia"	online
5 June	Alzheimer Europe Board	Brussels, Belgium
6-7 June	European Group of Governmental Experts on Dementia	Brussels, Belgium
6-7 June	European Working Group of People with Dementia	Brussels, Belgium
22 June	European Dementia Carers Working Group	online
6-7 June	Public Affairs meeting	Brussels, Belgium
4 July	Alzheimer's Association Academy on "Providing services and support for people with young onset dementia"	online
25 September	Alzheimer Europe Board	online
15-16 October	European Working Group of People with Dementia	Helsinki, Finland
15-16 October	European Dementia Carers Working Group	Helsinki, Finland
16 October	Annual General Meeting	Helsinki, Finland
13 November	Alzheimer's Association Academy on "Legal capacity and decision making"	online
14-16 November	AE Public Involvement event	Luxembourg, Luxembourg
28 November	Consultation with European Dementia Carers Working Group	online
4 December	Alzheimer Europe Board	Brussels, Belgium
5-6 December	Public Affairs meeting	Brussels, Belgium

Meetings attended by Alzheimer Europe representatives in the framework of the 2023 Operating Grant

Date	Meeting	Venue
13 January	Meeting with WHO Europe	online
13-14 February	High Level Meeting on Active and Autonomous Ageing of the Swedish EU Presidency	Stockholm, Sweden
1-2 March	EMA multi-stakeholder workshop on medicines shortages	online
3 March	Meeting of EMA Patients' and Consumers' Working Party	online
7 March	Hearing "Towards a European Health Union and European Global Health Strategy fully inclusive of Persons with Disabilities" of European Economic and Social Committee	online
19 April	EMA Webinar	online
21 April	European Commission webinar on European initiative on mental health	online
27 April	Launch of the European Disability Forum's human rights report on employment	online
10 May	European Commission Stakeholders Dialogue on pharmaceutical package	online

Date	Meeting	Venue
22 May	General Assembly of European Disability Forum	Brussels, Belgium
23 May	5 th European Parliament of Persons with Disabilities	Brussels, Belgium
25 May	EU4Health Civil Society Alliance meeting	online
25 May	EMA Patients and Consumers' Working Party	online
16 June	EMA webinar on the revision of the EU pharmaceutical legislation	online
20 June	ENGO meeting coordinated by the European Disability Forum	online
27-28 June	Meetings of EMA Patients' and Consumers' Working Party	Amsterdam, Netherlands
28 June	Strategic Dialogue on Annual Work programme of ESF+	online
5 July	European Commission/World Health Organization briefing on the partnership for long-term care	online
20 July	Joint meeting of EMA Patients' and Consumers' Working Party and FDA Patient Engagement Collaborative	online
19 September	European Disability Forum briefing on European Disability Card	online
19-20 September	EMA meetings of the Patients' and Consumers' and Healthcare Professionals' Working Parties	online
21 September	EU4Health Civil Society Alliance	online
4 October	European Parliament meeting on EU Cross Border Associations Directive	online
5 October	European NGO meeting hosted by European Disability Forum	online
10-12 October	"Regional summit on policy innovation for healthy ageing in the WHO European region" hosted by WHO Europe	Lisbon, Portugal
13 October	Presentation of report on persons with disabilities by European Court of Auditors	online
14 November	Consultation on WHO Europe Framework	online
14 November	EMA Patients' and Consumers' Working Party meeting	online
29 November-1 December	European Day of Persons with Disabilities (EDPD) conference	Brussels, Belgium
4 December	EMA/HMA Big Data Stakeholder Forum	online
7 December	EMA Network Advisory Group on Raw Data	online
12 December	17 th Rencontres France Alzheimer	Paris, France
15 December	Meeting with national representatives of EU Joint Action on Dementia	online

Other meetings organised by Alzheimer Europe

Date	Meeting	Venue
30 January	Consultation with EWGPWD for the EPND project	online
16 February	INTERDEM Academy Advisory Board	online
20 February	Alzheimer Europe Foundation Board	online
14 March	Alzheimer Europe Conference Committee	online
21 March	European Parliament lunch debate "Behavioural and psychological symptoms (BPSD) in dementia care"	Brussels, Belgium
21 March	Company round table	Brussels, Belgium
2 May	Alzheimer Europe Conference Committee	online
6 June	Company round table	Brussels, Belgium
6 June	European Parliament lunch debate "Modifiable risk factors of dementia"	Brussels, Belgium
7 July	Meeting with Chairs of the AAIC Public Involvement session	online
13 September	Alzheimer Europe Foundation Board	online
10 July	Alzheimer Europe Anti-Stigma Award Committee	online
26 July	Evidera consultation with members of EDCWG and EWGPWD	online
24 August	Field visit for the 33 rd Alzheimer Europe Conference	Helsinki, Finland
1 September	Evidera consultation with members of EDCWG	online
16-18 October	33 rd Annual Conference "New opportunities in dementia care, policy and research"	Helsinki, Finland
5 December	Company round table meeting	Brussels, Belgium
5 December	European Parliament lunch debate "Inequalities in access to dementia care and treatment in Europe"	Brussels, Belgium
11 December	Alzheimer's Association Academy meeting on "Sustainable Continence Care"	online

