

Alzheimer Europe Annual and Financial Report 2015



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Preface



I am very pleased to introduce Alzheimer Europe's 2015 activities. The year was marked by the growing involvement of people with dementia in our work, an increasing number of national dementia strategies among our members and wider recognition of dementia as a public health priority at the international level.

In 2015, AE's core activities were largely funded by an operating grant from the European Commission. We are very grateful for the support of the public health programme of the European Union which allows us to continue our work on behalf of – and with – people with dementia and their carers.

I am pleased that the members of our European Working Group of People with Dementia (EWGPWD) continue to participate in all aspects of AE's work. In 2015, they were very active during the Annual Conference in Slovenia and again took part in our ethics working group. For the first time, the members were also involved in the production of the 2015 Yearbook and provided input to the EPAD and PredictND projects.

We made important steps in our campaign to see dementia recognised as a European priority. The Glasgow Declaration campaign ran for much of 2015 and we collected close to 12,000 signatures in support of our call for a pan-European dementia strategy and national strategies in all European countries. I must heartily thank our member associations for their excellent support during the campaign. Our combined efforts have certainly helped to raise awareness of the need to keep dementia at the top of the public health agenda.

We were pleased to see the launch of new national dementia strategies in Austria, Ireland, Malta and a regional strategy in Germany's Saarland. Denmark and Norway have renewed their strategies and new ones are being developed in Gibraltar, Slovenia and Wales. The Luxembourg Presidency of the European Union also recognised dementia as a priority and their work resulted in the adoption of ambitious Council conclusions calling for greater EU collaboration and an exchange of good practices. It is therefore not surprising that the second Joint Action on Dementia was also launched at the end of 2015.

On a global level, 2015 saw the first WHO Ministerial Conference on Global Action Against Dementia in March, where delegates launched a global Call for Action against

dementia. I was fortunate enough to attend this event, which showed us that international cooperation on dementia has reached a higher level than we have ever seen.

A lasting benefit of our Glasgow Declaration campaign was the addition of 36 Members of the European Parliament who joined the European Alzheimer's Alliance (EAA) when they signed the declaration. By the end of 2015, EAA membership had grown to 126 MEPs from 27 Member States, making it one of the larger interest groups in the European Parliament. Their support included hosting two lunch debates in Brussels and contributions to the *Dementia in Europe* magazine that appeared during our Annual Conference in Slovenia. We are particularly grateful to MEPs Heinz Becker (Austria), Sirpa Pietikäinen (Finland) and Keith Taylor (UK) for hosting our two successful lunch debates.

The aim of our latest ethics publication – “Ethical dilemmas faced by health and social care professionals providing dementia care in care homes and hospital settings: a guide for use in the context of ongoing professional care training” – was to provide training materials for health and social care professionals who are faced with ethically sensitive situations and dilemmas. AE's 2015 yearbook focused on a dementia-friendly Europe: as in previous years, we compiled information from European countries in cooperation with our member associations. The work resulted in a comparative report identifying a number of good practices on how countries, regions, cities and associations are becoming more dementia-friendly.

The activities of our European Dementia Observatory continue to increase and I am very glad to see our communication activities reaching ever more European citizens. In 2015, we published three editions of the “Dementia in Europe” policy magazine that included interviews with EU and national policy makers, reports on the EU Presidency terms of Italy and Luxembourg and coverage of AE's European Parliament

lunch debates and Annual Conference. Meanwhile, the AE newsletter saw a remarkable increase in readers and ended the year with more than 7,400 subscribers. This was mainly due to our Glasgow Declaration campaign, as many signatories also chose to subscribe to the newsletter.

This growth in audience applies to our social media activities as well: AE's Twitter followers increased by 83% and we ended the year with just over 4,000 followers. In 2015, AE also set up an Expert Advisory Panel of 35 dementia experts to help ensure that our medical and scientific reporting continues to meet the highest possible standard.

AE's 25th Annual Conference took place under the motto "Dementia: putting strategies and research into practice" and was funded by the health programme of the European Union. Along with our colleagues from Spominčica – Alzheimer Slovenia, we were glad to host over 570 delegates, including 26 people with dementia. The programme featured some 150 speakers and I am pleased that the conference remains unique in showcasing both scientific and social care topics. Our Annual General Meeting immediately preceded the conference and we were pleased to welcome two new members to the AE family: Israel's EMDA and Udruženje AiR from Bosnia and Herzegovina

During the year, Alzheimer Europe continued to receive funding for participating in EU projects. In 2015, we saw the completion of the PharmaCog project and continued our activity in AETIONOMY, AFE-INNOVNET, EMIF, EPAD, NILVAD, PACE and PredictND. This funding reinforces our financial stability, so I am very pleased that AE has also joined the new SMART4MD and SyDAD projects. AE also participated in meetings of the European Innovation Partnership on

Active and Healthy Ageing (EIP-AHA), continued as an active partner of the European Patients' Forum and continued its cooperation with INTERDEM, a pan-European research network for psychosocial interventions in dementia

It is clear that the architects of our successful year are the staff members of Alzheimer Europe, headed by our Executive Director Jean Georges. In 2015, we saw the departure of Annette Dumas after many years of sterling work and welcomed Vanessa Challinor as the new Policy Officer. She is based in Luxembourg along with Kate Boor-Ellis, Ana Diaz, Dianne Gove, Gwladys Guillory, Stefanie Peulen, Alex Teligadas and Grazia Tomasini.

My colleagues on the AE Board also provided excellent support and I am grateful for their valuable insights and advice. I must also thank the numerous representatives from our national member associations and the external experts who freely gave of their time to collaborate in our activities and projects.

It remains only to thank the corporate sponsors that provided support for various AE activities in 2015. We very much appreciate the generosity of Biogen, GE Healthcare, GSK, Janssen-Cilag, Lilly, Lundbeck, Merz, Nestlé, Nutricia, Otsuka, Piramal, Roche, Sandoz and SCA Hygiene Products.

I look forward to an equally productive 2016 in cooperation with our member associations, external experts and corporate sponsors – and invite all of our readers to join us at the 26th Alzheimer Europe Conference in Copenhagen!

Heike von Lützu-Hohlbein
Chairperson of Alzheimer Europe

Executive Summary

In 2015, Alzheimer Europe:

Campaigned

- received support from the European Commission in the form of an operating grant for the organisation's core activities
- conducted the Glasgow Declaration campaign in support for national dementia strategies in every European country and received the endorsement of 203 organisations, 152 policy makers and 11,613 individuals
- attended the WHO Ministerial Conference on Global Action Against Dementia
- increased the membership of the European Alzheimer's Alliance (EAA) in the European Parliament to 126 MEPs from 27 Member States
- attended a meeting of the European Commission Group of Government Experts on dementia
- continued its active involvement in the European Patients' Forum (EPF) as a full member and the think tank of the European Federation of Pharmaceutical Industries and Associations (EFPIA)
- welcomed the adoption of national dementia strategies in Austria, Denmark and Norway, the recognition of dementia as a European priority thanks to the leadership of the Luxembourg Presidency of the European Union and the launch of a new Joint Action on Dementia
- joined the new SMART4MD and SyDAD projects
- represented Alzheimer's Disease International (ADI) at the 65th session of the World Health Organisation Regional Committee for Europe

Communicated

- produced the 2015 Dementia in Europe Yearbook, a comparative report on the development of dementia-friendly communities in Europe
- published 607 articles in 11 editions of its email newsletter
- created an Expert Advisory Panel to ensure accurate scientific reporting and published

- a scientific digest reviewed by the panel
- attracted 737,858 unique visitors to its website, an increase of 23.5% over the previous year
- produced a guide on the ethical dilemmas faced by health and social care professionals in hospitals and care homes
- launched the Alzheimer's Association Academy as a new way of sharing best practices and promoting capacity building among its members
- submitted a scientific article on guidelines for good continence care for people with dementia
- increased its social media presence to 4,034 Twitter followers (2,200 in 2014) and 5,873 "likes" on its Facebook page (up from 5,000)
- published three editions of the "Dementia in Europe" magazine that included interviews with EU and national policy makers, reports on the EU Presidency terms of Italy and Luxembourg and AE activities such as the European Parliament lunch debates and Annual Conference
- contributed to the European Patients' Forum position paper on discrimination in healthcare

Collaborated

- continued its collaboration with the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) on age-friendly environments
- partnered with Spominčica – Alzheimer Slovenia to organise the 25th Alzheimer Europe Conference in Ljubljana on 2–4 September under the motto "Dementia: putting strategies and research into practice", attracting 570 delegates of which 26 people with dementia
- worked with INTERDEM to call for greater EU collaboration on dementia and organised a joint meeting with the Cabinet of the EU Health Commissioner Vytenis Andriukaitis
- continued its collaboration with the AETIONOMY, AFE-INNOVNET, EMIF, NILVAD, PACE, PharmaCog and PredictND projects
- started its collaboration within EPAD (European

