



Annual and Financial Report 2016



Alzheimer Europe Annual and Financial Report 2016



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Preface



As the new Chairperson of Alzheimer Europe, I am very pleased to introduce this year's Annual Report highlighting Alzheimer Europe's activities in 2016. I was deeply honoured to be elected at our 2016 Annual Meeting to take the succession of Heike von Lützu-Hohlbein, our Chairperson of six years and hope to provide the same exemplary leadership to Alzheimer Europe in the coming years.

As in previous years, our core activities were funded by the EU health programme, in the form of an operating grant from the European Commission. Alzheimer Europe and its member organisations are very grateful for this ongoing support to improve the lives of people with dementia along with their families and carers.

In 2016, people with dementia were involved in all aspects of AE's work. The European Working Group of People with Dementia met on a regular basis to develop and carry out activities such as participating in European research projects and speaking at international conferences. These activities did not go unnoticed; the group was very pleased to receive an international award that recognised their work to enhance the health, wellbeing and quality of life of people with dementia and their families. In October, the group began its third two-year term by welcoming new members and electing a new Chairperson and Vice-Chairpersons to its Board. The group also organised a very popular symposium at the 26th Alzheimer Europe Conference and several members participated in the plenary sessions. In addition, the Chairpersons of the EWGPWD participated in all 2016 AE Board meetings as ex-facto members with full voting rights.

On a national level, we were pleased to note and report on the launch of new national dementia strategies or neurodegenerative disease strategies in four countries and extensions of existing strategies in another three. These countries are all represented in Alzheimer Europe and we are also following the progress of strategies that are still in development. This is a clear and welcome indicator of increased awareness of dementia in individual countries, but also on a European level.

In 2016, the Netherlands took over the six month EU Presidency from Luxembourg and maintained dementia as a priority, with an emphasis on the financial viability

of dementia care. In April, a dedicated conference on "Living well with(out) dementia" which was attended by numerous representatives from European Health Ministries and also AE and its member organisations. In July, the EU Presidency passed to Slovakia, which took similar steps to ensure that dementia stayed at the forefront of the European health agenda and organised a conference on Alzheimer's disease as the "epidemic of the third millennium".

In the European Parliament, we saw our European Alzheimer's Alliance (EAA) grow to reach 128 MEPs from 28 countries and it remains one of the Parliament's biggest interest groups. In 2016, members of the alliance provided articles for the Dementia in Europe magazine and hosted or attended our two lunch debates in Brussels. On 28 June, MEPs Marisa Matias (Portugal) and Sirpa Pietikäinen (Finland) co-hosted the debate entitled "Using the UN Convention on the Rights of Persons with Disabilities (UNCRPD) to support the rights of people living with dementia". On 6 December, the debate hosted by Nessa Childers, MEP (Ireland) and a Vice-Chairperson of the EAA, focused on comparing and benchmarking national responses to the dementia challenge.

The latter featured a presentation of the results of AE's European Dementia Monitor, a 2016 survey of national dementia strategies and policies. During the year, AE also produced its Dementia in Europe Yearbook – which focuses on decision making and legal capacity issues in dementia – and a discussion paper on ethical issues linked to the changing definitions and use of terms related to Alzheimer's disease.

In 2016, our European Dementia Observatory continued to grow, both in terms of content and audience reach. Alzheimer Europe published two issues of the Dementia in Europe magazine, which featured a variety of articles

on policy developments such as interviews with health ministers, the actions of the EU Presidencies and the global dementia initiatives of the WHO. The monthly AE newsletter, which now reaches close to 7,500 subscribers, published a total of 730 articles. In addition to policy issues, the newsletter reports on the activities of AE's members and the latest developments in dementia research.

This scientific coverage is bolstered by the Expert Advisory Panel, a group of acknowledged experts that helps us to accurately report on medical breakthroughs. All newsletter articles are posted on AE's website, which saw an increase to almost 770,000 unique visitors during the year. Our social media activities are also on the upswing, particularly on Twitter: the 2016 conference hashtag #26AEC had over 20 million tweet impressions and AE was named among the top ten most followed NGOs on Twitter by Members of the European Parliament in a survey carried out by Hill + Knowlton Strategies.

AE's 26th Annual Conference took place in Copenhagen, co-hosted by Alzheimerforeningen, the Danish Alzheimer Association. Our theme, "Excellence in dementia research and care", attracted over 710 delegates – including 35 people with dementia – with a programme featuring some 150 speakers and 189 poster presentations. The event was organised under the Honorary Patronage of Her Royal Highness Princess Benedikte of Denmark, who spoke at the Opening Ceremony and also attended the special session hosted by the European Working Group of People with Dementia. AE's Annual General Meeting took place just before the conference and we were pleased to accept Alzheimer Albania and the Hungarian Cluster Association as new provisional members of Alzheimer Europe. The delegates also elevated Italy's Alzheimer Uniti ONLUS to full member status and elected new members to the Alzheimer Europe Board for the 2016–2018 term.

In 2016, AE expanded its participation in EU research projects and is now an active partner in AETIONOMY, AMYPAD, EMIF, EPAD, INDUCT, MinD, MOPEAD, NILVAD, PACE, PredictND, ROADMAP, SMART4MD and SyDAD.

These projects provide an additional funding stream and also allow us to stay at the forefront of European dementia research. AE is also participating in DEM 2, the 2nd European Joint Action on Dementia which brings together ministries of health and academics. In addition, AE became a member of the European Disability Forum and continued its productive cooperation with INTERDEM, a pan-European research network for psychosocial interventions in dementia.

All of these accomplishments are due to the efforts of the staff members of Alzheimer Europe. I am pleased to commend the excellent work of this small team, which is headed by Executive Director Jean Georges and includes Kate Boor-Ellis, Vanessa Challinor, Ana Diaz, Dianne Gove, Gwladys Guillory, Stefanie Peulen, Alex Teligadas and Grazia Tomasini.

I would also like to thank the corporate sponsors that provided support to our 2016 activities. We very much appreciate the generosity of Axovant, Biogen, GE Healthcare, GlaxoSmithKline, Janssen, Lilly, Lundbeck, Merck, Merz, MSD, Nestlé, Newsweaver, Novartis, Nutricia, Otsuka, Pfizer, Piramal, Roche and SCA Global Hygiene.

Finally, I am most grateful to my fellow Board members for their helpful advice and recommendations; these are inspired by many years of experience of working with national Alzheimer associations across Europe. I would like to give a special mention to Heike von Lützu-Hohlbein, who stepped down from the Board in October after many years of dedicated service as Honorary Treasurer and Chairperson of Alzheimer Europe. In addition, I wish to thank all the representatives from our national member associations and the external experts who collaborated in our activities and projects.

I eagerly look forward to a very productive 2017 and our continued cooperation with our national member organisations, external experts and corporate sponsors.

Iva Holmerová
Chairperson of Alzheimer Europe

Executive summary

In 2016, Alzheimer Europe:

- received an operating grant from the European health programme for its core activities
- collaborated with the Dutch and Slovak EU Presidencies and actively contributed to their Presidency Conferences "Living well with(out) dementia" in Amsterdam May and "Alzheimer's disease – epidemic of the third millennium: Are we ready to face it?" in Bratislava in November
- participated as an observer in the meetings of the group of governmental experts on dementia convened by DG SANTE
- developed close working relationships with the new Joint Action on Dementia coordinated by the Scottish Government and contributed to the four priority actions of timely diagnosis and post-diagnostic support, crisis management and care coordination, quality of residential care and dementia-friendly communities
- was consulted by the World Health Organisation on the development of the Global Dementia Observatory and supported the campaign of Alzheimer's Disease International for the development of a global dementia action plan
- welcomed the launch of new dementia strategies in the Czech Republic, Denmark and Slovenia and the development of a neurodegenerative diseases strategy in Spain
- played an active role in the Patients' and Consumers' Working Party of the European Medicines Agency
- continued its work with the European Alzheimer's Alliance, which ended the year with 128 Members of the European Parliament from 27 out of 28 EU Member States
- involved members of the European Alzheimer's Alliance in the organisation of two lunch debates in the European Parliament
- supported a Written Declaration on the prioritisation of a European dementia strategy which was signed by 135 Members of the European Parliament
- played an active role as a member of the European Patients' Forum and supported the development of positions and statements from the broader patient and carer community in response to EU policy developments
- organised two face-to-face meetings of the public affairs committee for an exchange on EU and national policy developments and campaigns
- identified legal capacity and proxy decision making as the focus of its 2016 Yearbook, updated the existing national reports and developed new reports to describe national legislation in 31 European countries, produced a comparative report and identified best practices in this field
- continued with the development of its European Dementia Observatory by proactively identifying relevant policy and research developments and communicating them to its member organisations and wider community
- continued to partner with Newsweaver for sending its e-mail newsletter which covered 730 dementia-related news and expanded the list of people receiving the newsletter to almost 7,500
- involved its Expert Advisory Panel in commenting on and providing context to breaking research stories
- published a Research Digest at the end of the year highlighting the key scientific developments in different scientific areas
- promoted its website and attracted 769,489 unique website visitors in 2016
- ensured social media are a full part of the organisation's communication activities, reached 5,942 Twitter followers and 6,593 Facebook likes by the end of the year
- involved all AE staff in social media activities which collectively reached over 2.5 million tweet impressions
- was named one of the top ten most influential NGOs on Twitter for Members of the European Parliament
- continued to develop its European Dementia Ethics Network and identified the changing definition of Alzheimer's disease and its ethical implications as the priority of its work