EU project meetings

Date	Meeting	Venue
16 January	EPND technical meeting	online
17 January	Pattern-Cog Executive Committee	online
20 January	RADAR-AD steering committee meeting	online
24 January	ADIS advisory board	online
30 January	eBRAIN-Health General Assembly Meeting	online
31 January	EPND Research Community Expert Group	online
31 January-1 February	ADIS General Assembly	Tel Aviv, Israel
1 February	Fonds National de la Recherche webinar on project reporting	online
1 February	MinD Network meeting	online
2 February	AI-Mind General Assembly Meeting	online
7 February	ADIS Advisory Board	online
8 February	eBRAINS PI consultation	online
21 February	RECage Consensus conference	Brussels, Belgium
7 March	ADIS consultation with EWGPWD	online
13 March	PRIME webinar	online
13 March	bPRIDE meeting	online
14 March	eBRAIN-Health Public and Patient Advisory Group	online
16 March	RECOGNISED meeting	online
16-17 March	AI-Mind General Assembly	Zurich, Switzerland
22 March	VirtualBrainCloud consultation of EDCWG	Brussels, Belgium
24 March	PROMINENT meeting	online
5 April	Final VirtualBrainCloud meeting	online
17 April	Preparatory meeting of the Multi-MeMo project	online
18 April	EU FINGERS and LETHE Advisory Boards	online
19 April	MIND network meeting	online
21 April	LETHE Advisory Board	online
25 April	ADIS Advisory Board	online
2 May	EPND Research Community Experts' Group	online
10-12 May	PRIME General Assembly	Budapest, Hungary
11 May	PROMINENT kick-off meeting	online
15 May	RADAR-AD consortium and Public Event	Amsterdam, Netherlands
17 May	EU-FINGERS Advisory Board	online
17 May	EPND External Stakeholder Advisory Board	online
19 May	LETHE Advisory Board	online
26 May	eBRAIN-Health General Assembly	online
30 May	PROMINENT steering committee	online
30 May	Multi-MeMo kick-off meeting	online
30 May	eBRAIN-Health Public and Patient Advisory Group	online
2 June	PRODEMOS Annual General Meeting	Amsterdam, Netherlands
5 June	RADAR-AD Qualification Advice meeting with EMA	online
15 June	PREDICTOM meeting	online
20 June	ADIS advisory board	online
6 July	ADIS General Assembly meeting	online
14 July	Communication representatives' meeting at EBRAINS	online
17 July	EPND consortium meeting	Amsterdam, Netherlands
29 August	PROMINENT WP4 Meeting	online
18 September	RECOGNISED General Assembly	online
21 September	eBRAIN-Health Public and Patient Advisory Group	online
5 October	VirtualBrainCloud final review meeting	online

Date	Meeting	Venue
18 October	AI-Mind ethics workshop	Helsinki, Finland
19 October	Pattern-Cog General Assembly	Helsinki, Finland
19 October	AI-Mind General Assembly	Helsinki, Finland
7 November	PREDICTOM Advisory Board	online
9-10 November	PROMINENT Annual Meeting	Stockholm, Sweden
28-30 November	EPND Annual Meeting	Athens, Greece
1 December	INTEREST kick-off meeting	online
5 December	PREDICTOM Advisory Board	online
8 December	Meeting with INTERDEM	online
12 December	ADIS Advisory Board	online
13 and 15 December	EBISC Consultation with EWGPWD	online
18 December	EWGPWD Xmas get together	online
19 December	EU-FINGERS and LETHE Advisory Boards	online
22 December	BRIDGE-AD preparatory meeting for BRIDGE-AD	online

Other meetings

Date	Meeting	Venue
10 January	GSK Health Advisory Board	online
17 January	Management Group meeting of the Dementia Panel of the European Academy of Neurology	online
18 January	Meeting with Essity	online
23 January	Introductory meeting with International Psychogeriatric Association	online
23 January	Meeting with AWO Bezirksverband Niederrhein	Germany
24 January	ENVISION final event	online
25 January	20 th Anniversary Programme Committee of European Patients' Forum	online
26 January	Precision medicine in Parkinson's disease conference	Luxembourg, Luxembourg
30 January	Finding Alzheimer's Solutions Together (FAST) Council	online
5 February	Meeting with Alzheon	online
10 February	Meeting with BioArctic	online
16 February	Coordination meeting of ENGOS	online
17 February	Meeting of European Alzheimer's Disease Consortium	online
2 March	Meeting with Patiro	online
11 March	EURAG (European Federation of Older Persons) Conference on Healthy and Unhealthy Aging of the Human Brain	Prague, Czech Republic
15 March	EFPIA think tank	online
16 March	EBC meeting on "Global Partnerships on Brain Research"	online
28-29 March	Data Saves Lives EPF AI-Bootcamp	Lisbon, Portugal
30 March	Meeting with PAVE (Project Alzheimer's Value in Europe)	online
20-31 March	AD/PD Conference and meeting with representatives of Biogen, Davos Alzheimer's Collaborative, Lilly, Prothena and Roche	Gothenburg, Sweden
3 April	Meeting with	online
4 April	PAVE (Project Alzheimer's Value in Europe) meeting	online
5 April	Meeting with MedTechEurope	online
5 April	Meeting with European Union Geriatric Medicines Society (EUGMS)	online
6 April	Meeting with Euronews	online
6 April	Meeting with TauRx	online
17 April	Meeting with Innovative Health Initiative	online
18 April	Meeting with the EFPIA AD Platform	online
18 April	Meeting of Management Group of Dementia Panel of European Academy of Neurology	online
18 April	Meeting with EventsForce	online