Prevention of Alzheimer's Dementia) where Alzheimer Europe is co-leading the work package dedicated to communication and dissemination and contributing to the discussions on the ethical, legal and social implications of the project

- actively consulted people with dementia on its activities through the European Working Group of People with Dementia (EWGPWD), which involved ten people with dementia nominated by their national organisations

Coordinated

- welcomed new member associations EMDA (Israel) and Udruženje AiR (Bosnia and Herzegovina) during its Annual General Meeting
- brought together public affairs representatives of its member associations to exchange information and best practices on national dementia strategies and policies
- involved the European Working Group of People with Dementia in the preparations and organisation of the 2015 Annual Conference in Glasgow, in various meetings and projects and through its Chairperson in the Board of the organisation
- organised two lunch debates in Brussels entitled "The WHO and the World Dementia Council and global action on dementia: what role for the EU?" and "Dementia, a priority of two EU Presidencies"
- continued the development of its Clinical Trial and Guideline Watch projects which inventory clinical trials conducted in Europe and national guidelines for the diagnosis, treatment and management of dementia in Europe
- carried out a membership survey of past activities and future priorities and developed a new Strategic Plan (2016–2020) which was approved unanimously by the membership

Introduction

The Strategic Plan of Alzheimer Europe sets out the four main objectives of the organisation and highlights key aims and actions to be undertaken under each objective for the period covered by the plan (2011–2015). This year's Annual Report breaks down the organisation's core activities into these four key strategic objectives and follows the structure of the 2015 Annual Work Plan which was adopted at the Annual General Meeting in Glasgow in 2014.

In addition, the report highlights the activities undertaken by Alzheimer Europe in support of EU projects it had been partnering with and presents those activities which it has been able to carry out thanks to the support of its corporate sponsors.



Delegates at Alzheimer Europe's Annual General Meeting in Ljubljana, Slovenia (September)

AE Core Activities

In 2015, Alzheimer Europe received the support of the European Commission. The following core activities of the organisation were funded thanks to an operating grant to Alzheimer Europe in the framework of the Public Health Programme.

Objective 1: Making dementia a European priority

Glasgow Declaration campaign

Alzheimer Europe launched the Glasgow Declaration on 20 October 2014, the same day it was adopted unanimously by delegates from 26 AE member organisations. The Glasgow Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

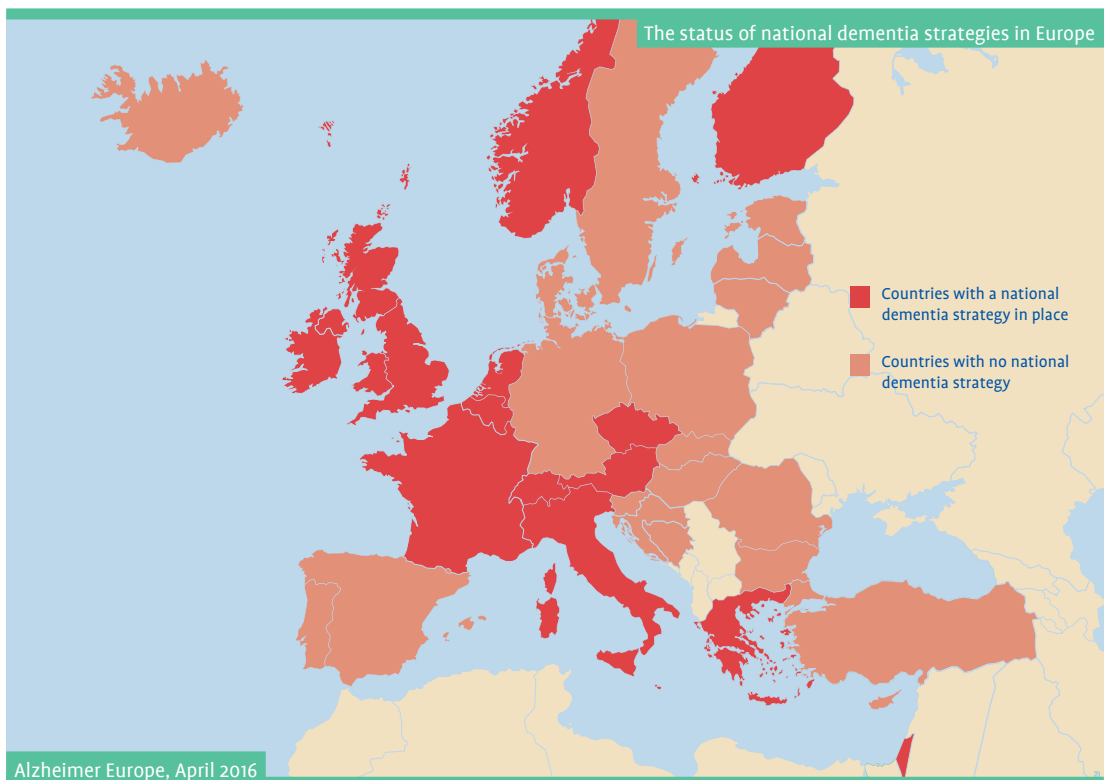
The campaign was conducted by AE and its members during 2015, with an aim to collect 10,000 individual signatures. The final results were: 11,613 individuals, 203 organisations and 152 policy makers, of which 83 MEPs. The MEP signatories also became members of the EAA, the European Alzheimer's Alliance.



Luxembourg delegates at the WHO Ministerial Conference on Global Action Against Dementia (March)

In December, the EU's Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council discussed the Conclusions of the Luxembourg EU Presidency and adopted, amongst others, a conclusion named "Supporting people living with dementia". This calls on all Member States to address dementia as a priority, to develop national strategies or actions plans, and to strengthen the collaboration between European countries.

2015 also saw the launch of the 2nd European Joint Action on Dementia which will be led by the Scottish Government on behalf of the United Kingdom and focus on timely diagnosis and post-diagnostic support, crisis management and



care coordination, quality of residential care and dementia-friendly initiatives.

On a global level, 2015 saw the first WHO Ministerial Conference on Global Action Against Dementia in March, where delegates launched a global Call for Action against dementia. Alzheimer Europe was represented by its Chairperson and Executive Director at this meeting.

Finally, Alzheimer Europe was pleased to see remarkable progress in the development of national dementia strategies in 2015:

- launch of new national dementia strategies in Austria, Ireland, Malta and a regional strategy in Germany's Saarland
- extension of Norway's strategy and a similar ongoing effort in Denmark
- continued development of strategies in Gibraltar, Slovenia and Wales

European Alzheimer's Alliance



During 2015, EAA membership grew to 126 MEPs from 27 Member States. Françoise Grossetête (France, EPP) continues as Chair of the Alliance. The Vice-Chairs are Nessa Childers (Ireland, S&D), Marisa Matias (Portugal, GUE/NGL), Sirpa Pietikäinen (Finland, EPP), Frédérique Ries (Belgium, ALDE) and Keith Taylor (UK, Green/EFA). The full EAA membership list is shown below.

Alzheimer Europe gratefully acknowledges the support of all the Members of the European Parliament who were present or represented at the various meetings organised by Alzheimer Europe (lunch debates, annual conference), signed the Glasgow Declaration, contributed to Alzheimer Europe's Dementia in Europe magazine or supported

national member organisations in their campaigns to make dementia a national and European priority.

Austria: Heinz K. Becker (EPP); Kappel Barbara (NI); Rübiger Paul (EPP). **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleni Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE). **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraiki (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg (EPP). **Hungary:** Ádám Kósa (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke 'Ming' Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). **Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian-Silviu Busoi,



EAA Chair
Françoise
Grossetête
France, EPP



Vice-Chair
Nessa Childers
Ireland, S&D



Vice-Chair
Marisa Matias
Portugal,
GUE/NGL



Vice-Chair
Sirpa
Pietikäinen
Finland, EPP



Vice-Chair
Frédérique Ries
Belgium, ALDE



Vice-Chair
Keith Taylor
UK, Green/EFA

MEP (EPP); Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP); Jana Žitňanská (ECR). **Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). **Spain:** Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estaràs Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ernest Maragall (Greens/EFA); Pablo Zalba Bidegain (EPP). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

clinical trial regulation, cross-border healthcare and the EU framework for data protection.

Alzheimer Europe continued its collaboration with other EU organisations, such as AGE Platform Europe, the Interest Group on Mental Health, Well-Being and Brain Disorders and the Interest Group on Carers of the European Parliament.

AE also participated in the think tank meetings of the European Federation of Pharmaceutical Industries and Associations (EFPIA) and attended the EFPIA Health Collaboration Summit.

The organisation also worked closely with its member associations and organised meetings with public affairs representatives to discuss EU policy developments and to have an active exchange on national lobbying and campaigning activities.

Collaboration with EU Initiatives



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Alzheimer Europe continued its collaboration with the European Medicines Agency (EMA) in 2015 as a full member of EMA's Patients' and Consumers' Working Party (PCWP). AE staff participated in PCWP meetings organised during the course of the year and the annual training session for representatives of patients' associations.