- set up a working group comprised of ethicists, clinicians, researchers and people with dementia and carers that met twice in 2016 to discuss the ethical issues raised by the changing definition of Alzheimer's disease
- published a discussion paper and Alzheimer Europe's position on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease
- organised three meetings of the European Working Group of People with Dementia (EWGPWD) with one meeting coinciding with AE's Annual Conference
- identified new members to join the EWGPWD for the new mandate of the group starting in November 2016 and ensured that 11 national organisations are represented in the group
- saw the work of the European Working Group recognised and given the international "Mano Amiga" award
- involved the EWGPWD in the organisation of the Annual Conference by including representatives in the Programme Committee to help with the selection of abstracts, by inviting them to deliver a keynote presentation and by asking them to organise a special symposium on the experiences of living with dementia
- involved the EWGPWD in various AE activities, EU projects and research activities where AE is asked to provide the views of people with dementia
- organised the 26th AE Conference in Copenhagen, Denmark from 31 October to 2 November under the motto "Excellence in dementia research and care" in collaboration with Alzheimerforeningen, the Danish Alzheimer's association
- involved its Expert Advisory Panel in the selection of breaking research topics and the selection of abstracts
- attracted 714 participants from 41 countries to the conference including 35 people with dementia
- organised its Annual General Meeting in the framework of the Annual Conference and elected a new Board with Iva Holmerová (Czech Republic) as new Chairperson, Charles Scerri (Malta) as Vice-Chairperson, James Pearson (UK-Scotland) as Honorary Secretary and Maria do Rosário Zincke dos Reis (Portugal) as Honorary Treasurer
- updated its member organisations on relevant EU policy developments and involved them in the development of policy positions through AE's public affairs working group
- organised its second Alzheimer's Association Academy in December 2016 which consisted of a series of capacity-building seminars on the working of the European institutions, lobbying activities and the clinical trial process
- welcomed Alzheimer Albania and the Hungarian Cluster Association as new provisional members and elevated Alzheimer Uniti ONLUS to full member

- improved collaboration with the INTERDEM network and contributed to two papers on social health and assistive technology
- continued to play an active role as a member of the European Patients' Forum
- reviewed its partnership agreement with ADI and continued to coordinate with ADI to develop common approaches to the ongoing G7, G20, OECD and WHO initiatives in the field of dementia
- continued its collaboration with AGE Platform Europe, the Interest Group on Mental Health, Well-being and Brain Disorders and the Interest Group on Carers
- joined the European Disability Forum as an ordinary member and became a founding member of the European Covenant on Demographic Change
- started its involvement in three new projects funded by the Innovative Medicines Initiative, namely AMYPAD (Amyloid imaging to prevent Alzheimer's disease), MOPEAD (Models of Patient Engagement for Alzheimer's disease) and ROADMAP (Real world outcomes across the Alzheimer's disease spectrum for better care: multi-model data access platform)
- continued its involvement in the EU funded projects AETIONOMY, EPAD, EMIF, NILVAD, PACE, PredictND and SMART4MD 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
- supported INDUCT, MinD and SyDAD, exchange projects funded under the Marie Curie programme
- developed a number of activities funded thanks to the support of its corporate sponsors and partners and organised three company round tables bringing together the AE Board, representatives of corporate sponsors and AE members
- published two editions of the Dementia in Europe magazine
- published on its website dementia-friendly information on ongoing phase III clinical trials conducted in two or more European countries (Clinical Trials Watch)
- collected 71 national guidelines on the diagnosis, treatment and management of dementia
- finalised the findings of the European Dementia Monitor and presented them at a lunch debate in the European Parliament
- developed, in collaboration with the University of Bangor, a survey on carers' experiences of diagnosis which will be conducted in 2017 in the Czech Republic, Finland, Italy, the Netherlands and the United Kingdom (Scotland) thanks to financial support of Roche



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 (2016–2020). This year's Annual Report breaks down the organisation's core activities into these four key strategic objectives and follows the structure of the 2016 Annual Work Plan, which was

adopted at the Annual General Meeting in Ljubljana in 2015.

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 it has been able to carry out thanks to the support of its corporate sponsors.



Alzheimer Europe Annual General meeting October 2016

AE core activities

In 2016, 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

Collaborating with EU initiatives

2016 saw a number of key developments at EU level, which Alzheimer Europe was able to contribute to and which marked a growing recognition of dementia as a European and national priority.

Both the Dutch and Slovak Presidencies of the European Union dedicated a conference to dementia. Alzheimer Europe participated in both "Living well with(out) dementia" on 9 and 10 May in Amsterdam and "Alzheimer's disease – epidemic of the third millennium: Are we ready to face it?" on 29 November in Bratislava. The Dutch Presidency Conference focused on three themes: living well with(out) dementia and the growing importance of prevention and risk reduction, living well at home and living well in care homes and provided the opportunity for a number of EU funded projects to be showcased. Similarly, the Slovak Presidency Conference centred on four

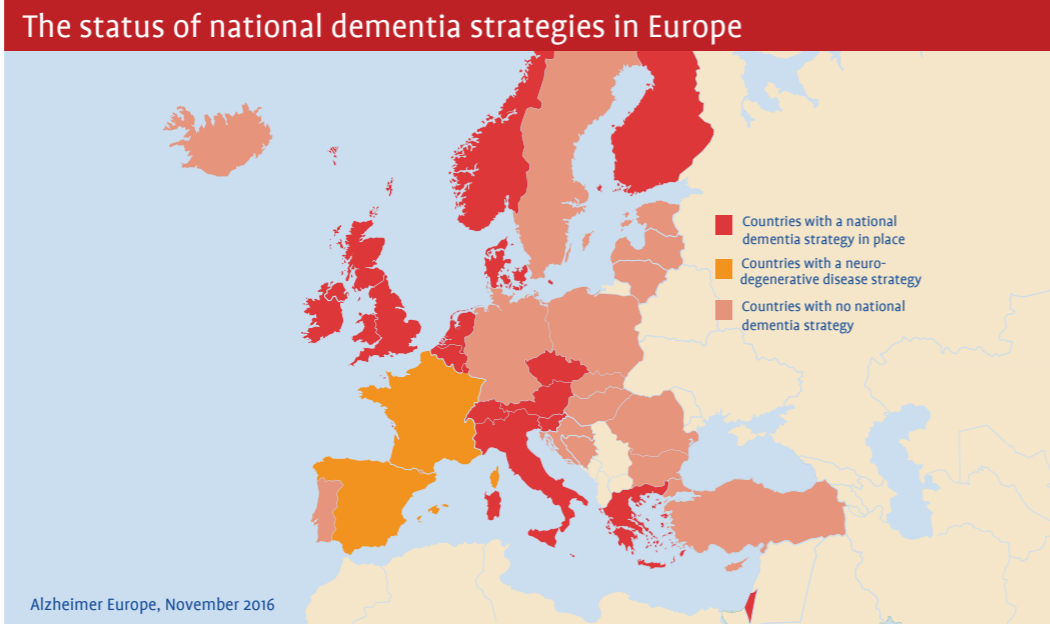
key themes: dementia as a global health priority, prevention and intervention strategies in Alzheimer's disease, national programmes and action plans on dementia and Alzheimer's disease as a European Presidency priority.

The group of EU governmental experts on dementia was convened twice by DG SANTE of the European Commission and met in February in Luxembourg and in November in Bratislava. The government experts exchanged information on ongoing national initiatives and dementia strategies and identified areas for the collection and exchange of good practices. Alzheimer Europe participates in these meetings in an observer capacity.

In 2016, Alzheimer Europe was also actively involved in the 2nd Joint Action on Dementia coordinated by the Scottish Government and participated in the Programme Board and the Evaluation and Dissemination Groups. Alzheimer Europe also contributed to the four policy priority areas on timely diagnosis and post-diagnostic support, care coordination and crisis management, quality of residential care and dementia-friendly communities. The organisation's European Working Group of People with Dementia provided input to the ongoing work on dementia-friendly communities.



Slovak EU Presidency Conference, Bratislava 2016



On a global level, the World Health Organisation (WHO) further developed its activities on dementia. A ministerial panel convened by the Swiss government on 23 May and supported by the health ministers of Austria, Ethiopia, Germany, Luxembourg, Malta, the Netherlands and the USA called for the development of a global dementia action plan. In response, the WHO started the development of the Global Dementia Observatory, a knowledge hub for dementia, which will provide epidemiological trends and a comparison of national data sources and policies on dementia. Alzheimer Europe was consulted during the development phase of the Global Dementia Observatory.