Date	Meeting	Venue
19 April	Study visit in Geneva for 34 th Alzheimer Europe Conference	Geneva, Switzerland
20 April	Roche workshop on inclusive dementia research	online
20 April	Meeting with EATRIS and Mission Lucidity	online
24 April	FAST (Finding Alzheimer's Solutions Together) policy squad meeting	online
25 April	Meeting with EFPIA	online
26 April	EuroHealthNet meeting	online
27-28 April	European Alzheimer's Disease Consortium meeting	Toulouse, France
28 April	INTERDEM taskforce on inequalities in dementia care	online
2 May	FAST (Finding Alzheimer's Solutions Together) Council	online
4 May	Meeting with Novo Nordisk	online
10 May	Meeting with Dementia Discovery Fund	Luxembourg, Luxembourg
15 May	Meeting with NHS England	online
22 May	Meeting with Alnylam	online
24 May	EFPIA Patient Think Tank	online
24-25 May	Euro-PAD neuroimaging symposium	London, UK
1 June	World-Wide FINGERS Network Meeting	online
9 June	Meeting with AAIC conference organisers	online
13 June	Council meeting of Alzheimer's Disease International	online
14 June	Meeting with TauRx	online
16 June	INTERDEM taskforce meeting on inequalities in dementia care	online
20 June	Meeting with representative of NH brand	online
21 June	Meeting of Davos Alzheimer's Collaborative	online
21 June	Meeting with EVIDERA	online
3 July	Meeting with Regenlife	online
3 July	Meeting with Essity	online
6 July	GSK Health Advisory Board	online
16 July	Meeting of WW Fingers collaboration	Amsterdam, Netherlands
16-20 July	Alzheimer's Association International Conference (AAIC)	Amsterdam, Netherlands
16-20 July	Meetings with Alector, Alzheimer's Association, Alzheon, Biogen, Bristol Myers Squibb, Davos Alzheimer's Collaborative, Eisai, Icometrix, Fundació Pasqual Maragall, GSK, Lilly, MSD, Novo Nordisk, PPD, Prothena, Scottish Brain Sciences, TauRx and World Dementia Council	Amsterdam, Netherlands
19 July	International Scientific Advisory Board of Amsterdam Alzheimer Center	Amsterdam, Netherlands
4 September	INTERDEM Task Force Inequalities in Dementia Care	online
6 September	Patient Think Tank meeting hosted by EFPIA	online
11 September	Meeting with Alector	online
12 September	Meeting with Bristol Myers Squibb	online
28 September	SciCom Luxembourg 2023 event	Luxembourg, Luxembourg
28 September	DataSavesLives Core Group meeting	online
29 September	Information Session about AE Public Involvement Pool	online
10 October	Steering group meeting of PAVE project	Lausanne, Switzerland
10-12 October	Lausanne X Workshop	Lausanne, Switzerland
24 October	NovoNordisk panel at AD strategy summit	online
25 October	5 th Annual Liverpool Dementia & Ageing Research Conference	Liverpool, UK
7 November	EFPIA roundtable on timely detection and care	Brussels, Belgium
9-11 November	X CEFA conference	Gijón, Spain
20 November	Meeting with Essity	online
21 November	Meeting with Novo Nordisk	online
22 November	EFPIA Patient Think Tank	online
12 December	Italian Knowledge Leaders, The Exchange	Florence, Italy
15 December	EFPIA AD Platform	online

Annex 2: Scientific publications in 2023

In 2023, Alzheimer Europe staff contributed to the following scientific publications:

Alzheimer Europe (2023). European Dementia Monitor 2023 - Comparing and benchmarking national dementia strategies and policies. ISBN 978-2-919811-12-0, Luxembourg, Alzheimer Europe.

Alzheimer Europe (2023). Guide on the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) and how national Alzheimer's associations can participate in the review process. ISBN 978-2-919811-13-7, Luxembourg, Alzheimer Europe

Alzheimer Europe (2023). Guidelines for the ethical and inclusive communication about/portrayal of dementia and people with dementia: for the media, researchers, journalists, policy makers and anyone responsible for the portrayal of or communication about dementia. ISBN 978-2-919811-07-6, Luxembourg, Alzheimer Europe

Alzheimer Europe (2023). Linee guida per comunicare e rappresentare in modo etico e inclusivo la demenza e le persone con demenza: Rivolte a media, ricercatori, giornalisti, politici e chiunque si trovi a trattare il tema della demenza. ISBN 978-2-919811-08-3, Luxembourg, Alzheimer Europe

Alzheimer Europe (2023). Sex, Gender and Sexuality in the Context of Dementia: A guide to raise awareness amongst health and social care workers. ISBN 978-2-919811-06-9, Luxembourg, Alzheimer Europe

Bradshaw A, Hughes N, Vallez-Garcia D, Chokoshvili D, Owens A, Hansen C et al. (2023). Data sharing in neurodegenerative disease research: challenges and learnings from the innovative medicines initiative public-private partnership model. *Frontiers in Neurology*. 20;14:1187095. DOI: [10.3389/fneur.2023.1187095](https://doi.org/10.3389/fneur.2023.1187095)

Brem A-K, Kuruppu S, De Boer C, Muurlin M, **Diaz-Ponce A**, **Gove D** et al. (2023). Digital endpoints in clinical trials of Alzheimer's disease and other neurodegenerative diseases: challenges and opportunities. *Frontiers in Neurology*. 14. DOI: [10.3389/fneur.2023.1210974](https://doi.org/10.3389/fneur.2023.1210974)

Ellison TS, Cappa SF, Garrett D, **Georges J**, Iwatsubo T, Kramer JH et al. (2023). Outcome measures for Alzheimer's disease: A global inter-societal Delphi consensus. *Alzheimer's & Dementia*. DOI: [10.1002/alz.12945](https://doi.org/10.1002/alz.12945)

Frisoni GB, Altomare D, Ribaldi F, Villain N, Brayne C (.../...) **Georges J** et al. (2023). Dementia prevention in memory clinics: recommendations from the European task force for brain health services. *The Lancet Regional Health - Europe*. DOI: [10.1016/j.lanepe.2022.100576](https://doi.org/10.1016/j.lanepe.2022.100576)

Hawksworth C, Salih F, Cresswell K, Steukers L, Diaz C (.../...) **Bradshaw A** et al. (2023). Participating in innovative medicines initiative funded neurodegenerative disorder projects—An impact analysis conducted as part of the NEURONET project. *Frontiers in Neurology*. 16;14:1140722. DOI: [10.3389/fneur.2023.1140722](https://doi.org/10.3389/fneur.2023.1140722)