Alzheimer Europe also participated in meetings of the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA). In the period from 2012 to 2015, the EIP-AHA worked on five key topics, namely adherence to medical plans, falls prevention, integrated care systems, ICT solutions for independent living and age-friendly environments.

In June, the Health Directorate General of the European Commission convened a meeting of governmental experts on dementia. AE was represented at the meeting by Jean Georges, who gave an update on the association's work on national care pathways and the Glasgow Declaration campaign.

Jointly developing policy

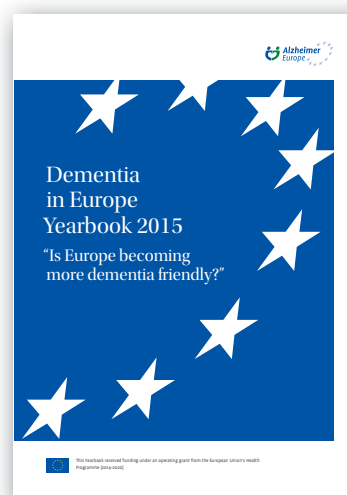


As in previous years, Alzheimer Europe was an active member of the European Patients' Forum and contributed alongside other European organisations to the development of cross-diseases positions on EU consultations and legislative proposals. In particular, the organisation followed discussions on the

Objective 2: Supporting policy with facts

Comparing national systems and identifying best practices

In collaboration with representatives of its national member organisations, Alzheimer Europe produced a comparative report that looks at the development of the concept "dementia-friendly communities" in Europe.



33 national organisations representing 31 countries participated in the 2015 Yearbook, including most Members States of the European Union as well as Jersey, Norway, Monaco, Switzerland and Turkey. For the first time, the European Working Group of People with Dementia was involved in the development of the report. Their testimonies provided a powerful insight into how people with dementia would like to see communities, villages, cities and countries become more inclusive and dementia-friendly.

The report highlights the huge relevance of the work towards creating a society that is more inclusive and respectful of every citizen, and in particular of those living with dementia. This means a society where people with dementia can live well, enjoy meaningful lives, and feel safe, empowered and enabled to take decisions about how they want to live their lives as members of the community. The report claims that



European Dementia Observatory

Over the past years, Alzheimer Europe (AE) has continuously improved the information it provides to its members and external stakeholders on key developments in the field of dementia.

In 2015, AE published 11 editions of its newsletter, on a monthly basis – except for August and September, which were combined. These 11 e-newsletters contained information on AE's activities and those of its member organisations, as well as updates on projects in which AE is involved. AE also reported on interesting policy initiatives both at national and European level, including news about the European Alzheimer's Alliance. It also reported on scientific developments, human interest stories about people living with dementia were also covered, new resources and publications, and a small number of job opportunities in the field.

A total of 607 articles were featured in AE's 2015 monthly e-newsletter (558 in 2014). They can be broken down into categories, as follows:

 www.facebook.com/alzheimer.europe
 @AlzheimerEurope

good examples of such societies are provided in the concept of dementia-friendly communities (DFCs) and provides examples of countries where this concept has been implemented or where it is now being developed. Core features of DFCs are to keep people with dementia at the centre, to increase awareness and to change attitudes to dementia in our society.

The concept of whole communities becoming dementia friendly has not yet been developed everywhere in Europe. This absence should, however, not be interpreted as if these countries are not undertaking major efforts to provide appropriate support and care, to improve the quality of life, and to involve people with dementia as much as possible in the community. Building on the framework developed by the World Health Organisation to create age-friendly cities, the report provides a comparative overview of national policies and notable practices in Europe that aim at creating physical and social environments that enable people with dementia to be part of their communities and to feel respected and valued. Relevant topics addressed in the report include: outdoors spaces and safety, housing, driving, transportation, participation in social and cultural life, employment, voting, stigma and involvement of people with dementia in the development of policies and practices that matter to them.

Subject	Number of articles	
	2015	2014
Activities and projects of Alzheimer Europe	137	95
European policy developments in the field of dementia and European Alzheimer's Alliance	80	81
National policy developments	55	52
Activities and projects of AE member organisations	159	117
Scientific developments	108	117
Dementia in Society, and new (as from September 2015) "Living with dementia" section	27	46
New resources, publications and job opportunities	43	50

The reduced number of articles in the Dementia in Society section, as compared with 2014, has been as a result of feedback from our online newsletter survey and our AGM survey, both of which expressed some of our readership's desire to focus less on this area.

The AE newsletter had almost 7,400 subscribers at the end of 2015, many of whom subscribed during the year (+2,746). This dramatic increase is in large part thanks to the Glasgow Declaration campaign, which gave signatories the opportunity to join the newsletter mailing list if they signed online.

During 2015, AE set up an Expert Advisory Panel to help ensure the information the organisation provides on medical and scientific breakthroughs is of the highest possible standard. It consists of 35 experts in various areas of dementia from 19 European countries. For the first time, AE published a research digest consisting of all the scientific articles published in AE's 2015 newsletters. The Expert Advisory Panel contributed to this publication and also evaluated conference abstracts for the 25th Alzheimer Europe Conference in Slovenia.

Visitors		
Month	2015	2014
January	73,928	44,600
February	67,766	50,902
March	73,978	60,736
April	66,911	57,019
May	61,105	51,784
June	64,949	49,992
July	49,906	37,423
August	51,052	37,788
September	59,382	49,015
October	67,765	55,666
November	72,897	64,008
December	51,898	56,623
Total:	737,858	597,393

AE's website continued the trend of increasing its website visitors each year, with more visitors in 2015 than in previous years. The website attracted 23.5% more visitors, with the total number of unique visitors increasing from 597,393 in 2014 to 737,858 in 2015.

Also in 2015, AE continued to step up its social media presence, particularly on Twitter and Facebook. Based on advice from social media experts, AE decided to convert its Facebook account to a Facebook page, which is better suited to organisations and companies, as opposed to individuals. AE's previous Facebook account had already reached the maximum 5,000 friends in 2014, which were converted to "likes" on its new page. This had increased to 5,873 likes as at the end of 2015.

As for Twitter, the association had reached 4,034 Twitter followers at the end of 2015 (2,200 in 2014) and had tweeted 1,479 times (583 in 2014). Social media has become a daily part of AE's activities and an integral part of communications related to the Annual Conference, as well as other events and projects. The 2015 conference hashtag #25AEC had over one million "tweet impressions", meaning that this huge number of Twitter users had access to information about AE and its conference. All AE team members who are involved in projects and attend AE events are now active Twitter users, tweeting from events where they represent the organisation. The total number of Tweets by AE and its team members in 2015 was 2,707 and tweet impressions reached over 1.9 million. Twitter is also used by AE as a means to increase website traffic, which likely explains the further increase in the number of "unique visitors" to the website in 2015 as compared with 2014.

AE's Twitter account activity in 2015:

Month	Tweets	Tweet impressions	New followers
January	57	38,000	130
February	78	46,700	173
March	136	88,400	217
April	71	40,600	135
May	28	32,400	115
June	54	46,200	142
July	105	89,000	139
August	90	75,400	180
September	258	161,000	275
October	237	117,000	207
November	216	204,000	193
December	149	239,000	115
Total:	1,479	1,177,700	2,021

Objective 3: Basing our actions on ethical principles

As in previous operating grants, AE continued to focus on ethical issues. In 2015, AE worked on ethical dilemmas faced by health and social care professionals providing dementia care in care homes and hospitals. This work was carried out in collaboration with experts identified through the European Dementia Ethics Network.

The aim of this year's publication was to provide training materials for health and social care professionals, in care homes and hospitals, faced with ethically sensitive situations and dilemmas, which would:



Meeting of the Ethics working group in Luxembourg (April)

- enable them to reflect on a range of ethically challenging situations,
- empower them to tackle any they might encounter,
- enable them to reflect on the approach they adopt and
- (if they feel the need) enable them to justify the approach they adopt to themselves and anyone who might ask

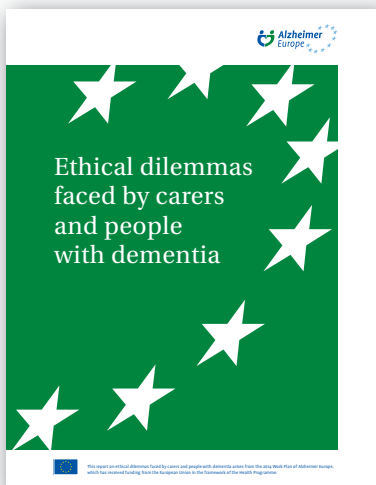
The working group met twice in 2015, once in Luxembourg and once in Ljubljana (Slovenia). At these meetings, the experts discussed various ethical dilemmas that are frequently experienced by health and social care professionals working with people with dementia in care homes and hospitals, the kind of support that might be beneficial to them, the most suitable format for the proposed publication and the necessary content, style and ethical guidelines to correspond to those requirements.