On a national level, Alzheimer Europe was very satisfied to see the launch of new national dementia strategies in the Czech Republic, Denmark and Slovenia, a new neurodegenerative disease strategy in Spain and extensions of existing strategies in Flanders, Norway and Switzerland. During the year, there were also ongoing efforts to develop strategies in Bosnia and Herzegovina, Portugal, Sweden and Wales.

Finally, Alzheimer Europe also continued its collaboration with the European Medicines Agency (EMA) in 2016 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. In addition, Ana Diaz participated in a series of user tests of a prototype of the EMA's clinical trial data publication website. Ana was also a member of the Task Force convened to develop EU Guidelines on Summaries of Clinical Trial Results for Laypersons.

European Alzheimer's Alliance

During 2016, EAA membership grew to 128 MEPs from 27 Member States. Françoise Grossetête (France, EPP) continued 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 (United Kingdom, Green/EFA).

Alzheimer Europe gratefully acknowledges the support of all the Members of the European Parliament who were present or represented at the Alzheimer Europe lunch debates, 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.

11 Members of the European Parliament submitted a Written Declaration on the prioritisation of a European dementia strategy, which received the support of 135 of their colleagues. Unfortunately, the declaration lapsed on 11 July as it did not receive the backing of half of the Members of the European Parliament.



Jointly developing policy

As in previous years, Alzheimer Europe was an active member of the European Patients' Forum (EPF) and contributed, alongside other European organisations, to the development of cross-disease positions on EU consultations and legislative proposals. In particular, EPF invited AE to contribute to recommendations for patient-centred implementation of the provisions of the new EU Clinical Trials Regulation (Regulation 536/2014). This study consisted of a survey focusing on informed consent and information to patients. In August, AE also contributed via EPF to the European Commission draft guidance on lay summaries of clinical trials.

AE 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.



capacity in dementia" provides an update on information collected in both these earlier reports.

Objective 2: Supporting policy with facts

Comparing national systems and identifying best practices

In December, Alzheimer Europe published its 2016 Dementia in Europe Yearbook, entitled "Decision making and legal capacity in dementia". These were not new topics for AE, since the organisation had started looking at these issues almost two decades ago in 1997, with its Lawnet project on legislation relating to the rights of people with dementia from the then 15 Member States of the European Union. The Lawnet project was presented in AE's 2010 Dementia in Europe Yearbook, while the 2009 report focused on national laws in Europe, with regard to health-care decision making by people with dementia. The 2016 Dementia in Europe Yearbook, "Decision making and legal

All AE members as well as experts from Lithuania and Latvia were invited to participate, with a total of 31 countries contributing. In addition, some members of the European Working Group of People with Dementia (EWGPWD) participated, providing personal accounts of their experiences related to the main topics discussed.

The first part of the report provides information on how legislation regulates the issue of legal capacity in questions such as: contractual capacity, testamentary capacity, criminal responsibility, civil responsibility/ liability, marriage and political rights (i.e. the right to vote). The second section of the report looks at issues related to consent to treatment and research, and refers to the legal framework in each country and provisions for consent for people lacking the capacity to consent. The final section introduces the topic of systems of substitute decision making and reviews the existing legislation across Europe applying to court-appointed decision makers (i.e. guardians) and powers of attorney.

European Dementia Observatory

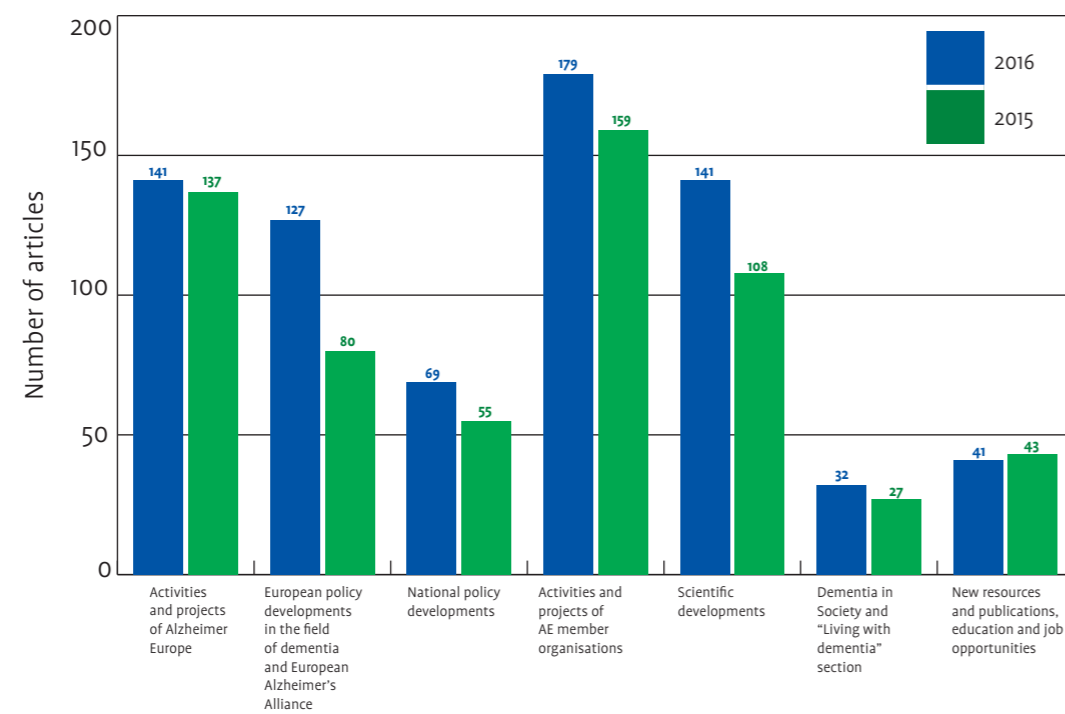
Over the past years, Alzheimer Europe has continuously improved the information it provides to its members and external stakeholders on key developments in the field of dementia.

In 2016, AE published 11 editions of its monthly e-mail newsletter, with July and August being combined. These e-newsletters contained information on AE's activities

and those of its member organisations, updates on projects in which AE is involved, interesting policy initiatives both at national and European level, scientific developments, human interest stories, new resources and publications and, job opportunities, as well as publishing accounts written by people living with dementia.

A total of 730 articles were featured in AE's 2016 monthly e-newsletter (607 in 2015). They can be broken down into categories, as follows:

Graph 1: Number of articles



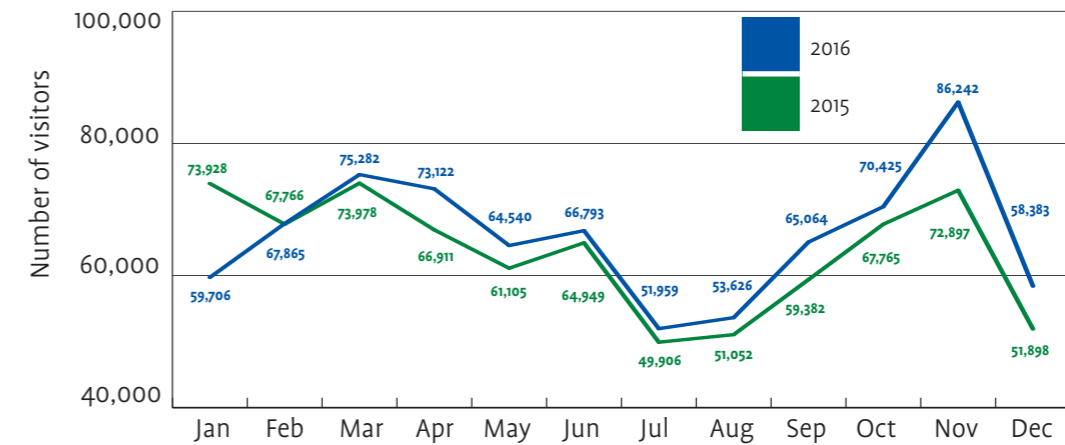
The AE newsletter had almost 7,500 subscribers at the end of 2016.

AE's Expert Advisory Panel, set up in 2015, helped ensure that information provided by the organisation on medical and scientific breakthroughs is of the highest possible standard. It consists of 35 experts in various areas of dementia from 18 European countries. In 2016, AE published a research digest consisting of all the scientific articles published in the year's newsletters. The Expert

Advisory Panel contributed to this publication, provided a number of commentaries on breaking scientific stories and also evaluated conference abstracts for the 26th Alzheimer Europe Conference in Denmark.

AE's website continued the trend of increasing the number of visitors, attracting 4.29% more visitors, with the total number of unique visitors increasing from 737,858 in 2015 to 769,489 in 2016.

Graph 2: Number of visitors



In 2016, AE also continued to step up its social media presence, particularly on Facebook and Twitter.