Muurling M, Pasmooij AMG, Koychev I, Roik D, Lutz F, (.../...) **Diaz-Ponce A**, **Gove D** et al. (2023). Ethical challenges of using remote monitoring technologies for clinical research: A case study of the role of local research ethics committees in the RADAR-AD study. *PLoS ONE*. 7;18(7):e0285807. DOI: [10.1371/journal.pone.0285807](https://doi.org/10.1371/journal.pone.0285807)

Rommerskirch-Manietta M, Manietta C, Hoffmann AL, Rohra H, **Gove D** (.../...) **Diaz A** et al. (2023). Participatory development of a framework to actively involve people living with dementia and those from their social network, and healthcare professionals in conducting a systematic review: the DECIDE-SR protocol. *Research Involvement and Engagement*. 1;9(1):52. DOI: [10.1186/s40900-023-00461-2](https://doi.org/10.1186/s40900-023-00461-2)

Tate A, Suárez-Calvet M, Ekelund M, Eriksson S, Eriksson M (.../...) **Georges J** et al. (2023). Precision medicine in neurodegeneration: the IHI-PROMINENT project. *Frontiers in Neurology*. 14:1175922. DOI: [10.3389/fneur.2023.1175922](https://doi.org/10.3389/fneur.2023.1175922)

Vaudano E, **Georges J**, Hofman-Apitius M, Lo D. (2023). Editorial: Impacts of public-private collaborative research on Alzheimer's disease: the case of the innovative medicines initiative. *Frontiers in Neurology*. DOI: [10.3389/fneur.2023.1321225](https://doi.org/10.3389/fneur.2023.1321225)

Veronese N, Soysal P, Demurtas J, Solmi M, Bruyère O (.../...) **Georges J** et al. (2023). Physical activity and exercise for the prevention and management of mild cognitive impairment and dementia: a collaborative international guideline. *European Geriatric Medicine*. DOI: [10.1007/s41999-023-00858-y](https://doi.org/10.1007/s41999-023-00858-y)

Ziebuhr B, Zanasi M, Bueno Aguado Y, Losada Durán R, Denning T (.../...) **Diaz A** et al. (2023). Living Well with Dementia: Feeling Empowered through Interaction with Their Social Environment. *International Journal of Environmental Research and Public Health*. 20,6080. DOI: [10.3390/ijerph20126080](https://doi.org/10.3390/ijerph20126080)

Financial Report

Preface

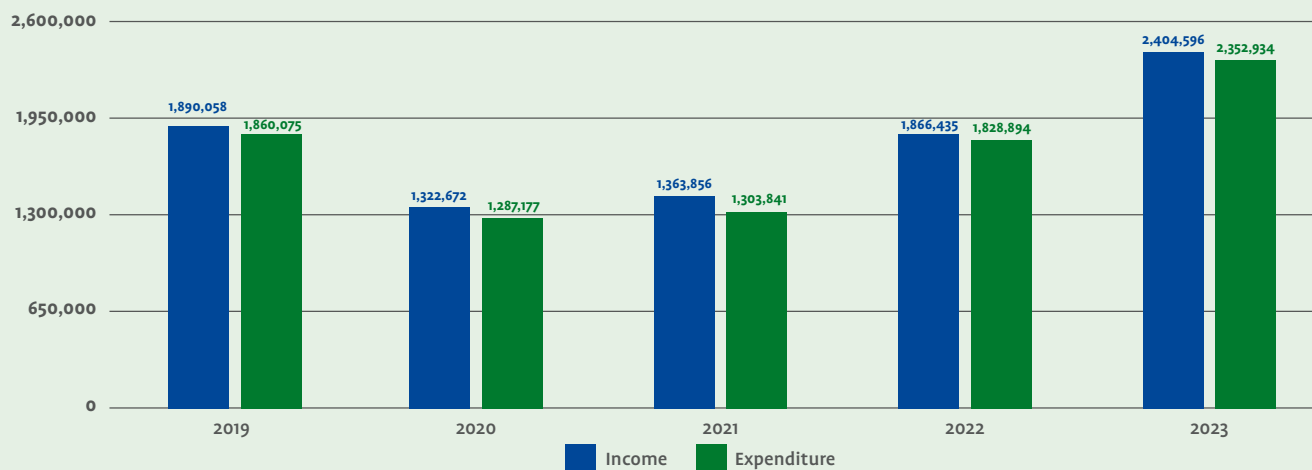
A few words from our Honorary Treasurer



Marco Blom

It gives me great pleasure to present another positive set of financial accounts for Alzheimer Europe. 2023 was a record year in many respects: with EUR 2.4 million income, it was the first time that the total income of the association exceeded EUR 2 million. As can be seen from the below graph; the total income increased by close to 29% compared to 2022 and by 76% compared to 2021, when the income was still affected by the COVID pandemic.

Evolution of income and expenditure



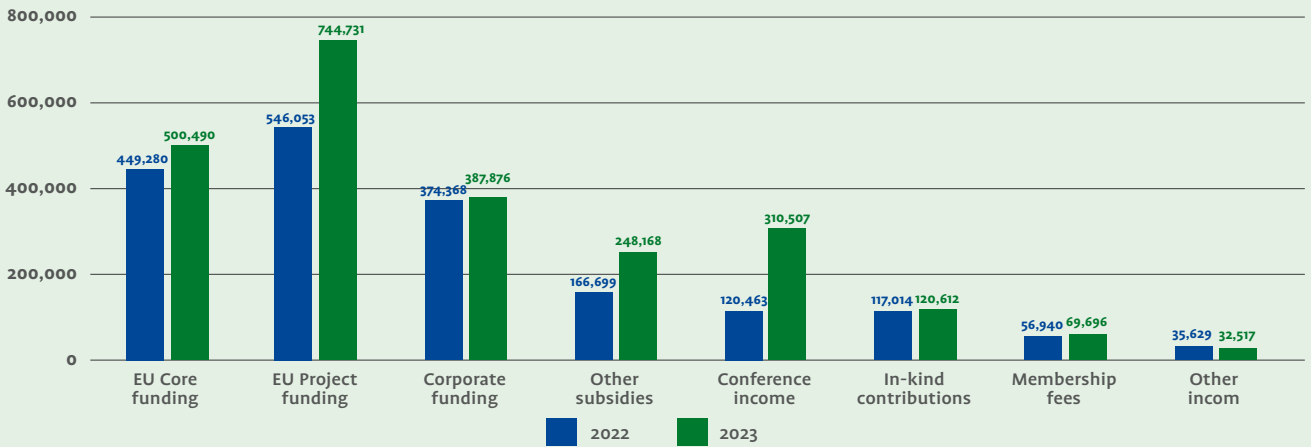
As can be seen from the graph (top of p51), almost all income categories exceeded the 2022 levels by a healthy margin. However, the increase in overall income was particularly driven by the increase in EU project funding and the income from the Annual Conference in Helsinki which attracted record numbers of participants.