The guide was produced by a group of renowned experts and highly trained professionals in the field of ethics and dementia care. The working group was chaired by Dianne Gove

(Director for Projects, Alzheimer Europe) and also included a member of the European Working Group of People with Dementia and representatives from Alzheimer Associations. The final draft of the guide benefited from feedback from independent health and social care professionals in the United Kingdom, Portugal and Finland.

Work on the literature review, the ethical framework and the drafting of the vignettes, as well as some of the ethical commentaries, was carried out by the following:

- Dr Dianne Gove, Alzheimer Europe (Luxembourg), Chair of the ethics working group
- Prof. June Andrews, Dementia Services Development Centre, Stirling (UK)
- Ms Lydie Diederich, Alzheimer Association of Luxembourg (Luxembourg)
- Prof. Chris Gastmans, Catholic University of Leuven (Belgium)
- Mr Jean Georges, Alzheimer Europe (Luxembourg), Executive Director
- Dr Debby Gerritsen, Radboud University Medical Center, Nijmegen (Netherlands)
- Dr Fabrice Gzil, Fondation Méderic Alzheimer, Paris (France)
- Dr Dana Hradcová, Centre of Expertise in Longevity, Charles University, Prague (Czech Republic)
- Prof. Julian Hughes, Newcastle University and Nuffield Council on Bioethics (UK)
- Dr Caroline Kilty, University College Cork (Ireland)
- Mr Denis Mancini, Alzheimer Association of Luxembourg (Luxembourg)
- Dr Alistair Niemeijer, University of Humanistic Studies, Utrecht (Netherlands)
- Ms Lucília Nóbrega, Alzheimer Society of Portugal, Madeira (Portugal)
- Dr Eila Okkonen, Muistiliitto/Alzheimer's Society of Finland (Finland)



- Prof. Jan Oyebode, Bradford Dementia Group, University of Bradford (United Kingdom)
- Prof. Nathalie Rigaux, University of Namur (Belgium)

Five independent reviews were obtained prior to the finalisation of the guide, namely from Aileen Beatty (United Kingdom), Patrícia Castro, Deolinda Fernandes and Gonçalo Fernandes (Portugal) and Roland Ngang (Finland).

The guide starts with brief background information and then more detailed information covering values, principles and theories, an ethical framework to guide reflection and a structured approach to tackling ethical dilemmas in daily practice. This is then followed by a set of vignettes and a set of corresponding ethical commentaries which not only demonstrate how to reflect ethically on ethically challenging situations but also do so in accordance with the structured approach developed by the working group.

The materials in the guide should be used in the context of ongoing professional care training (e.g. with moderated group discussions, professional guidance and role playing). Ideally, the various information, guidelines, vignettes (short stories), commentaries and activities should be presented in stages (not all at once) and discussion adapted to the level of experience and knowledge of different health and social care professionals.

Objective 4: Building a stronger organisation

European Working Group of People with Dementia



Thanks to its 2010 operating grant and the consultation of its member organisations, user involvement was identified as a key priority for Alzheimer Europe and this led to the setting up of a European Working Group of People with Dementia in 2012.

The working group met three times in 2015 and the Chair of the Working Group participated in the meetings of the AE Board as a full Board member. The Group was consulted and asked to ensure user representation and involvement in all AE activities.

Members of the working group were nominated by the national member organisations of Alzheimer Europe and AE supported the attendance of one person with dementia



EWGPWD members and carers in Ljubljana, Slovenia (September)

from nominating organisations as well as that of a carer or other supporter.

Alzheimer Europe was able to involve ten different people with dementia who were nominated by their national organisations in the Czech Republic, Finland, Germany, Ireland, Jersey, Norway, Slovenia, Sweden and the United Kingdom (England and Scotland).



Agnes (L), Helga and Hilary at the EWGPWD meeting in Ljubljana (September)

In 2015, the EWGPWD and/or its members attended the following meetings:

1. 19–20 March: meeting of the Executive of the EWGPWD in Luxembourg
2. 2 April: telephone meeting of the Executive of EWGPWD
3. 14–16 May: meeting of the group in Brussels, including a consultation for the INTERDEM research on outcome measures
4. 1 September: meeting of the full group followed by a symposium organised by the members and a presentation by Alv Orheim in the plenary session of Alzheimer Europe's annual conference in Ljubljana
5. 5 September: meeting of Alzheimer Europe's working group on ethical dilemmas faced by health and social care professionals of people with dementia in care homes and hospitals (Agnes Houston)
6. December: two consultations of the EWGPWD held in Brussels for the EPAD and PredictND projects
7. Representation of the EWGPWD by Helga Rohra (Chair) and Agnes Houston (Vice Chair) at the Board meetings of Alzheimer Europe

25th Alzheimer Europe Conference



Opening ceremony of the 25th Alzheimer Europe Conference in Ljubljana, Slovenia (October)

Alzheimer Europe held its 25th Annual Conference in Ljubljana on 2–4 September 2015 together with Spominčica – Alzheimer Slovenia. This year’s motto was “Dementia: putting strategies and research into practice” and the event attracted over 570 delegates, including 26 people with dementia. The programme featured some 150 speakers and 140 poster presentations, including a competition for the best posters. The conference was also an opportunity to celebrate AE’s 25th anniversary. The event was organised under the Honorary Patronage of Mr Borut Pahor, President of Slovenia.

The first plenary session focused on putting research into practice and the second session was entitled “Dementia Strategies and Policies”. This included a presentation by Mr Alv Orheim, who is living with dementia in Norway. Plenary session three featured presentations on the development of a dementia-friendly society. The final plenary session focused on innovation and care.

Conference delegates were also able to attend 21 parallel sessions about legal, ethical and scientific aspects of living with dementia, including three sessions featuring Slovenian dementia experts. In addition, three special symposia focused on the EPAD (European Prevention of Alzheimer’s dementia) project, the INTERDEM research group and the activities of the European Working Group of People with Dementia. The EWGPWD played an integral part in the organisation and planning of the event and nominated several keynote speakers to deliver presentations on living with dementia. In addition, the group members operated an information booth throughout the conference.

The Annual General Meeting of Alzheimer Europe also took place in the framework of the 25th Alzheimer Europe Conference. At the meeting, the members of the organisation welcomed new member associations from Bosnia and Herzegovina and Israel, adopted the 2014 Annual and Financial Reports and approved the 2016 Work Plan and Budget. The members also discussed the results of the membership survey aimed at evaluating the activities undertaken under Alzheimer Europe’s previous Strategic Plan (2011–2015) and approved the organisation’s new Strategic Plan (2016–2020).

Supporting and involving member organisations

Alzheimer Europe consistently involves its member organisations in meetings, projects and activities. In 2015, three successful meetings brought together the public affairs representatives of various national associations.



Jim Pearson (UK-Scotland), Stefanija Lukic-Zlobec (Slovenia), Maria Seleari (Cyprus) and Xenia Maiovi (Greece) at AE’s public affairs meeting in Luxembourg (February)

The meetings held in February and June had similar agendas, aiming to exchange information on national dementia strategies and policies and the campaigning and advocacy activities of AE and its members. The delegates discussed the following topics:

- AE projects: Clinical Trial Watch, Policy Watch, Dementia Monitor, Glasgow Declaration campaign and the Alzheimer’s Association Academy
- AE’s 2015 Dementia in Europe Yearbook, “Is Europe becoming more dementia friendly?”
- AE’s Communication and Public Affairs strategies
- the new European Parliament and the further development of the European Alzheimer’s Alliance (EAA)
- members’ activities from their countries, including awareness campaigns and lobbying work. These presentations serve to share best practices among the AE group

In December, AE changed the format of its public affairs meeting and held the first Alzheimer’s Association Academy instead. The new format included presentations from various experts in the following topics that are of interest to AE and its members:

- involving people with dementia in Alzheimer associations
- integrated campaigning thanks to social media
- the Innovative Medicines Initiative (IMI) and EU dementia research
- the EPAD project: prevention of Alzheimer’s dementia
- data protection and privacy and big data projects on dementia
- informing the general public about clinical trials and dementia research



Top: Group photo from AE’s public affairs meeting in Luxembourg (February)
Centre: Panellists Iva Holmerova, Karine Fauria and Adam Smith at the Alzheimer’s Association Academy (December)
Bottom: Alv Orheim (Norway) and Helen Rochford-Brennan (Ireland) speaking at the Alzheimer’s Association Academy (December)



Group photo from AE’s Public Affairs meeting in Brussels (June)

Membership development



In 2015, the Annual General Meeting voted to accept EMDA (The Alzheimer's Association of Israel) and the Panhellenic Federation of Alzheimer's Disease and Related Disorders as new full members of AE – the latter in lieu of previous full member Alzheimer



Hellas. In addition, Udruženje AIR (Bosnia and Herzegovina) was voted in as a provisional member. Foundation Compassion Bulgaria and Alzheimer Uniti (Italy) continue to be provisional members.