AE's Facebook page registered 6,593 "likes" at the end of 2016, an increase from 5,873 likes at the end of 2015. As for Twitter, the association had reached 5,942 followers at the end of 2016 (4,034 in 2015) and had tweeted 1,521 times (1,479 in 2015).

Social media is 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 2016 conference hashtag #26AEC had 20,407,711 tweet impressions and over 1,100 users were actively tweeting about the conference using the hashtag.

All AE team members who are involved in projects and attend AE events are active Twitter users, tweeting from events where they represent the organisation. The total number of Tweets by AE and its team members in 2016 was 3,605 (2,707 in 2015) and tweet impressions reached 2.57 million (1.9 million in 2015). The table below shows AE's own Twitter account activity in 2016:

In July, Alzheimer Europe was named among the top ten most influential NGOs on Twitter in the EU, alongside such household names as Amnesty International, WWF and Greenpeace. This was part of a report produced by Hill + Knowlton Strategies, based on the number of MEPs following NGOs' accounts.

Table 1: Twitter statistics

Month	Tweets	Tweet impressions	New followers
January	75	162,000	142
February	88	77,900	144
March	126	114,000	148
April	101	106,000	139
May	202	129,000	162
June	262	157,000	226
July	113	98,200	155
August	27	40,200	115
September	67	85,000	197
October	143	153,000	220
November	210	134,000	169
December	107	77,700	122
Total:	1,521	1,334,000	1,939

Objective 3: Basing our actions on ethical principles

As in previous operating grants, AE continued to focus on ethical issues in 2016. In December, the organisation published the "Discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease".

Recent and ongoing developments in the field of research into the causes and development of AD have led to new ways of understanding this condition. Researchers now suggest AD should be considered as a continuum, ranging from an "at risk" state through to

a dementia state, emphasising AD as a possible cause rather than a form of dementia.

AE welcomed continued work towards a better understanding of AD, resulting in the possibility of preventive measures, effective treatments and good quality care. At the same time, it recognised the need to ensure these definitions have a positive impact on people who already have or may develop AD and ensure they are adequately supported, fully respected and treated fairly.

With this in mind, the Ethics Working Group reflected on a range of ethical issues linked to the new AD model and brought them together in the new publication which is a discussion paper containing the position of Alzheimer Europe on this issue. The working group, chaired by Dianne Gove from Alzheimer Europe, was comprised of the following experts in the fields of ethics, the experience of dementia, ageing, psychiatry, psychology, dementia research and policy: Hilary Doxford (United Kingdom), Karine Fauria (Spain), Jean Georges (Luxembourg), Julian Hughes (United Kingdom), Tina Leonard (Ireland), Anneli Sarvimäki (Finland), Mark Schweda (Germany), Sarah Smith (United Kingdom), Hinesh Topiwala (United Kingdom) and Guy Widdershoven (Netherlands).

AE is confident that recent research, leading to the new terminology surrounding AD, as discussed in this paper, will improve understanding of the stages preceding the development of dementia and hopefully one day provide better treatment to prevent, halt or delay the apparition of symptoms. It hopes to compliment these positive developments with this discussion paper, by helping ensure that the ethical and societal implications of these developments are fully addressed.



The Ethics Working Group meeting, Amsterdam 2016

Objective 4: Building a stronger organisation

European Working Group of People with Dementia

The European Working Group of People with Dementia (EWGPWD) was originally set up by AE in 2012, following consultations with its member organisations where involvement was identified as a key priority for Alzheimer Europe. The working group met three times in 2016 (21-23 March, 30 October, 12-14 December) and the Chairperson participated in AE Board meetings as a full Board member. The group was consulted to ensure user representation and involvement in all AE activities.

For the 2014-2016 term, 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).

In October 2016, the group received the international "Mano Amiga" award for its innovative work and initiatives that contribute, in a meaningful and significant way, to enhance the health, wellbeing and quality of life of people with dementia and their families.

Also in October, the group welcomed new members from Bosnia and Herzegovina, Denmark, Finland, Portugal and the United Kingdom (Scotland and Wales) for the next two-year term and elected Helen Rochford-Brennan (Ireland) as the new Chairperson and Alv Orheim (Norway) and Chris Roberts (United Kingdom) as Vice-Chairpersons.

In 2016, the EWGPWD and/or its members contributed towards

- AE activities (2016 Yearbook on decision making and legal capacity in dementia, discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease, clinical trials watch etc.)
- AE Conference in Copenhagen with the organisation of a special symposium entitled "Living well with dementia"
- EU projects where AE is involved (EPAD, MinD, SMART4MD, PredictND)
- Research activities carried out by other organisations (INTERDEM, ADDIA, Joint Action on Dementia WP5 "Dementia-friendly communities" etc.)
- Two peer-reviewed papers which have both been accepted for publication in a scientific journal (on social health and on people with dementia as peer researchers)



EWGPWD 2016-2018, poses with the Mano Amiga Award, Copenhagen 2016

In addition, members of the group participated in the following meetings:

- Alzheimer Europe Board meetings by Chairpersons Helga Rohra (February, June, October) and Helen Rochford-Brennan (December)
- Seminar organised by Roche on the importance of timely diagnosis in Lindau (Germany) on 6–7 June (Helen Rochford-Brennan)
- Session entitled “Facing the challenge of Alzheimer’s and other dementias” at the European Health Forum Gastein on 28–30 September (Helen Rochford-Brennan)



European Health Forum Gastein, September 2016

- IMI Stakeholder Forum in Brussels on 29 September (Hilary Doxford)
- Award ceremony for the “Mano Amiga” award on 14 October (Helen Rochford-Brennan)
- INTERDEM Masterclass “Involving people with dementia as advisors in your research” in Copenhagen on 2 November (Helga Rohra)

26th Alzheimer Europe Conference

The 26th Alzheimer Europe Conference (26AEC) was organised from 31 October to 2 November 2016 in Copenhagen together with Alzheimerforeningen, Denmark’s national Alzheimer association. This year’s theme was “Excellence in dementia research and care” and the conference attracted 714 delegates – including 35 people with dementia – with a programme featuring 150 speakers and 189 poster presentations. The event was organised under the Honorary Patronage of Her Royal Highness Princess Benedikte of Denmark, who spoke at the Opening Ceremony and also attended the special session organised by the European Working Group of People with Dementia.

The first plenary session was entitled “A rights-based approach to dementia” while the second session was a round table discussion with five global, European and national officials with an interest in dementia – including Hilary Doxford, Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) and Board Member of the World Dementia Council. The third plenary session, “Detection and timely diagnosis”, featured a presentation by Helen Rochford-Brennan, Chair of the EWGPWD and the final session focused on the treatment and management of dementia. In addition to the four plenaries, delegates at 26AEC had the choice of 30 different parallel sessions on specific legal, ethical, scientific and human aspects of living with dementia.

The Annual General Meeting of Alzheimer Europe also took place in the framework of the Conference. At the meeting, the delegates adopted AE’s 2015 Annual and Financial reports and approved the 2017 Work Plan and Budget. In addition, the delegates elected new members to the Alzheimer Europe Board for the period 2016–2018 with Iva Holmerová (Czech Republic) as new Chairperson, Charles Scerri (Malta) as Vice-Chairperson, James Pearson (UK-Scotland) as Honorary Secretary and Maria do Rosário Zincke dos Reis (Portugal) as Honorary Treasurer.

Supporting and involving member organisations

Alzheimer Europe consistently involves its member organisations in meetings, projects and activities. In 2016, three successful meetings brought together the public affairs representatives of various national associations.

The meeting held in March mainly focused on the development of AE’s 2016 Yearbook “Decision making and legal capacity in dementia”. The delegates also heard about AE’s new public affairs strategy and AE member representatives gave updates on their countries’ awareness campaigns and lobbying work.

June’s meeting focused on developing a model national dementia strategy, based on elements and best practices of existing strategies in the following AE member countries: Austria, France, Ireland, Malta, Switzerland and the UK (England and Scotland). The agenda also included a presentation of the MinD project, which aims to help people with dementia engage in social contexts to improve psychosocial wellbeing.

In December, AE held its 2nd Alzheimer’s Association Academy. This interactive capacity building event included presentations from various experts on six key topics:

- The workings of the European institutions
- Lobbying for change at national level
- Understanding the clinical trial process
- Researching new medicines for Alzheimer’s disease
- Understanding research results
- Pricing, reimbursement and health technology assessment of new AD medicines.

Membership development

In October 2016, the Annual General Meeting voted to accept Alzheimer Albania and the Hungarian Social Cluster Association as new provisional members of Alzheimer Europe. The delegates discussed and adopted new rules for dealing with multiple full member associations from a single country. This was followed by a vote that elevated Italy’s Alzheimer Uniti ONLUS to full member status. As a result, Alzheimer Europe counted 39 members at the end of 2016 with 35 full members and four provisional members in 34 countries.