The expenditure (see graph at bottom of p51) increased in line with the expansion of the income and 2023 was also the first year that the expenditure exceeded EUR 2 million. This was primarily due to the increase in AE staff members working on the expanding list of European projects, as well as the successful Annual Conference in Helsinki which led to a corresponding increase in subsistence costs for delegates, as well as an increase in external staff dealing with the organisational aspects for the conference.

I am particularly proud as Honorary Treasurer that we were able to deal with this expanding role of Alzheimer Europe in EU projects and the increasing cost of its Annual Conference and still close the year with a small operating surplus of EUR 51,663. Unlike previous years though, it was not possible to provide an additional grant to the Alzheimer Europe Foundation.

The reserves of the association increased from EUR 570,053 to EUR 621,715 which represent close to 4 months' running costs, but combined with the reserves of the Alzheimer Europe Foundation, we are closer to 8 months' running costs. I am therefore confident that the financial outlook of Alzheimer Europe continues to be positive.

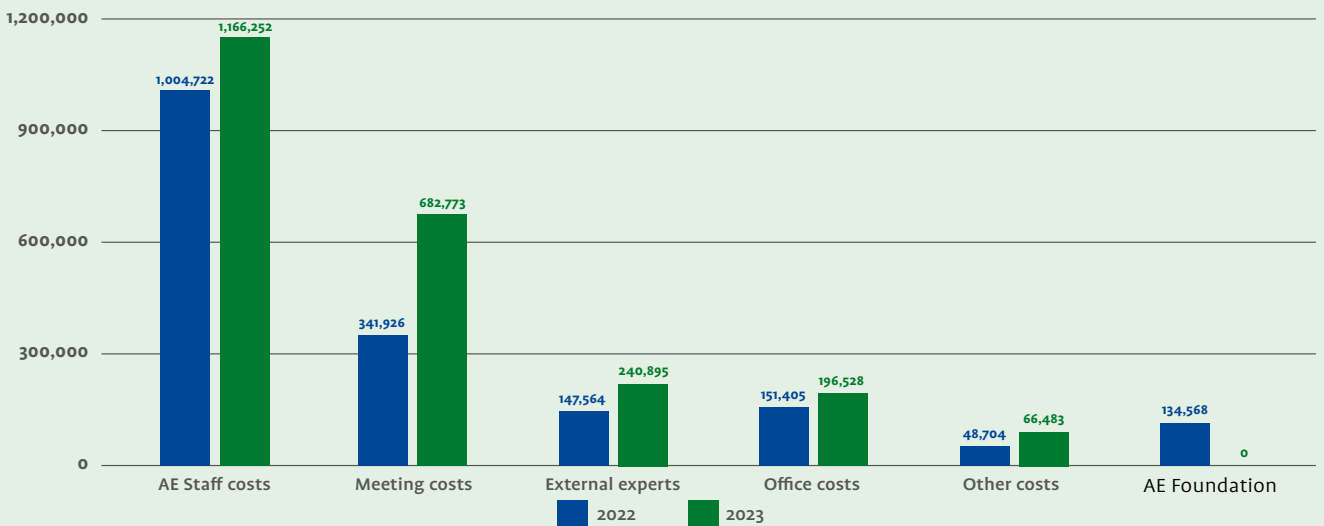
Total income in 2022 and 2023



Over the years, Alzheimer Europe has consistently been able to adapt to changing financial circumstances and was able to deal with the economic and health impact of the COVID pandemic, as well as the discontinuation of the framework partnership agreements under the European Union health programme. Instead, the association has now been able to implement the second operating grant under the disability

strand of the Citizens, Equality, Rights and Values programme of the European Union. In addition, the association has significantly expanded its project portfolio and has been able to identify a range of foundations, associations and corporate partners with whom to partner. This diversification of funding sources should make Alzheimer Europe more resilient for future financial challenges.

Total expenditure in 2022 and 2023



It will be impossible to thank all the sponsors and partners of the association in this preface, but I would like to encourage you to check out the page with all our supporters at the end of this financial report. Let me single out the Luxembourg Fondation Alzheimer though for again providing us with an incredibly generous unrestricted grant of EUR 88,000 for our activities in 2023.

I would also like to thank Stefanie Peulen, our Finance Officer and Jean Georges, our Executive Director for their accurate book keeping, monitoring of the financial situation compared to the budget and their

effective fundraising. Their due diligence and detailed reports made it easy for my colleagues in the Board to assess and understand the financial situation of Alzheimer Europe throughout the year. I am therefore confident that we will be able to continue in a similar fashion in 2024 and have another successful year both for the activities of the association, as well as for our finances.