Strategic partnerships



Alzheimer Europe continued to cooperate with ADI in 2015 in particular around the ongoing global activities on dementia at G7 and WHO level. In April, AE was represented by Helga

Rohra at ADI's Annual Conference in Perth and Jean Georges was invited to sit on ADI's Strategy and Communication Committees in September. Vanessa Challinor represented both AE and ADI at the 65th session of the World Health Organisation (WHO) Regional Committee for Europe.



In 2015, Alzheimer Europe continued as an active member of the European Patients' Forum. Specifically, AE contributed to the EPF position paper on discrimination in healthcare and participated in the EPF Working Group on "Access to healthcare" and the Public Affairs Group meeting. AE was represented by Annette Dumas in these activities.



In 2015, AE continued its cooperation with INTERDEM, a pan-European research network for psychosocial interventions in dementia. In May, a joint delegation from AE and INTERDEM made a case for greater EU collaboration on dementia during a meeting with Paula Duarte-Gaspar, a representative of EU Health Commissioner Vytenis Andriukaitis. In September, the INTERDEM researchers held a series of meetings and also presented their work during the 25th Alzheimer Europe conference in Ljubljana. In October, AE, INTERDEM, ADI and other partners co-authored a letter entitled "Dementia prevention: call to action" that was published in the Lancet research journal. AE was represented in INTERDEM's activities by Heike von Lützu-Hohlbein, Jean Georges, Dianne Gove and Ana Diaz.



AE's Vanessa Challinor addressing WHO Europe delegates in Vilnius (September)

Other activities and projects

EU Project participation

PharmaCog



PharmaCog, or “Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development”, was an IMI project which started on 1 January 2010 and ended at the end of 2015. Throughout the project, AE hosted and updated the PharmaCog website within the AE website.



PharmaCog Steering Committee meeting in Lille (December)

On 2 December, Dr Régis Bordet (Academic Coordinator) gave a presentation on PharmaCog at AE’s Alzheimer’s Association Academy. AE was represented by Alex Teligadas at the final Steering Committee meeting on 18 December in Lille, France.

NILVAD



In 2015, Alzheimer Europe continued its collaboration with the NILVAD project, a phase III clinical trial of the drug nilvadipine.



Group photo of the NILVAD Steering Committee meeting in Thessaloniki (June)

Alzheimer Europe is a partner in work package 7 (Dissemination and Communication) and is also involved in a sub-study on the experiences of the trial participants and their caregivers. This was developed by AE and the University of

Lille. During 2015 the protocol and relevant documentation for this study was jointly developed by the University of Lille, the Centre Mémoire de Ressources et de Recherche in Lille and AE.

AE was represented by Ana Diaz at a meeting on 28 April in Lille and Alex Teligadas attended the General Assembly on 13–14 June in Thessaloniki, Greece.

EMIF



The five year European Medical Information Framework project began in 2013 with the aim of developing a framework for evaluating, enhancing and providing access to human health data across Europe. Alzheimer Europe is a partner in work package 15 – “Use and sustainability models, community building and outreach” and work package 16 – “Programme management and dissemination”.

The organisation was represented by Alex Teligadas at project meetings on 9–10 and 22–24 June.



EMIF project meeting in Ghent (June)

AETIONOMY



AETIONOMY is a five-year project that began in February 2014. It aims to identify subgroups of dementia and Parkinson’s disease – based on the underlying genetic or molecular causes of the variants – in order to allow tailored therapies.

Alzheimer Europe is a partner in work package 4 (Ethical and Legal Governance) and in 2015, Dianne Gove and Ana Diaz wrote the section on ethics for the report entitled “Legal and ethical guidelines on data processing and patient stratification in non-curable diseases”. The organisation was

represented by Alex Teligadas on 16–17 June in Slough (UK) and 28–29 June in Brussels and by Dianne Gove and Ana Diaz on 3–4 November in Barcelona.

On 2 December, Prof. Duncan McHale (co-coordinator) gave a presentation about the project at AE's Alzheimer's Association Academy.

PACE



The aim of PACE is to compare the effectiveness of palliative care for elderly people in long term care facilities in Europe. This project is coordinated by the Vrije Universiteit Brussel (Belgium).

In 2015, Alzheimer Europe ensured work on the dissemination of information about the project and took part in a user-led workshop in Brussels, led by Age Platform, at which Sabine Henry from the Ligue Alzheimer in Belgium, Hilary Doxford from the European Working Group of People with Dementia and Peter Paniccia (her partner) took part, along with Ana Diaz and Dianne Gove from Alzheimer Europe.

AFE-INNOVNET



AFE-INNOVNET (Innovation for age-friendly environments in the European Union) is a network coordinated by AGE Platform Europe. Its overarching goal has been to set up a large EU-wide community of local and regional authorities and other stakeholders who want to work together to find solutions to support active and healthy ageing and develop age-friendly environments.

In 2015, Alzheimer Europe ensured that people with dementia were considered in the development of age-friendly initiatives and in the identification of dementia-friendly initiatives for the repository which was developed as part of the AFE-INNOVNET project. Some of the initiatives collected by Ana Diaz during her work on dementia-friendly communities were integrated by various member associations into the repository.

AFE-INNOVNET also developed the Covenant on Demographic Change, which aims to gather local, regional and national stakeholders that commit to cooperate and implement evidence-based solutions to support active and healthy ageing as a comprehensive answer to Europe's demographic challenge. Sabine Henry, Randi Kill and Krista Pajala from Alzheimer Europe's member associations in Belgium, Norway and Finland, respectively, took part in the workshops following the launch of the Covenant in December.

This project is linked to the activities of the European Innovation Partnership on Active and Healthy Ageing.

PredictND



The PredictND project is coordinated by VTT Technical Research (Finland) and aims to provide an objective and systematic ICT-based approach for the diagnosis of neurodegenerative diseases.

Alzheimer Europe carried out a consultation with the members of the European Working Group of People with Dementia (EWGPWD) in December 2015, together with five carers (partners of some of the members of the working group). This consisted of a hands-on / "talking aloud" observation in which the participants tried out the citizen portal, combined with a group discussion. The discussion was lively and resulted in concrete feedback which the PredictND technical designers will be able to use to improve the portal. Dianne Gove, Ana Diaz and Gwladys Guillory organised and conducted the consultation.

Jean Georges and Dianne Gove represented Alzheimer Europe at several project meetings throughout the year.

EPAD



EPAD, the European Prevention of Alzheimer's dementia initiative is a collaborative research project funded by the Innovative Medicines Initiative to improve the chance of successfully preventing Alzheimer's dementia and to better understand early aspects of Alzheimer's disease before dementia develops. EPAD will establish a European-wide register of 24,000 participants, of which 1,500 will be invited to participate in a trial to test new treatments for prevention of Alzheimer's dementia.

Alzheimer Europe is co-leading Work Package 6: Dissemination, with the participation of Jean Georges, Kate Boor-Ellis



Group photo from the EPAD General Assembly in Edinburgh (May)

and Alex Teligadas. In addition, Dianne Gove is active in Work Package 8: Ethics, which is developing an initial ethics policy review and an information governance framework. In 2015, Dianne and Ana Diaz were also involved in a consultation on behalf of the project with members of the European Working Group of People with Dementia aimed at developing approaches to the communication of Alzheimer's disease risk. Ana carried out a series of consultations in Spain on the same topic.

On 2 December, Prof. Craig Ritchie (EPAD Academic Coordinator) gave a presentation about the project at AE's Alzheimer's Association Academy.

SMART4MD



The aim of SMART4MD (formerly MIAMI-MD) is to adapt an existing internet-based health management tool to the specific needs of people with dementia, focusing on monitoring the evolution of their dementia and promoting independent living as well as quality of life. The project is coordinated by Anglia Ruskin University (UK) and will run for four years (2015–2019).

The kick-off meeting, at which Alzheimer Europe was represented by Kate Boor Ellis and Dianne Gove, was held in Chelmsford (UK) in April 2015. Kate and Dianne presented the dissemination, communication strategy and proposed involvement of Alzheimer Europe in this project. Kate is involved in dissemination activities related to the project, along with Alex Teligadas. Dianne Gove and Ana Diaz have been involved in the preparations for a series of focus groups involving people with dementia and carers, as well as in discussions related to the ethical approval application. Ana and Dianne will also be involved in working with people with dementia to help draft case studies and to rate the usability of the proposed tool.

SyDAD



SyDAD (Synaptic Dysfunction in Alzheimer's Disease) is a European Training Network sponsored by Horizon 2020 Marie Skłodowska Curie Actions. The research programme will support and train 15 Early Stage Researchers (ESRs, PhD students) with an interest in the area of Alzheimer's disease and synaptic dysfunction. The project is led by the

Department of Neurobiology, Care Sciences and Society at Karolinska Institutet (Sweden).

Ana Diaz attended the first project meeting on behalf of Alzheimer Europe.