Social Cluster Association Hungary

Strategic partnerships

Alzheimer Europe continued its cooperation with INTERDEM, a pan-European research network for psychosocial interventions in dementia. The INTERDEM researchers – including Ana Diaz and Dianne Gove – held a series of master classes and meetings at AE’s 26th Annual Conference in Copenhagen. Several of them were speakers at the conference and also participated in the selection of topics to be addressed. Ana and Dianne contributed towards two papers (on social health and assistive technology) with INTERDEM members which were subsequently published in peer-reviewed journals.

The organisation also signed a memorandum of understanding with Alzheimer’s Disease International outlining



areas for collaboration. In particular, AE supported the campaign of ADI to see dementia recognised as a global and WHO priority. In October, Alzheimer Europe – along with ADI, Dementia Alliance International (DAI) and Global Alzheimer’s and Dementia Action Alliance (GADAA) – submitted a joint formal response to the World Health Organization (WHO) Zero Draft Global Plan on the Public Health Response to Dementia. A final version of the Plan will be considered by the 70th World Health Assembly (WHA70) in May 2017.



Alzheimer’s Disease International
The global voice on dementia

Jean Georges joined the ADI delegation for the 69th World Health Assembly (WHA69) of the World Health Organization on 23 May, where Health Ministers called for greater WHO collaboration on dementia and Vanessa Challinor represented ADI at the 66th European Regional Committee of WHO.

In 2016, Alzheimer Europe also 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 and participated in the think tank meetings of EFPIA – the European Federation of Pharmaceutical Industries and Associations. AE also developed closer ties with the European Disability Forum and was accepted as an ordinary member at the end of 2016.

In January, Alzheimer Europe officially became one of the 68 founding members of the European Covenant on Demographic Change and Dianne Gove was elected to the first Board of Directors. The Covenant will work closely with the World Health Organization (WHO) Global Network of Age-Friendly Cities and Communities.

Other activities and projects

Involvement in new EU projects

Alzheimer Europe has been a full partner in a number of projects funded by the European research programme and the Innovative Medicines Initiative. In these projects, the organisation typically ensures the views of people with dementia, carers and Alzheimer's associations are reflected, contributes to the discussion of the ethical issues raised by the projects and supports or leads the dissemination activities. In 2016, AE started its involvement in the following new projects.

AMYPAD

The "Amyloid imaging to prevent Alzheimer's disease" project aims to improve the diagnostic workup of patients suspected to have Alzheimer's disease and their management. The partners aim to improve knowledge of the natural history of AD in a pre-symptomatic stage, in order to better select patients for trials. In addition, they will monitor changes in beta amyloid deposition in the brain, in order to quantify the impact of novel therapies.



Alzheimer Europe is co-leading the work package on ethics and dissemination. AE was represented by Jean Georges, who attended project meetings in October and December.

MOPEAD

MOPEAD or "Models of Patient Engagement for Alzheimer's Disease" will create an effective interface between the existing EMIF and EPAD projects, in order to identify and test models of efficient earlier identification of mild AD dementia and prodromal AD. The project will also seek to raise awareness of Alzheimer's disease, memory complaints, and cognitive decline risks.

Alzheimer Europe is involved in ethics discussions and dissemination activities. In 2016, the association was represented by Kate Boor-Ellis and Jean Georges, who



attended the first official project meeting in December. The project also held a special session during Alzheimer Europe's 26th Annual Conference in October.

ROADMAP

The "Real world outcomes across the Alzheimer's disease spectrum for better care: multi-modal data access platform" project will provide the foundation for an integrated data environment and framework for real world evidence (RWE) in Alzheimer's disease. This will include the development of consensual key outcome measures and data integration tools for dataset characterisation and outcome classification, as well as guidelines on the handling and interpretation of RWE data.

Alzheimer Europe was represented by Jean Georges and Alex Teligadas, who respectively attended project meetings in March and April. Jean Georges, Dianne Gove and Ana Diaz attended the kick-off meeting in November in Barcelona.



Continued participation in EU projects

In 2016, Alzheimer Europe also continued its involvement in the following EU projects.

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.



The organisation was represented by Ana Diaz during a Steering Committee meeting in March and by Dianne Gove and Jean Georges at a project meeting in October. Dianne and Jean also attended the General Assembly in December. Dianne and Ana have contributed towards the ethics guidance documents developed in work package 4.

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 Kate Boor-Ellis, Jean Georges, Dianne Gove and Alex Teligadas in meetings in March and the General Assembly in May. In addition, Dianne Gove and Ana Diaz are active in Work Package 8: Ethics and have been involved in research looking at the "Approaches to the Communication of Alzheimer's disease Risk" (ACAR). This work involved carrying out four focus groups in Spain and one focus group in Brussels with the EWGPWD. The EPAD project also organised a special symposium at the 26th Alzheimer Europe Conference in October.

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 full partner, representing the interests of people with dementia and their carers.



The organisation was represented by Alex Teligadas at the 4th General Assembly in March.

NILVAD

In 2016, Alzheimer Europe continued its collaboration with the NILVAD project, a phase III clinical trial of the drug nilvadipine. Alzheimer Europe is a partner in work package 7 (Dissemination and Communication) and is also involved in a substudy on the experiences of trial participants and their caregivers. This was developed by AE and the University of Lille. The protocol and relevant documentation for this study was jointly developed in 2015 by the University of Lille, the Centre Mémoire de Ressources et de Recherche in Lille and AE.



In 2016, Alzheimer Europe was represented by Alex Teligadas, who attended the General Assembly in May and Ana Diaz, who continued to work on the substudy.

PACE

The aim of PACE is to compare the effectiveness of palliative care at the end of life for elderly people with and without dementia in long-term care facilities in Europe. This project is coordinated by the Vrije Universiteit Brussel in Belgium.

In 2016, Kate Boor-Ellis and Dianne Gove attended project meetings on behalf of AE in May. Dianne and Ana regularly contribute to the discussions of the Impact/Dissemination work package and the user-led forums, which are organised in collaboration with AGE Platform.



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.

Jean Georges and Dianne Gove represented Alzheimer Europe at several project meetings throughout the year, including the Management Board and consortium meetings in February and October.



Mild Dementia (SMART4MD). The app will be designed to help people with mild dementia adhere to treatment regimens as well as allowing them to share health-related data with their carers and doctors. As well as giving people more control over their care, the aim is to slow cognitive and functional decline and to reduce pressure on carers as well as costs for healthcare providers, through use of the app. It will be piloted with 1,100 volunteers from several EU countries. The project is coordinated by Anglia Ruskin University in the UK.



SMART4MD

The four year SMART4MD project is developing an app called Support, Monitoring and Reminder Technology for

Alzheimer Europe was represented by Ana Diaz, Kate Boor-Ellis and Dianne Gove, who attended meetings in January, April, July and October.

Support of European research activities

In addition to the projects described above, Alzheimer Europe plays a minor role and supports a number of other research projects at European level.

INDUCT

INDUCT (Interdisciplinary Network for Dementia Utilising Current Technology) is a four year project under the Marie Skłodowska-Curie Actions Programme. The main aim of INDUCT is to develop a premier quality multi-disciplinary, multi-professional and intersectorial education and training research framework for Europe aimed at improving technology and care for people with dementia, and to use the coherent themes and interrelated Early Stage Researchers ESRs within INDUCT to provide the evidence to show how technology can improve the lives of people with dementia.

In 2016, Alzheimer Europe was represented by Dianne Gove, who attended the project kick-off meeting in April.



MinD

MinD (Designing for People with Dementia) is a four-year project under the Marie Skłodowska-Curie Actions Programme. It aims to help people with dementia engage in social contexts to improve psychosocial wellbeing. Design can offer novel ways of complementing existing care approaches to empower people with dementia in everyday social situations. The project partners will use the concept of mindful design to investigate innovative design solutions, in order to enable self-empowerment and confidence building of people living with dementia. There are two focus areas: a) personal difficulties with social interaction and b) environmental influences on social engagement. In these two contexts, the researchers will study how personal, wearable designs can help mediate perceptions of identity and emotion management; and how environmental aspects can reduce feelings of information overload and instil feelings of self-empowerment and control.



Alzheimer Europe, which is represented by Ana Diaz and Dianne Gove in this project, co-hosted together with the University of Luxembourg a two-week visit of the project partners in Luxembourg in June. In addition, numerous members of the project attended AE's lunch debate and Public Affairs meeting in June.

SyDAD

SyDAD (Synaptic Dysfunction in Alzheimer's Disease) is a European Training Network sponsored by Horizon2020 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 in April on behalf of Alzheimer Europe.

Corporate affairs

European Parliament lunch debates

In 2016, Alzheimer Europe organised two successful lunch debates in the European Parliament in Brussels:

On 28 June, MEPs Marisa Matias (Portugal) and Sirpa Pietikäinen (Finland) co-hosted a lunch debate entitled "Using the UN Convention on the Rights of Persons with Disabilities (UNCRPD) to support the rights of people living with dementia". The event featured three speakers: Helen Rochford-Brennan, Vice-Chair of the European Working Group of People with Dementia; Jill Stavert, Professor of Law and Director of the Centre for Mental Health and Incapacity Law at Edinburgh Napier University and



Jill Stavert



Jonathan Stabenow

Jonathan Stabenow from the Cabinet of Marianne Thyssen, Commissioner for Employment, Social Affairs, Skills and Labour Mobility at the European Commission.