Marco Blom
Honorary Treasurer
Alzheimer Europe

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, 2023



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, 2023, 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, 2023, 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 26th 2024

For AUDITEURS ASSOCIES, Cabinet de révision agréé
30, boulevard Joseph II
L-1840 Luxembourg

Philippe SLENDZAK
Partner

Appendix:

- Annual accounts as at December 31st, 2023

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Balance sheet as of December 31, 2023

	Notes	2023 (Euro)	2022 (Euro)
ASSETS			
C. Fixed assets	3, 1	24.795,64	44.613,17
I. Intangible fixed assets	4	9.396,36	23.849,99
II. Tangible fixed assets	5	15.399,28	20.763,18
D. Current assets		1.810.010,32	1.720.097,75
II. Debtors	3, 2, 6	400.407,02	410.886,31
a) becoming due and payable within one year		400.407,02	410.886,31
IV. Cash at bank and in hand		1.409.603,30	1.309.211,44
E. Prepayments and accruals	3, 3, 7	8.769,82	39.694,63
		1.843.575,78	1.804.405,55
LIABILITIES			
A. Capital and reserves		621.715,26	570.052,59
V. Profit or loss brought forward		570.052,59	532.510,82
VI. Profit or loss for the financial year		51.662,67	37.541,77
B. Provisions	3, 4, 8	64.416,64	45.009,00
C. Creditors	3, 5, 9	867.899,90	1.023.363,96
a) becoming due and payable within one year		867.899,90	1.023.363,96
D. Deferred income	3, 6, 10	289.543,98	165.980,00
		1.843.575,78	1.804.405,55

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, 2023**

	Notes	2023 (Euro)	2022 (Euro)
4. Other operating income	3.7, 11	2.396.464,50	1.866.107,20
5. Raw materials and consumables and other external expenses	12	-1.153.576,71	-654.027,62
b) Other external expenses		-1.153.576,71	-654.027,62
6. Staff costs	13, 14	-1.166.251,97	-1.004.727,26
a) Wages and salaries		-1.027.860,99	-888.505,36
b) Social security costs			
i) relating to pensions		-85.287,47	-71.862,22
ii) other social security costs		-53.103,51	-44.359,68
7. Value adjustments		-26.302,68	-28.770,85
a) in respect of formation expenses and of tangible and intangible fixed assets		-26.302,68	-28.770,85
8. Other operating expenses	15	-6.697,29	-141.068,79
11. Other interest receivable and similar income			
b) other interest and similar income		8.131,22	328,19
14. Interest payable and similar expenses			
b) other interest and similar expenses		-104,40	-299,10
		51.662,67	37.541,77

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, 2023

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

3.1. 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

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.

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2023

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, 2023**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	1,735.65	1,735.65
Gross book value – closing balance	53,037.77	53,037.77
Accumulated value adjustments – opening balance	27,452.13	27,452.13
Allocations for the year	16,189.28	16,189.28
Accumulated value adjustments – closing balance	43,641.41	43,641.41
Net book value – opening balance	23,849.99	23,849.99
Net book value – closing balance	9,396.36	9,396.36

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2023**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	36,105.88	58,028.39	21,934.99	116,069.26
Additions for the year	-	4,749.50	-	4,749.50
Gross book value – closing balance	36,105.88	62,777.89	21,934.99	120,818.76
Accumulated value adjustments – opening balance	25,151.82	49,679.25	20,475.01	95,306.08
Allocations for the year	3,252.18	6,496.23	364.99	10,113.40
Accumulated value adjustments – closing balance	28,404.00	56,175.48	20,840.00	105,419.48
Net book value – opening balance	10,954.06	8,349.14	1,459.98	20,763.18
Net book value – closing balance	7,701.88	6,602.41	1,094.99	15,399.28

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2023**NOTE 6. DEBTORS**

Debtors consist of:

	2023 (Euro)	2022 (Euro)
Accruals for EU and other public funding	305,020.99	296,056.82
Other receivables	<u>95,386.03</u>	<u>114,829.49</u>
	400,407.02	410,886.31

NOTE 7. PREPAYMENTS AND ACCRUALS

Prepayments and accruals can be broken down as follows:

	2023 (Euro)	2022 (Euro)
Prepayments	0.00	11,818.07
Other accruals	<u>8,769.82</u>	<u>27,876.56</u>
	8,769.82	39,694.63

NOTE 8. PROVISIONS

Provisions are composed of:

	2023 (Euro)	2022 (Euro)
Provision for untaken holidays	34,728.96	31,719.74
Audit provision	10,471.50	9,149.50
Other debts	<u>19,216.18</u>	<u>4,139.76</u>
	64,416.64	45,009.00

NOTE 9. CREDITORS

The amounts due and payable for creditors are as follows:

	2023 (Euro)	2022 (Euro)
EU and other public funding received on account	772,339.63	823,406.97
Trade creditors	29,887.61	150,948.42
Social security debts	35,167.65	25,445.70
Tax debts	27,655.03	22,616.31
Other creditors	<u>2,849.98</u>	<u>946.56</u>
	867,899.90	1,023,363.96

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2023**NOTE 10. DEFERRED INCOME**

Deferred income consists of:

	2023 (Euro)	2022 (Euro)
Corporate funding received on account	167,500.00	141,500.00
Project participation and other funding received on account	5,000.00	7,000.00
Deferred funding	<u>117,043.98</u>	<u>17,480.00</u>
	289,543.98	165,980.00

NOTE 11. OTHER OPERATING INCOME

Other operating income is composed of:

	2023 (Euro)	2022 (Euro)
EU and other public funding	1,245,219.88	995,334.50
Corporate funding (*)	377,876.31	374,365.49
Project participation and other subsidies	364,384.57	173,698.55
AE Conference registration fees	310,506.56	120,462.50
Co-financing in kind	120,611.78	117,013.69
Membership fees and contributions	69,696.00	56,940.00
Donations	4,774.33	19,194.91
Deferred income	18,653.33	11,653.33
Other operating income	959.05	4,444.23
Project participation received on account	<u>-116,217.31</u>	<u>-7,000.00</u>
	2,396,464.50	1,866,107.20

(*) 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:

	2023 (Euro)	2022 (Euro)
Hoffmann-La Roche	86,425.00	82,950.00
Lilly	82,054.46	65,000.00
TauRx	32,500.00	25,275.50
NovoNordisk	26,121.85	12,838.90
Eisai	25,000.00	25,000.00
Prothena	20,000.00	0.00
Danone/Nutricia	15,000.00	12,500.00
Biogen	12,500.00	80,691.09
Grifols	12,500.00	25,000.00
GE Healthcare	12,500.00	12,500.00
Other sponsors	<u>53,275.00</u>	<u>32,610.00</u>
	377,876.31	374,365.49

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2023**NOTE 12. OTHER EXTERNAL EXPENSES**

Other external expenses are composed of:

	2023 (Euro)	2022 (Euro)
Accommodation expenses	554,738.44	218,919.00
External experts	240,895.04	147,563.62
Travel expenses	128,034.73	83,283.46
Communication costs	68,994.88	49,050.87
Publication and Information material	54,447.14	36,522.80
Office rent and associated costs	53,312.17	51,241.09
Equipment and Leasing	37,435.01	49,721.00
Bank charges	6,723.25	2,749.67
Membership fees	3,850.00	3,850.00
Office stationery and related costs	3,787.05	6,174.34
Recruitment costs	0.00	3,001.05
Other costs	<u>1,359.00</u>	<u>1,950.72</u>
	1,153,576.71	654,027.62

NOTE 13. STAFF

The association employed an average of 13 persons on a full time equivalent basis during the financial year (2022: 12), one Executive Director and 12 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:

	2023 (Euro)	2022 (Euro)
Grant to Alzheimer Europe Foundation	0.00	134,567.97
Software licenses	6,697.29	6,170.82
Other expenses	<u>0.00</u>	<u>330.00</u>
	6,697.29	141,068.79

NOTE 16. OFF-BALANCE SHEET COMMITMENTS

As at December 31, 2023, the association had rental guarantees of EUR 93,267.09 granted to the owners of the current and future offices used by the association.

ALZHEIMER EUROPE

Association sans but lucratif
RCS Luxembourg F2773

Notes to the annual accounts as at December 31, 2023**NOTE 17. AUDIT FEES**

Audit fees for the year under review amounted to EUR 10,471.50 (2022: EUR 9,149.50).

NOTE 18. RELATED-PARTY TRANSACTIONS

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

	2023 (Euro)	2022 (Euro)
Service fees and other support received from Alzheimer Europe Foundation	52,827.72	12,218.29
Grant to Alzheimer Europe Foundation	0.00	134,567.97
Grant from Fondation Alzheimer, Luxembourg	87,000.00	87,000.00
Membership fees and conference fees from Alzheimer Nederland	25,742.50	8,310.00

Breakdown of income

Funding source	Core funding received (2023)	As % of AE core income (2023)	Project funding received (2023)	As % of AE Project income (2023)	Total funding received (2023)	As % of AE total income (2023)	As % of AE total income (2022)
Roche		0.00%	87,700	5.48%	87,700	3.65%	4.55%
Lilly		0.00%	82,054	5.13%	82,054	3.41%	3.48%
TauRx		0.00%	32,500	2.03%	32,500	1.35%	1.35%
Novo Nordisk		0.00%	26,122	1.63%	26,122	1.09%	0.69%
Eisai		0.00%	25,000	1.56%	25,000	1.04%	1.34%
Prothena		0.00%	20,000	1.25%	20,000	0.83%	0.00%
Biogen		0.00%	12,500	0.78%	12,500	0.52%	4.32%
Grifols		0.00%	12,500	0.78%	12,500	0.52%	1.34%
GE Healthcare		0.00%	12,500	0.78%	12,500	0.52%	0.67%
EFPIA		0.00%	10,000	0.62%	10,000	0.42%	0.00%
Janssen		0.00%	10,000	0.62%	10,000	0.42%	0.00%
MSD		0.00%	7,500	0.47%	7,500	0.31%	0.00%
BioArctic		0.00%	7,500	0.47%	7,500	0.31%	0.00%
Alector		0.00%	4,000	0.25%	4,000	0.17%	0.00%
Evidera		0.00%	3,975	0.25%	3,975	0.17%	0.00%
GlaxoSmith-Kline		0.00%	300	0.02%	300	0.01%	0.02%
AbbVie		0.00%		0.00%	-	0.00%	0.67%
Orion		0.00%		0.00%	-	0.00%	0.27%
Various donors		0.00%		0.00%	-	0.00%	0.10%
Sub-total Pharmaceutical funding	0	0.00%	354,151	22.13%	354,151	14.73%	18.80%
Nutricia		0.00%	15,000	0.94%	15,000	0.62%	0.67%
Essity		0.00%	10,000	0.62%	10,000	0.42%	0.54%
Newsweaver-Poppulo	4,662	0.58%		0.00%	4,662	0.19%	0.25%
Hoyng Rokh Monegier		0.00%		0.00%	-	0.00%	0.70%
Microsoft		0.00%		0.00%	-	0.00%	0.09%
Sanador		0.00%		0.00%	-	0.00%	0.05%
Sub-total: Other corporate sources	4,662	0.58%	25,000	1.56%	29,662	1.23%	2.30%
Total Corporate funding	4,662	0.58%	379,151	23.69%	383,813	15.96%	21.10%
European Commission	500,490	62.22%	463,883	28.99%	964,373	40.11%	46.36%
Luxembourg National Research Fund (FNR)		0.00%	280,847	17.55%	280,847	11.68%	6.97%
Irish Ministry for Agriculture, Food & Marine		0.00%		0.00%	-	0.00%	0.11%
Total: Public funding	500,490	62.22%	744,730	46.54%	1,245,220	51.78%	53.44%
Gates Ventures		0.00%	157,149	9.82%	157,149	6.54%	0.00%
Time donated by experts	113,100	14.06%		0.00%	113,100	4.70%	3.23%