Corporate affairs

European Parliament lunch debates



MEP Heinz Becker with fellow Austrians Monika Natlacen (L) and Antonia Croy in Brussels (June)

In 2015, Alzheimer Europe organised two successful lunch debates in Brussels:

On 30 June, Heinz Becker, MEP (Austria) hosted a lunch debate entitled "The World Health Organisation and the World Dementia Council and global action on dementia: what role for the European Union?" in the European Parliament featuring three speakers: Dr Tarun Dua, Medical Officer for the Programme for Neurological Diseases and Neuroscience, WHO; Dr Raj Long, UK Government Director for Integrated Development and Senior Regulatory Officer for Integrated Development at the Bill & Melinda Gates Foundation; Gill Ayling, Deputy Director of Global action against dementia in the UK.

On 1 December, MEPs Keith Taylor (United Kingdom) and Sirpa Pietikäinen (Finland) co-hosted an AE lunch debate entitled "Dementia, a priority of two EU Presidencies" in Brussels. The speakers were Jean Georges (Executive Director of Alzheimer Europe), Anne Calteux (Senior Policy Advisor at the Luxembourg Ministry of Health), Dr Jacqueline Hoogendam (Senior Policy Advisor at the Dutch Ministry of Health, Welfare and Sports) and Michael Hübel (Directorate-General for Health and Food Safety, European Commission). Ms Pietikäinen also made closing remarks.

Both lunch debates were well-attended; delegates included Members of the European Parliament and representatives from the European Commission, the pharmaceutical industry and AE member associations.



The speakers' table at AE's lunch debate in Brussels (December)

Dementia in Europe Magazine

In 2015, Alzheimer Europe published three issues of the Dementia in Europe magazine.

These magazines included a variety of articles on policy developments, as well as interviews with the following European and national policy makers:

- Vytenis Andriukaitis, European Commissioner for Health & Food Safety
- Corinne Cahen, Luxembourg's Minister for Family Affairs and Integration
- Milojka Kolar Celarc, Slovenian Minister of Health
- Kathleen Lynch, Irish Minister of Health
- Lydia Mutsch, Luxembourg's Minister of Health

The 2015 issues include articles about the Italian and Luxembourg EU Presidency terms, reports of the WHO dementia conference and the European Commission's dementia activities since 2009.

Issue 19 (March) included coverage of AE's 2014 conference in Glasgow, while issue 20 (June) featured a special section on Slovenia, host country of the 2015 AE conference. This was composed of an interview with Slovenia's Health Minister, a profile of Spominčica – Alzheimer Slovenia, statements

of support from six Slovenian MEPs and an article about living with dementia.

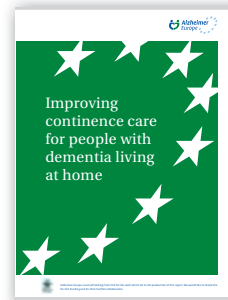
Clinical Trial and Guideline Watch

AE's Clinical Trial Watch gathers information about existing resources that can help people with dementia and their families to obtain information about clinical trials in Europe. In 2015, AE worked with the members of the EWG-PWD to connect people with dementia and their families with high quality information in a format that is adapted to their needs.

The Guideline Watch is an AE database that contains information about national guidelines for the diagnosis, treatment and management of dementia in Europe. During 2015, AE included information on 71 national guidelines in English, French and Spanish into the database. These had been collected the previous year from 63 organisations and experts in Europe.

Promoting continence care

Between January 2013 and December 2014 Alzheimer Europe partnered with SCA Global Hygiene to develop guidelines to improve continence care for people with dementia living at home. The final version of the guidelines was launched at Alzheimer Europe's Annual Conference in Glasgow in 2014 and a shorter, more dementia-friendly version, solely for people with dementia, was made available on Alzheimer Europe's website. In 2015, the working group met again to draft a scientific article about the guidelines; this was submitted for publication in a peer-reviewed journal.



Meetings attended by AE representatives

Meetings organised by AE in the framework of the 2015 Operating Grant

Date	Meeting	Location
23–25 February	AE Board and Public Affairs meetings	Luxembourg, Luxembourg
19–20 March	Meeting of the Executive of the European Working Group of People with Dementia (EWGPWD)	Luxembourg, Luxembourg
7 April	Meeting of the ethics working group	Luxembourg, Luxembourg
14–16 May	Meeting of the EWGPWD	Brussels, Belgium
27–29 June	AE Board and Public Affairs meetings	Brussels, Belgium
1 September	Meeting of the EWGPWD	Ljubljana, Slovenia
2–4 September	AE Board meeting, AE Annual General Meeting and the 25 th Alzheimer Europe Conference	Ljubljana, Slovenia
5 September	Meeting of the ethics working group	Ljubljana, Slovenia
30 Nov–2 December	AE Board meeting and Alzheimer's Association Academy	Brussels, Belgium
1–2 December	Meeting of the EWGPWD	Brussels, Belgium

Meetings attended by AE representatives in the framework of the 2015 Operating Grant

Date	Meeting	Location
7 January	Meeting with Association Luxembourg Alzheimer	Luxembourg, Luxembourg
8 January	Exploratory meeting for new Joint Action on Dementia	Luxembourg, Luxembourg
21 January	Meeting with University of Wolverhampton	Luxembourg, Luxembourg
9 February	Preparatory meeting for IMI call	Munich, Germany
3 March	Meeting with MEP Nessa Childers and The Alzheimer Society of Ireland	Brussels, Belgium
9–10 March	European Summit on Innovation for Active & Health Ageing	Brussels, Belgium
24 March	ESRC seminar: "Towards a European understanding of advance decision-making: a comparative interdisciplinary approach"	Leeds, UK
30 March	EPF Access Working Group meeting	Brussels, Belgium
1 April	Meeting with MEP Françoise Grossetête's assistant	Brussels, Belgium
4 May	Meeting with cabinet of Health Commissioner Vytenis Andriukaitis	Brussels, Belgium

Date	Meeting	Location
7 May	Meeting of the European Parliament Interest Group on Carers: "Family vs state responsibility for long-term care across the EU – the feasibility of one model?"	Brussels, Belgium
19 May	European Patients' Forum General Assembly Meeting	Brussels, Belgium
20–21 May	European Patients' Forum conference "Empowered patients are an asset to society"	Brussels, Belgium
21 May	Conference "Politiques publiques et Recherche Alzheimer : Influences et enjeux réciproques"	Paris, France
26 May	EMSP conference: "Breaking down the barriers – Call to Action: Access to employment for people with multiple sclerosis"	Brussels, Belgium
1 June	Dementia Awareness Week Conference of Alzheimer Scotland	Glasgow, UK
2 June	Meeting with MEPs and the European Union Geriatric Medicine Society EUGMS	Brussels, Belgium
3 June	Meeting with Elena Gentile MEP 'Health Discussions'	Brussels, Belgium
9 June	European Patients' Forum Public Affairs Group meeting	Brussels, Belgium
15–16 June	Meeting on "Addressing the challenge of elder abuse in Europe"	Brussels, Belgium
24–25 June	European Commission meeting of government experts on dementia	Luxembourg, Luxembourg
6 July	Meeting of the taskforce on guidelines for lay summaries of clinical trial results for lay persons	London, UK
2 September	INTERDEM meeting	Ljubljana, Slovenia
3 September	INTERDEM workshop on outcome measures	Ljubljana, Slovenia
21–23 September	European Patients' Forum training on strategic communication	Brussels, Belgium
1 October	Launch of Alzheimer's Society of Ireland pre-budget submission	Dublin, Ireland
1–2 October	In-MINDD Policy symposium	Dublin, Ireland
14 October	European Parliament Interest Group on Brain, Mind & Pain	Brussels, Belgium
20 October	European Parliament Interest Group on Carers	Brussels, Belgium
30 October	EPF working group on Access	Brussels, Belgium
3–4 November	DSDC International Dementia Conference	Birmingham, UK
10 November	EFPIA Annual Health Care Summit	Brussels, Belgium
10 November	European Parliament Interest Group on Innovation in Health and Social Care	Brussels, Belgium
19 November	EPF Policy Advisory Group Meeting	Brussels, Belgium
24–25 November	CHRODIS Conference	Vilnius, Lithuania
10 December	Mental Health Europe annual event	Brussels, Belgium