On 6 December, Alzheimer Europe's lunch debate was hosted by Nessa Childers, MEP (Ireland) and a Vice-Chairperson of the European Alzheimer's Alliance (EAA). The first speaker was AE Executive Director Jean Georges, who presented the concept and the results of the European Dementia Monitor, an AE survey of national dementia strategies and policies. He was followed by Tim Muir, Health and Social Policy Analyst at OECD, the Organisation

for Economic Co-operation and Development. He presented "Measuring Dementia – an overview of the facts and figures we have now and those we need to develop in the future".

Both lunch debates were well-attended, with delegates from the European Parliament and Commission, the pharmaceutical industry and AE member associations.

Dementia in Europe magazine

In 2016, Alzheimer Europe published two issues of the Dementia in Europe magazine. The magazines featured a variety of articles on policy developments, including interviews with the following national policy makers:

- Sophie Løhde, Danish Minister for Health and the Elderly
- Sabine Oberhauser, Austrian Minister of Health
- Martin van Rijn, Dutch Secretary of State for Health, Welfare and Sport

The 2016 issues include articles about the Luxembourg and Dutch EU Presidencies, reports of the WHO's dementia activities and news on national dementia strategies in Austria, Denmark, Norway and Slovenia.



Issue 23 (November) also featured a special section entitled "Human rights and the UNCRPD". This section contained an article on the lunch debate that AE dedicated to this topic, information on how the UN convention can help people with dementia and testimonials from nine Members of the European Parliament.

Clinical Trial and Guideline Watch

Alzheimer Europe's Clinical Trial Watch gathers information about phase III clinical trials being conducted in at least two European countries. In September 2016, AE officially launched the collected information on a new section of its website with details of the nine clinical trials. Information is provided in an easy-to-understand language and trials are presented by country and by condition. A dementia-friendly version of each study is available for download and all information has been checked by a representative of the European Working Group of People with Dementia for understanding and a company representative for accuracy.

The Guideline Watch is a database that contains information about national guidelines for the diagnosis,

treatment and management of dementia in Europe. By the end of 2016, 71 national guidelines had been identified for inclusion in the database.

European Dementia Monitor

With the European Dementia Monitor, Alzheimer Europe aimed to compare and benchmark national dementia policies with a view of highlighting the relative strengths and weaknesses of national responses to dementia. In 2016, the organisation focused on the following ten priority areas:

- Availability and reimbursement of AD medicines
- Availability of care services
- Affordability of care services
- Availability of clinical trials
- Involvement in European dementia research programmes
- Recognition of dementia as a national priority
- Recognition of legal rights
- Ratification of International human rights treaties and conventions
- Carer and employment support
- Dementia-friendly Communities and inclusiveness

Information was collected during 2016 from AE's member associations, as well as publicly available data sources. The preliminary results were presented at a meeting in the European Parliament in December 2016 and will be published as a report in 2017.

Promoting good continence care

In 2016, the paper "Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges" was published in the Journal of Clinical Nursing. The paper features Dianne Gove as the principal author and describes the results of the 2014 AE project that was supported by SCA.

Carers' Survey

Thanks to an educational grant from Roche, Alzheimer Europe and its member organisations from the Czech Republic, Finland, Italy, the Netherlands and the United Kingdom (Scotland) collaborated with the University of Bangor to develop a questionnaire targeted at carers to better understand the diagnostic process, experiences of carers and existing barriers.

Annex 1: Meetings attended by AE representatives

Meetings organised by Alzheimer Europe in 2016

Date	Meeting	Venue
29 February–2 March	AE Board and Public Affairs meetings	Luxembourg, Luxembourg
21–23 March	EWGPWD meeting	Brussels, Belgium
8 April	European Dementia Ethics Network meeting	Amsterdam, Netherlands
17 June	European Dementia Ethics Network meeting	Amsterdam, Netherlands
27–28 June	AE Board meeting	Brussels, Belgium
29 June	AE Public Affairs meeting	Brussels, Belgium
30–31 October	EWGPWD meeting	Copenhagen, Denmark
31 October – 2 November	AE Board meeting, AE Annual General Meeting and the 26th Alzheimer Europe Conference	Copenhagen, Denmark
3 November	European Dementia Ethics Network meeting	Copenhagen, Denmark
5–6 December	AE Board meeting	Brussels, Belgium
6–7 December	Alzheimer's Association Academy	Brussels, Belgium
12–14 December	EWGPWD meeting	Brussels, Belgium

Meetings attended by AE representatives in the framework of the 2016 Operating Grant

Date	Meeting	Venue
12 January	EP Interest Groups on Carers and Mental Health	Brussels, Belgium
21 January	Joint Innovation Information and Matchmaking Event on "Living well with dementia"	Brussels, Belgium
22 January	Scientific Advisory Committee Meeting of Neighbourhoods and Dementia Study	Manchester, UK
1–2 February	Meeting of government experts on dementia	Luxembourg, Luxembourg
24 February	IMI Lunch Debate in the European Parliament	Brussels, Belgium
24 February	European Parliament Interest Group on Brain, Mind and Pain	Brussels, Belgium
10 March	Conference of the European Institute for Innovation through Health Data	Paris, France
15 April	EFGCP workshop	Brussels, Belgium
16–18 April	ICCA Association Expert seminar	Frankfurt, Germany
20–21 April	ADI Board and Council meeting	Budapest, Hungary
21 April	Conference on better prevention and management of chronic diseases	Brussels, Belgium
21–24 April	ADI Annual Conference	Budapest, Hungary

Date	Meeting	Venue
26 April	Dementia Platform UK conference	London, UK
27–28 April	IMI patient engagement workshop	Brussels, Belgium
2 May	Meeting on Swiss dementia strategy	Bern, Switzerland
9–10 May	EU Presidency Conference	Amsterdam, Netherlands
23–25 May	16th International Conference for Integrated Care	Barcelona, Spain
25 May	European Brain Council meeting	Brussels, Belgium
2 June	Board meeting for the European Covenant on Demographic Change	Groningen, Netherlands
3 June	DAW Conference of Alzheimer Scotland	Edinburgh, UK
10 June	Francophone conference on Alzheimer's disease	Lyon, France
14 June	Workshop on dementia care organised by the European Centre	Vienna, Austria
15 June	EU Interest Group on Carers	Brussels, Belgium
16 June	European Commission meeting on elder abuse	Brussels, Belgium
17 June	GetReal Stakeholder Conference	London, UK
21–22 June	DISTALZ Advisory Board meeting	Lille, France
4 July	European Patients Foundation, Policy Advisory Group (EPF)	Brussels, Belgium
21 July	Preparation of AE Conference	Copenhagen, Denmark
13 September	Google training with SOCIALware	Brussels, Belgium
14 September	Opening of the BarcelonaBeta Research Centre	Barcelona, Spain
21 September	World Alzheimer's Day conference	Schengen, Luxembourg
28 September	European Brain Council workshop	Brussels, Belgium
14 October	International Mano Amiga Award ceremony	León, Spain
19 October	3rd meeting of health and social care professionals on dementia	Lisbon, Portugal
24 October	EU Lay Summaries Taskforce meeting	London, UK
27–28 October	Workshop: The Road to 2025: Delivering next generation Alzheimer's treatment	Lausanne, Switzerland
1 November	Meeting with France Alzheimer	Copenhagen, Denmark
1–2 November	INTERDEM Masterclass and meetings	Copenhagen, Denmark
2 November	Meetings with European Alzheimer's Disease Consortium	Copenhagen, Denmark
8 November	IMI meeting in the European Parliament	Brussels, Belgium
17 November	European Patients Forum meeting	Brussels, Belgium
28 November	European Commission meeting of government experts on dementia	Bratislava, Slovakia
28–29 November	European Disability Forum meeting	Brussels, Belgium
29 November	Public-Private Partnership event at the European Parliament	Brussels, Belgium
29 November	Slovak EU Presidency conference on dementia	Bratislava, Slovakia
6 December	Workshop of Swedish Ministry of Health and Social Affairs	Stockholm, Sweden
12–13 December	EU meeting on chronic diseases	Brussels, Belgium