Funding source	Core funding received (2023)	As % of AE core income (2023)	Project funding received (2023)	As % of AE Project income (2023)	Total funding received (2023)	As % of AE total income (2023)	As % of AE total income (2022)
Fondation Alzheimer, Luxembourg	87,000	10.82%		0.00%	87,000	3.62%	4.66%
Alzheimer Europe Foundation	4,892	0.61%	43,386	2.71%	48,278	2.01%	0.43%
Deferred income	11,653	1.45%	7,000	0.44%	18,653	0.78%	0.62%
Fondation Médéric Alzheimer		0.00%	5,625	0.35%	5,625	0.23%	0.00%
bPRIDE		0.00%	5,500	0.34%	5,500	0.23%	0.29%
University of Nottingham - DISTINCT		0.00%	5,000	0.31%	5,000	0.21%	1.88%
PAVE		0.00%	5,000	0.31%	5,000	0.21%	0.40%
University of Eastern Finland - ADAIR		0.00%	5,000	0.31%	5,000	0.21%	0.13%
Fraunhofer Research UK		0.00%	5,000	0.31%	5,000	0.21%	0.00%
Brain Health Scotland		0.00%	5,000	0.31%	5,000	0.21%	0.00%
SPAN+		0.00%	5,000	0.31%	5,000	0.21%	0.00%
Fundació Pasqual Maragall		0.00%	3,750	0.23%	3,750	0.16%	0.00%
Finnish Institute for Health and Welfare		0.00%	3,750	0.23%	3,750	0.16%	0.00%
Concenctris - PRIME		0.00%	3,000	0.19%	3,000	0.12%	0.16%
The Poise Project		0.00%	1,875	0.12%	1,875	0.08%	0.00%
Geneva Tourism & Conventions Foundation		0.00%	1,575	0.10%	1,575	0.07%	0.00%
Danish Dementia Research Centre-TIMING		0.00%	1,500	0.09%	1,500	0.06%	0.08%
BrightFocus Foundation		0.00%	1,500	0.09%	1,500	0.06%	0.00%
Various organisations		0.00%	943	0.06%	943	0.04%	0.18%
VUMC - MIRIADE		0.00%	378	0.02%	378	0.02%	0.06%
University of Vechta		0.00%	80	0.00%	80	0.00%	0.00%
DZNE		0.00%		0.00%	-	0.00%	0.54%
DAC		0.00%		0.00%	-	0.00%	0.33%
University of Edinburgh - EPAD		0.00%		0.00%	-	0.00%	0.26%
EBC/EFPIA		0.00%		0.00%	-	0.00%	0.26%
Ferb Onlus RECage		0.00%		0.00%	-	0.00%	0.08%
Income received on account		0.00%	-116,217	-7.26%	-116,217	-4.83%	-0.38%
Total Foundations and organisations	216,645	26.93%	150,794	9.42%	367,439	15.28%	13.23%
Individuals (conference fees, donations, publication sales)	4,789	0.60%	310,507	19.40%	315,296	13.11%	6.58%
Total: Individuals	4,789	0.60%	310,507	19.40%	315,296	13.11%	6.58%
AE member organisations	69,696	8.66%	15,000	0.94%	84,696	3.52%	5.64%
Total: Member organisations	69,696	8.66%	15,000	1%	84,696	3.52%	5.64%
Bank interest and similar	8,132	1.01%		0.00%	8,132	0.34%	0.02%
Total: Bank interest and similar	8,132	1.01%	0	0.00%	8,132	0.34%	0.02%
Total Income	804,414	100%	1,600,182	100%	2,404,596	100%	100%

Our sponsors and supporters



Alzheimer Europe Board and staff

Members of the Alzheimer Europe Board (2022–2024)



Maria do Rosário Zincke
dos Reis
Chairperson
(Portugal)



Charles Scerri
Vice-Chairperson
(Malta)



Mario Possenti
Honorary Secretary
(Italy)



Marco Blom
Honorary Treasurer
(Netherlands)



Chris Roberts
Chairperson of
EWGPWD
(United Kingdom)



Sonata Mačiulskytė
Chairperson of EDCWG
(Lithuania)



Stefanie Becker
(Switzerland)



René Friederici
(Luxembourg)



Lorène Gilly
(France)



Andy Heffernan
(Ireland)



Martina Mátlová
(Czech Republic)



Mary-Frances Morris
(United Kingdom)



Katariina Suonu
(Finland)



René Thyrian
(Germany)

Alzheimer Europe staff members in 2023



Jean Georges
Executive Director



Christophe Bintener
Project Communications Officer



Cindy Birck
Project Officer



Kate Boor Ellis
Director for Communications and Policy



Angela Bradshaw
Director for Research



Ana Diaz
Public Involvement Lead



Dianne Gove
Director for Public Involvement and Ethics



Gwladys Guillory
Conference Co-ordinator



Tara Klassen
Executive Assistant



Daphné Lamirel
Public Involvement Officer



Owen Miller
Policy Officer



Soraya Moradi-Bachiller
Public Involvement Officer



Cristina Pencea
Events Coordinator



Stefanie Peulen
Finance Officer



Grazia Tomasini
Communications Assistant



**Co-funded by
the European Union**

Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Commission. Neither the European Union nor the granting authority can be held responsible for them.



Alzheimer Europe a.s.b.l. • 5, Heienhaff • L-1736 Senningerberg • Luxembourg
R.C.S. LUXEMBOURG F2773 • EU TRANSPARENCY REGISTER NUMBER: 37399753690-65
Tel.: +352-29 79 70 • Fax: +352-29 79 72
Website: www.alzheimer-europe.org



www.facebook.com/alzheimer.europe



[@AlzheimerEurope](https://twitter.com/AlzheimerEurope)

ISBN 978-2-919811-18-2