Other meetings organised by AE or attended by AE representatives in 2015

Date	Meeting	Location
14–15 January	EPAD consortium meeting	Paris, France
15 January	GSK HAB meeting	Brentford, UK
23 January	MIND-AD project meeting	Stockholm, Sweden
29 January	Meeting with Sandoz	Luxembourg, Luxembourg
12–13 February	EPAD WP6 meeting	Barcelona, Spain
24 February	AE Company round table	Luxembourg, Luxembourg
27 February	Incontinence working group meeting	Brussels, Belgium
3–4 March	PredictND project and board meeting	London, UK
4–5 March	EMA Patients and Consumers' Working Party	London, UK
5–6 March	AFE-INNOVNET project consortium meeting	Brussels, Belgium
12–13 March	PACE consortium meeting	Vollendam, Netherlands
16 March	VPH-DARE@IT General Assembly	Rotterdam, Netherlands
16–18 March	WHO Ministerial Conference on Dementia and CEOi Initiative Meeting on Dementia	Geneva, Switzerland
19–22 March	Symposium on IMI Alzheimer's Platform and AD/PD Conference	Nice, France
24 March	EFPIA Think Tank meeting	Brussels, Belgium
24–25 March	Roche Dementia Forum	Amsterdam, Netherlands
27 March	PredictND Review Meeting	Brussels, Belgium
9–10 April	EPAD WP6 meeting	Barcelona, Spain
21–24 April	Meeting for AEC 2016 venues	Tallinn, Estonia
23–24 April	MIAMI-MD kickoff meeting	Chelmsford, UK
8 May	Lilly Working Group on AD environment	Erl Wood, UK
8 May	LUX-MICE conference	Luxembourg, Luxembourg
13–14 May	NILVAD General Assembly	Thessaloniki, Greece
19–20 May	IMEX conference	Frankfurt, Germany
19–21 May	EPAD General Assembly	Edinburgh, UK
3–4 June	EMA Patients' and Consumers' Working Party meeting	London, UK
4 June	AETIONOMY legal and ethical workshop	Hannover, Germany
4–5 June	"Herausforderungen Demenz": symposium of health ministries of German-speaking countries	Bern, Switzerland
9 June	EMIF WP15 meeting	Zaventem, Belgium
11 June	EFPIA Patients Think Tank	Brussels, Belgium
11–12 June	Meeting with AEC2015 suppliers	Ljubljana, Slovenia
11–13 June	Kuopio Alzheimer Symposium	Kuopio, Finland
12 June	GSK Health Advisory Board meeting	Brentford, UK
15–16 June	Janssen Patient Advocacy Engagement Workshop	Brussels, Belgium

Date	Meeting	Location
16–17 June	Site inspection for AEC2016 venues	Copenhagen, Denmark
23–24 June	EMIF General Assembly	Ghent, Belgium
28 June	Lunch debate at the European Parliament	Brussels, Belgium
1 July	Round table on incontinence	Brussels, Belgium
1 July	AE Company round table	Brussels, Belgium
2 July	Roche Forum	Brussels, Belgium
13 August	EPAD ethics workshop	Amsterdam, Netherlands
5 September	EPAD Communications team meeting	Ljubljana, Slovenia
15–16 September	AFE-INNOVNET consortium meeting	Brussels, Belgium
25 September	PACE user forum	Brussels, Belgium
1–2 October	PredictND management and consortium meeting	Perugia, Italy
15 October	Meeting with Lilly	Brussels, Belgium
28–29 October	EFPIA 2015 Health Collaboration Summit	Brussels, Belgium
3 November	AETIONOMY Steering Committee meeting	Barcelona, Spain
3, 5–6 November	Meeting of the EPAD project focus groups	Barcelona, Spain
4 November	AETIONOMY General Assembly	Barcelona, Spain
4–7 November	CTAD conference	Barcelona, Spain
10–11 November	SyDAD start-up meeting	Stockholm, Sweden
23 November	Meeting with Quintiles	Luxembourg, Luxembourg
25 November	EMA training session for patients and consumers	London, UK
26 November	EMA Patients and Consumers Working Party	London, UK
27 November	GSK Health Advisory Board	London, UK
1–2 December	AE lunch debate and company round table	Brussels, Belgium
7 December	Launch of AFE-INNOVNET Covenant	Brussels, Belgium
8 December	EFPIA Think Tank Meeting	Brussels, Belgium
8–9 December	Joint AFE-INNOVNET and WHO Europe workshop on age-friendly environments	Brussels, Belgium
10 December	Meeting with Travel Pro	Luxembourg, Luxembourg
10–11 December	Lilly Working Group meeting	Erl Wood, UK
15–16 December	OECD Workshop	Lausanne, Switzerland
18 December	PharmaCog Steering Committee meeting	Lille, France

Alzheimer Europe's Board and staff

Members of the Alzheimer Europe Board (2014–2016)



Left to right: Maria do Rosário Zincke dos Reis, Jim Pearson, Iva Holmerová, Štefanija Lukić Zlobec, Charles Scerri, Heike von Lützu-Hohlbein, Marie-Odile Desana, Sabine Henry, Helga Rohra. Absent: Sirpa Pietikäinen, Jesús Rodrigo.

Alzheimer Europe staff members



Jean Georges
Executive Director



Vanessa Challinor
Policy Officer



Ana Diaz
Project Officer



Kate Ellis
Communications Officer



Dianne Gove
Director for Projects



Gwladys Guilloiry
Event and Conference
Coordinator



Stefanie Peulen
Finance Officer



Alex Teligadas
Director for
Communication



Grazia Tomasini
Administrative Assistant

Financial report

Report from the auditors



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, 2015



To the Board of Directors of
ALZHEIMER EUROPE
Association sans but lucratif

R.C.S. Luxembourg F 2773

14, rue Dicks
L-1417 LUXEMBOURG

REPORT OF THE REVISEUR D'ENTREPRISES AGREE

Following our appointment by the General Meeting of the Shareholders dated September 2, 2015, we have audited the accompanying annual accounts of **ALZHEIMER EUROPE**, which comprise the balance sheet as at December 31, 2015 and the profit and loss account for the year then ended, and a summary of significant accounting policies and other explanatory information.

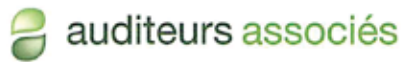
Responsibility of the Board of Directors' for the annual accounts

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 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.

Responsibility of the réviseur d'entreprises agréé

Our responsibility is to express an opinion on these annual accounts based on our audit. We conducted our audit in accordance with International Standards on Auditing as adopted for Luxembourg by the Commission de Surveillance du Secteur Financier. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the annual accounts are free from material misstatement.





An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the annual accounts. The procedures selected depend on the réviseur d'entreprises agréé's judgement, including the assessment of the risks of material misstatement of the annual accounts, whether due to fraud or error. In making those risk assessments, the réviseur d'entreprises agréé considers internal control relevant to the entity's preparation and fair presentation of the annual accounts 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 entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the Board of Directors, as well as evaluating the overall presentation of the annual accounts.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the annual accounts give a true and fair view of the financial position of **ALZHEIMER EUROPE** as of December 31, 2015, and of the results of its operations for the year then ended in accordance with Luxembourg legal and regulatory requirements relating to the preparation of the annual accounts.

Luxembourg, February 29, 2016

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



Philippe SLENDZAK
Partner

Appendix:

- Annual accounts as at December 31st, 2015

Balance sheet as of December 31, 2015

	2015 (Euro)	2014 (Euro)
ASSETS		
Fixed assets		
Other fixed assets	29 066	28 597
Current assets		
Debtors European Commission	167 803	123 382
Other debtors	235 593	31 653
Cash at bank and on deposit	556 999	167 130
	960 395	322 165
Prepayments	1 611	2 589
	991 072	353 350
LIABILITIES		
Capital and reserves		
Results brought forward	197 798	183 738
Result of the year	19 763	14 060
	217 561	197 798
Creditors		
EU Subsidies received on account	395 583	55 596
Tax and social security	27 163	19 456
Payments received on account	250 000	-
Trade creditors	48 367	51 149
Other liabilities	31 324	20 291
	752 437	146 492
Deferred income	21 074	9 060
	991 072	353 350

Deferred income represents a part of income received in 2015 and which will be used in 2016.

As at December 31, 2015, the non-profit organisation had a rental guarantee of KEUR 16 granted to the owner of the offices used by the non-profit organisation.

Profit and loss account Year ended December 31, 2015

	2015 (Euro)	2014 (Euro)
Support and revenue		
Other operating income		
EU Subsidy	611 498	465 297
Corporate sponsorship	287 386	296 608
Sponsorship received on account	- 21 074	- 9 060
AE Conference registration fees	123 191	164 362
Project participation and other subsidies	98 153	109 915
Co-financing in kind	85 200	56 700
Membership fees and contributions	58 377	57 790
Deferred income	9 060	5 991
Publication sales and royalties	1 712	5 693
Donations	574	498
Other operating income	6 846	9 248
External charges		
Accommodation expenses	- 200 638	- 172 543
External experts	- 140 403	- 142 542
Publication and Information material	- 79 869	- 95 053
Travel expenses	- 74 075	- 59 274
Office rent and associated costs	- 41 220	- 47 646
Alzheimer Europe Foundation	- 40 686	- 29 422
Communication costs	- 39 957	- 31 572
Equipment and Leasing	- 15 185	- 33 561
Office stationery and related costs	- 3 454	- 7 486
Bank charges	- 3 023	- 4 203
Membership fees	- 1 120	- 1 000
Other costs	- 1 517	- 67
Staff costs		
Wages and salaries	- 521 716	- 448 171
Social security costs	- 68 486	- 67 532
Depreciation	- 10 670	- 9 469
Interest receivable and similar income	860	558
	19 763	14 060

Breakdown of income

In 2015, Alzheimer Europe had an audited income of EUR 1,261,781.96 of which EUR 857,376.42 (67.95%) were for the organisation's core activities (including the organisation's Annual Conference) and EUR 404,405.54 (32.05%) were for the organisation's annual conference, corporate affairs activities and other projects.