Other meetings organised by AE or attended by AE representatives in 2016

Date	Meeting	Venue
1 February	EMA meeting on clinical data publication website	London, UK
5 February	Roche Dementia Forum	Frankfurt, Germany
15 February	PredictND project meeting	Kuopio, Finland
18–20 February	ICCA suppliers' workshop	Uppsala, Sweden
1 March	AE Company Round Table	Luxembourg, Luxembourg
3–4 March	2nd Joint Action on Dementia meeting	Luxembourg, Luxembourg
8–9 March	EMA meeting	London, UK
10 March	EPAD project meeting	Luxembourg, Luxembourg
14 March	AETIONOMY project meeting	Bonn, Germany
14–16 March	EMIF project meeting	Budapest, Hungary
16 March	EFPIA Think Tank meeting	Brussels, Belgium
21–23 March	EPF Annual General Meeting	Brussels, Belgium
5 April	AE Carers' Survey meeting	Amsterdam, Netherlands
7 April	ROADMAP project meeting	Brussels, Belgium
18–19 April	INDUCT project meeting	Nottingham, UK
19 April	IMEX conference	Frankfurt, Germany
17–20 May	EPAD project meeting	Barcelona, Spain
22–24 May	PACE project meeting	Helsinki, Finland
24 May	AETIONOMY project meeting	Paris, France
24–25 May	NILVAD project meeting	Dublin, Ireland
1 June	EFPIA Patient Think Tank meeting	Brussels, Belgium
6–7 June	Roche meeting	Lindau, Germany
14 June	EMA meeting	London, UK
15 June	PACE project meeting	Brussels, Belgium
20 June–1 July	MinD project meetings	Luxembourg, Luxembourg
28 June	European Parliament Lunch Debate and AE Company Round Table	Brussels, Belgium
5–6 July	WHO Global Dementia Observatory	Geneva, Switzerland
7 July	EMA meeting for clinical data website	London, UK
7–8 July	Programme Board of the Joint Action on Dementia	Edinburgh, UK
15 July	GSK Health Advisory Board	London, UK
23–29 July	Alzheimer's Association International Conference	Toronto, Canada
30 August–1 September	MICE suppliers' conference	Amsterdam, Netherlands
5–6 September	Site inspection for 2018 AE conference	Barcelona, Spain
12–15 September	WHO Regional Committee meeting	Copenhagen, Denmark
14 September	EDF – EESC hearing on the progress on the rights of persons with disabilities in the EU	Brussels, Belgium
19–20 September	EMA workshop and meeting	London, UK
21 September	Janssen symposium on dementia	Beerse, Belgium

Date	Meeting	Venue
22–23 September	Meeting of the 2nd EU Joint Action on dementia	Lyon, France
28–30 September	M&I suppliers' meeting	Prague, Czech Republic
5–6 October	AMYPAD project meeting	London, UK
10–11 October	AETIONOMY project meeting	Barcelona, Spain
13–14 October	Meeting of the 2nd EU Joint Action on dementia	Athens, Greece
18 October	Lilly Alzheimer's University	Barcelona, Spain
20–21 October	SMART4MD project meeting	Torremolinos, Spain
25–26 October	PredictND project meeting	Amersham, UK
1 November	Meetings with Lilly and MSD	Copenhagen, Denmark
2 November	Meetings with Roche and AbbVie	Copenhagen, Denmark
3 November	EPAD project meeting	Copenhagen, Denmark
10 November	HRG suppliers' event	Luxembourg, Luxembourg
14–15 November	EMA workshop	London, UK
16–17 November	ROADMAP project meeting	Barcelona, Spain
24 November	MinD project meeting	Luxembourg, Luxembourg
29–30 November	EMA training session and meeting	London, UK
1–2 December	AETIONOMY General Assembly	Paris, France
6 December	European Parliament Lunch Debate and AE Company Round Table	Brussels, Belgium
8 December	EFPIA Think Tank meeting	Brussels, Belgium
8–11 December	Clinical Trials on Alzheimer's disease conference	San Diego, USA
13 December	AMYPAD project meeting	Munich, Germany
14–15 December	MOPEAD project meeting	Barcelona, Spain

Alzheimer Europe's Board and staff

Members of the Alzheimer Europe Board (2016–2018)



Iva Holmerová
Chairperson
(Czech Republic)



Charles Scerri
Vice-Chairperson
(Malta)



Jim Pearson
Honorary Secretary
(UK-Scotland)



Maria do Rosário
Zincke dos Reis
Honorary Treasurer
(Portugal)



Helen Rochford- Brennan
Chairperson of EWGPWD
(Ireland)



Stefanie Becker
(Switzerland)



Marie-Odile Desana
(France)



Sabine Henry
(Belgium)



Sabine Jansen
(Germany)



Sirpa Pietikäinen
(Finland)



Jesús Rodrigo
(Spain)



Štefanija Lukič Zlobec
(Slovenia)

Alzheimer Europe staff members



Jean Georges
Executive Director



Christophe Bintener
Project Officer



Cindy Birck
Project Officer



Kate Boor Ellis
Communications Officer



Vanessa Challinor
Policy Officer



Ute Corail
Administrative Assistant



Ana Diaz
Project Officer



Gwladys Guillory
Event and Conference Coordinator



Dianne Gove
Director for Projects



Stefanie Peulen
Finance Officer



Grazia Tomasini
Administrative Assistant

Financial report



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, 2016



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 October 31st, 2016, we have audited the accompanying annual accounts of **ALZHEIMER EUROPE**, which comprise the balance sheet as at December 31, 2016 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, 2016, 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 27th, 2017

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

Philippe SLENDZAK
Partner

Appendix:

- Annual accounts as at December 31st, 2016

Balance sheet as of December 31, 2016

	2016 (Euro)	2015 (Euro)
ASSETS		
Fixed assets		
Other fixed assets	29.551	29.066
Current assets		
Debtors European Commission	186.847	167.803
Other debtors	53.317	235.593
Cash at bank and on deposit	640.814	556.999
	<u>880.978</u>	<u>960.395</u>
Prepayments	2.559	1.611
	<u>913.088</u>	<u>991.072</u>
LIABILITIES		
Capital and reserves		
Results brought forward	217.561	197.798
Result of the year	21.579	19.763
	<u>239.140</u>	<u>217.561</u>
Creditors		
EU Subsidies received on account	423.438	395.583
Tax and social security	28.838	27.163
Payments received on account	10.000	250.000
Trade creditors	59.657	48.367
Other liabilities	34.615	31.324
	<u>556.548</u>	<u>752.437</u>
Deferred income	117.400	21.074
	<u>913.088</u>	<u>991.072</u>

Deferred income represents a part of income received in 2016 and which will be used in 2017.

As at December 31, 2016, 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, 2016**

	2016 (Euro)		2015 (Euro)
Support and revenue			
Other operating income			
EU Subsidy	594.889		611.498
Corporate sponsorship	535.757		287.386
Sponsorship received on account	117.400	-	21.074
AE Conference registration fees	184.382		123.191
Project participation and other subsidies	101.589		98.153
Co-financing in kind	123.686		85.200
Membership fees and contributions	55.666		58.377
Deferred income	21.074		9.060
Publication sales and royalties	7.110		1.712
Donations	703		574
Other operating income	8.576		6.846
External charges			
Accommodation expenses	320.162	-	200.638
External experts	215.485	-	140.403
Travel expenses	88.761	-	74.075
Publication and Information material	79.829	-	79.869
Office rent and associated costs	43.378	-	41.220
Alzheimer Europe Foundation	38.536	-	40.686
Equipment and Leasing	32.207	-	15.185
Communication costs	26.833	-	39.957
Recruitment costs	5.604	-	813
Office stationery and related costs	5.078	-	3.454
Bank charges	4.013	-	3.023
Membership fees	1.000	-	1.120
Other costs	49	-	704
Staff costs			
Wages and salaries	543.996	-	521.716
Social security costs	76.126	-	68.486
Depreciation	14.221	-	10.670
Interest receivable and similar income	825		860
	<hr/>		
	21.579		19.763

Breakdown of income

Introduction

In 2016, Alzheimer Europe had an audited income of EUR 1,516,859 of which EUR 962,085 (63.43%) were for the organisation's core activities (including the organisation's Annual Conference) and EUR 554,774 (36.57%) were for the organisation's corporate affairs activities and other projects.

Funding of core activities (EUR 962,085)

In 2016, the core funding of Alzheimer Europe was composed as follows:

- EUR 434,192 (45.13%) from public funding,
- EUR 88,910 (9.24%) from foundations and other non-profit organisations,
- EUR 166,066 (17.26%) from member organisations,
- EUR 87,005 (9.04%) from corporate sources,
- EUR 185,085 (19.24%) from private individuals,
- EUR 827 (0.09%) from bank interest and similar.

Public funding

In 2016, Alzheimer Europe received EUR 434,192 as an operating grant from the European Commission.

Foundations and organisations

The EUR 88,910 which Alzheimer Europe received in 2016 from foundations and other non-profit organisations can be broken down as follows:

- EUR 87,000 as direct support from Fondation Alzheimer, Luxembourg,
- EUR 1,250 from University of Stirling for the AE Conference in Copenhagen and EUR 660 from Fondation Médéric Alzheimer to support AE's work on the ethical challenges linked to the new definition of Alzheimer's disease.

Funding from member organisations

In 2016, the EUR 166,066 funding from member organisations can be broken down as follows:

- EUR 55,666 in membership fees and contributions,
- EUR 110,400 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 2016, Alzheimer Europe received EUR 87,005 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 20,000 from Hoffmann-La Roche, EUR 10,000 from Lilly and EUR 5,000 from Biogen and Piramal to support the AE Conference in Copenhagen,
- EUR 4,188 from Newsweaver which provided an e-mail facility free of charge,
- EUR 7,817 from Microsoft as discount on software purchases.