Funding of core activities (EUR 857,376.42)

In 2015, the core funding of Alzheimer Europe was composed as follows:

- EUR 422,880 (49.32%) from public funding
- EUR 96,294.80 (11.23%) from foundations and other non-profit organisations
- EUR 137,877.29 (16.08%) from member organisations
- EUR 75,700 (8.83%) from corporate sources
- EUR 123,764.76 (14.44%) from private individuals
- EUR 859.57 (0.10%) from bank interest and similar

Public funding

In 2015, Alzheimer Europe received EUR 422,880 as an operating grant from the European Commission

Foundations and organisations

The EUR 96,294.80 which Alzheimer Europe received in 2015 from foundations and other non-profit organisations can be broken down as follows:

- EUR 87,000 as direct support from Fondation Alzheimer, Luxembourg
- EUR 5,294.80 from Fondation Roger de Spoelberch for the publication of the Alzheimer Europe Care Manual in Portuguese
- EUR 4,000 from Fondation Médéric Alzheimer to support AE's work on ethical challenges faced by professional carers

Funding from member organisations

In 2015, the EUR 137,877.29 funding from member organisations can be broken down as follows:

- EUR 58,377.29 in membership fees and contributions
- EUR 79,500 in co-financing from Board members and representatives of member organisations in time donated to the organisation (at EUR 300 per day)

Corporate support

In 2015, Alzheimer Europe received EUR 75,700 from

corporate sources as core-funding which can be broken down as follows:

- EUR 35,000 from GlaxoSmithKline as support to the organisation's core activities
- EUR 10,000 from Hoffmann-LaRoche and Lilly to support the AE Conference in Ljubljana
- EUR 5,700 from Newsweaver which provided an e-mail facility free of charge
- EUR 5,000 from Nestlé, Piramal and SCA Global Hygiene to support the AE Conference in Ljubljana

Private individuals

In 2015, AE received EUR 123,764.76 from individuals which can be broken down as follows:

- EUR 123,191.25 in conference registrations
- EUR 573.51 in donations

Bank interest and similar

In 2015, Alzheimer Europe had an income of EUR 859.57 from bank interest and similar income.

Funding of project activities (EUR 404,405.54)

In 2015, Alzheimer Europe received EUR 404,405.54 for its participation in various EU projects, a project on good incontinence care and its corporate affairs activities, of which

- EUR 217,385.51 (53.75%) came from corporate sponsors
- EUR 1,712.04 (0.42%) from private individuals
- EUR 188,617.52 (46.64%) from public sources
- EUR 8,704.32 (2.15%) from foundations and other non-profit organisations
- EUR -12,013.85 (-2.97%) was project income deferred to 2016

Corporate support

The corporate support received by Alzheimer Europe for its activities in 2015 (EUR 217,385.51) can be broken down as follows:

- Lilly contributed EUR 41,280 as a gold sponsor of AE's corporate programme and as travel support
- SCA Global Hygiene contributed EUR 32,350 as a bronze sponsor of AE's corporate programme and towards the AE/SCA joint project on good incontinence care
- Hoffmann-LaRoche contributed EUR 20,025 as a silver sponsor of AE's corporate programme and as travel support
- GE Healthcare and Janssen contributed EUR 20,000

- each as silver sponsors of AE's corporate programme
- Nutricia contributed EUR 15,000 towards AE's corporate programme
- Lundbeck, Nestlé and Otsuka contributed EUR 12,500 each towards AE's corporate programme
- Merz and Piramal provided EUR 10,000 as bronze sponsors of AE's corporate programme
- Sandoz and Biogen provided EUR 5,000 as sponsors of AE's corporate programme
- GSK provided EUR 1,230.51 in travel support and honoraria

- EUR 9,628.72 for NILVAD
- EUR 9,561.46 for Smart4MD
- EUR 7,370.98 for a JPND health outcomes project
- EUR 7,119.47 for EMIF

Foundations and organisations

In 2015, Alzheimer Europe received a total of EUR 8,704.32 for other organisations and foundations, including EUR 6,846.27 from various organisations as travel grants and EUR 1,858.05 for secretarial costs provided to the Alzheimer Europe Foundation.

Private individuals

In 2015, Alzheimer Europe received EUR 1,712.04 in publication sales.

Public funding

In 2015, Alzheimer Europe received EUR 188,617.52 as public funding from its participation in various EU projects:

- EUR 52,650.11 for EPAD
- EUR 26,411.36 for AETIONOMY
- EUR 23,212.33 for AFE-INNOVNET
- EUR 22,757.35 for PharmaCog
- EUR 15,786.22 for PredictND
- EUR 14,119.52 for PACE

Deferred income

In 2015, Alzheimer Europe was able to contribute EUR 9,060.19 to its project activities which came from deferred income in 2014 and reported EUR 21,074.04 of its project income to 2016.

Overall funding

The following table lists all sources of income received in 2015.

In line with the policy of the European Medicines Agency on transparency requirements for accredited patients' organisations, this is presented in total amounts as well as in terms of percentages of the overall income of the organisation.

Funding source	Funding received	As % of AE income	
		2015	2014
Lilly	51,280.00	4.06%	4.46%
GlaxoSmithKline	36,230.51	2.87%	3.01%
Hoffmann-LaRoche	30,025.00	2.38%	1.74%
GE Healthcare	20,000.00	1.59%	0.86%
Janssen	20,000.00	1.59%	1.72%
Piramal	15,000.00	1.19%	1.29%
Lundbeck	12,500.00	0.99%	0.90%
Otsuka	12,500.00	0.99%	
Merz	10,000.00	0.79%	0.86%
Biogen	5,000.00	0.40%	
Sandoz	5,000.00	0.40%	0.43%
Novartis			0.86%
Pfizer			0.86%
Sub-total: Pharmaceutical funding	217,535.51	17.24%	16.98%
SCA Global Hygiene	37,350.00	2.96%	3.57%
Nestlé	17,500.00	1.39%	0.64%

Nutricia	15,000.00	1.19%	1.72%
Newsweaver	5,700.00	0.45%	0.49%
Bupa			0.86%
Kaizo			1.72%
Sub-total: Other corporate sources	75,550.00	5.99%	9.00%
Total: Corporate funding	293,085.51	23.23%	25.98%
European Commission	611,497.52	48.46%	39.99%
Scottish Government			1.17%
Total: Public funding	611,497.52	48.46%	41.15%
Fondation Alzheimer, Luxembourg	87,000.00	6.90%	7.48%
Other organisations	6,846.27	0.54%	2.71%
Fondation Roger de Spoelberch	5,294.80	0.42%	
Fondation Médéric Alzheimer	4,000.00	0.32%	
Alzheimer Europe Foundation	1,858.05	0.15%	
Life Changes Trust			0.80%
Malta Tourism Authority			
Total: Foundations and organisations	104,999.12	8.32%	10.99%
Individuals (Conference fees, donations, publications)	125,746.08	9.94%	14.21%
Total: Individuals	125,746.08	9.94%	14.21%
AE member organisations	137,877.29	10.93%	6.64%
Total: Member organisations	137,877.29	10.93%	6.64%
Deferred income	-12,013.85	-0.95%	-0.26%
Total: Deferred income	-12,013.85	-0.95%	-0.26%
Bank interest and similar	859.57	0.07%	0.05%
Total: Bank interest and similar	859.57	0.07%	0.05%
Other income			1.24%
Total: Other income			1.24%
Total Income	1,261,781.96	100.00%	100.00%

Our sponsors and supporters



Our members are helping people with dementia and their carers in 32 countries

Alzheimer Europe Members



AUSTRIA – VIENNA
Alzheimer Austria



BELGIUM – BRUSSELS
Ligue Nationale Alzheimer Liga



BOSNIA & HERZEGOVINA - SARAJEVO
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ICELAND – REYKJAVIK
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ISRAEL – RAMAT GAN
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ITALY – MILAN
Federazione Alzheimer Italia



ITALY – ROME
Alzheimer Uniti Onlus



JERSEY – ST HELIER
Jersey Alzheimer's Association



LUXEMBOURG – LUXEMBOURG
Association Luxembourg Alzheimer



MALTA – MSIDA
Malta Dementia Society



MONACO – MONTE-CARLO
AMPA - Association Monégasque pour la recherche sur la maladie d'Alzheimer



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ROMANIA – BUCHAREST
Societatea Alzheimer



SLOVAKIA – BRATISLAVA
Slovak Alzheimer's Society



SLOVENIA – LJUBLJANA
Association "Forget-me-not"



SPAIN – MADRID
Fundación Alzheimer España



SPAIN – PAMPLONA
C.E.A.F.A.



SWEDEN – LUND
Alzheimerföreningen i Sverige



SWEDEN – STOCKHOLM
Demensförbundet



SWITZERLAND – YVERDON-LES-BAINS
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