Private individuals

In 2016, AE received EUR 185,085 from individuals which can be broken down as follows:

- EUR 184,382 in conference registrations and
- EUR 703 in donations.

Bank interest and similar

In 2016, Alzheimer Europe had an income of EUR 827 from bank interest and similar income.

Funding of project activities (EUR 554,774)

In 2016, Alzheimer Europe received EUR 554,774 for its participation in various EU projects, a project on good incontinence care, the Alzheimer Europe care survey and its corporate affairs activities, of which:

- EUR 369,227 (66.55%) came from corporate sponsors,
- EUR 7,110 (1.28%) from private individuals,
- EUR 161,297 (29.07%) from public sources and
- EUR 17,140 (3.09%) from foundations and other non-profit organisations.

Corporate support

The corporate support received by Alzheimer Europe for its activities in 2016 (EUR 369,227) can be broken down as follows:

- Hoffmann-La Roche contributed EUR 190,700 for the development of the organisation's care survey project and as a gold sponsor of AE's corporate programme and as travel support,
- Lilly contributed EUR 65,780 as a gold sponsor of AE's corporate programme, as contributions to the organisation's guideline project and as travel support,
- Novartis contributed EUR 40,000 as a gold sponsor of AE's corporate programme,
- GE Healthcare, Pfizer and MSD contributed EUR 20,000 as silver sponsors of AE's corporate programme,
- Nutricia contributed EUR 15,000 to the organisation's corporate activities,
- Axovant contributed EUR 12,500 to the organisation's corporate activities,
- Lundbeck and Otsuka contributed EUR 11,250 to the Alzheimer's Association Academy,
- Biogen, Janssen, Merz, Piramal and SCA contributed EUR 10,000 as bronze sponsors of AE's corporate programme,
- Amoneta provided EUR 3,515 for Alzheimer Europe's contribution to the ADDIA project
- Nestlé contributed EUR 2,500 to participate in the organisation's company round table meetings,
- GSK provided EUR 500 as honoraria for the participation of the Executive Director in GSK meetings,

- Various companies provided EUR 2,558 in travel support,
- EUR 21,074 was income received in account from sponsorship in 2015,
- (EUR 117,400) will be deferred to 2017 as deferred income.

Private individuals

In 2016, Alzheimer Europe received EUR 7,110 in publication sales.

Public funding

In 2016, Alzheimer Europe received EUR 161,297 as public funding for its participation in various EU projects:

- EUR 53,702 for EPAD,
- EUR 30,291 for AETIONOMY,
- EUR 24,186 for Smart4MD,
- EUR 12,397 for PredictND,
- EUR 10,003 for PACE,
- EUR 8,521 for EMIF,
- EUR 8,195 for AMYPAD,
- EUR 6,400 for ROADMAP,
- EUR 4,804 for MOPEAD,
- EUR 1,381 for NILVAD,
- EUR 1,153 for AFE-INNOVNET,
- (EUR 336) for PharmaCog.

Alzheimer Europe also received EUR 600 from the Swiss Ministry of Health as travel support.

Foundations and organisations

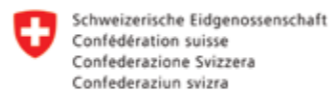
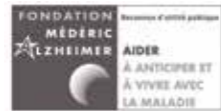
In 2016, Alzheimer Europe received a total of EUR 17,140 from other organisations and foundations, including EUR 2,605 from the University of Wolverhampton for the organisation's participation in the MIND project, EUR 2,102 from Nottinghamshire Healthcare for the INDUCT project, EUR 2,000 from Université de Lille in honoraria, EUR 8,576 from various organisations as travel grants and EUR 1,857 for secretarial costs provided to the Alzheimer Europe Foundation.

Overall funding

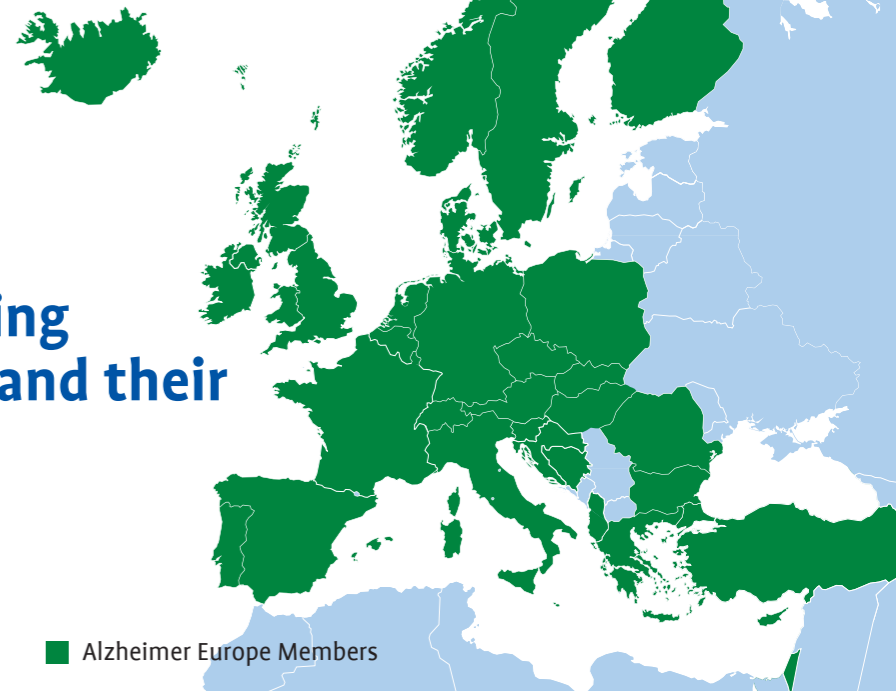
The following table lists all sources of income received in 2016. In line with the policy of the European Medicines Agency on transparency requirements for accredited patients' organisations, this is presented in total amounts as well as in terms of percentages of the overall income of the organisation.

Funding source	Funding received (2016)	As % of AE income (2016)	As % of AE income (2015)
Hoffmann-La Roche	210,700	13.89%	2.38%
Lilly	75,780	5.00%	4.06%
Novartis	40,000	2.64%	
GlaxoSmithKline	35,500	2.34%	2.87%
GE Healthcare	20,000	1.32%	1.59%
MSD	20,000	1.32%	
Pfizer	20,000	1.32%	
Biogen	15,000	0.99%	0.40%
Piramal	15,000	0.99%	1.19%
Axovant	12,500	0.82%	
Lundbeck	11,250	0.74%	0.99%
Otsuka	11,250	0.74%	0.99%
Janssen	10,000	0.66%	1.59%
Merz	10,000	0.66%	0.79%
Amoneta	3,515	0.23%	
Various companies	2,558	0.17%	
Income received on account	21,074	1.39%	
Deferred income	-117,400	-7.74%	-0.95%
Sandoz		0.00%	0.40%
Sub-total: Pharmaceutical funding	416,727	27.47%	17.24%
Nutricia	15,000	0.99%	1.19%
SCA Global Hygiene	10,000	0.66%	2.96%
Microsoft	7,817	0.52%	
Newsweaver	4,188	0.28%	0.45%
Nestlé	2,500	0.16%	1.39%
Sub-total: Other corporate sources	39,505	2.60%	5.99%
Total: Corporate funding	456,232	30.08%	23.23%
European Commission	594,829	39.21%	48.46%
Swiss Ministry of Health	660	0.04%	
Total: Public funding	595,489	39.26%	48.46%
Fondation Alzheimer, Luxembourg	87,000	5.74%	6.90%
Various organisations	8,576	0.57%	0.54%
University of Wolverhampton	2,605	0.17%	
Nottinghamshire Healthcare	2,102	0.14%	
Université de Lille	2,000	0.13%	
Alzheimer Europe Foundation	1,857	0.12%	0.15%
University of Stirling	1,250	0.08%	
Fondation Médéric Alzheimer	660	0.04%	0.32%
Fondation Roger de Spoelberch			0.42%
Total: Foundations and organisations	106,050	6.99%	8.32%
Individuals (Conference fees, donations, publications)	192,195	12.67%	9.94%
Total: Individuals	192,195	12.67%	9.94%
AE member organisations	166,066	10.95%	10.93%
Total: Member organisations	166,066	10.95%	10.93%
Bank interest and similar	827	0.05%	0.07%
Total: Bank interest and similar	827	0.05%	0.07%
Total income	1,516,859	100.00%	100.00%

Our sponsors and supporters



Our members are helping people with dementia and their carers in 34 countries



Alzheimer Europe Members

- | | | |
|---|---|--|
| <p>ALBANIA – TIRANA
Alzheimer Albania</p> | <p>GREECE – THESSALONIKI
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Alzheimer Vakfı</p> |
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