

Alzheimer Europe Annual and Financial Report 2014



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Preface



It gives me great pleasure to introduce Alzheimer Europe's activities for 2014. This was a year of rebuilding our support in the European Parliament, increasing our activity in European research projects, raising our online profile and seeking new opportunities for the future.

In 2014, AE was able to count once again on the financial support of the public health programme of the European Commission. This stability has given us the ability to maintain our key activities and to explore further opportunities to help people with dementia and their carers.

I am pleased to report positive results from our efforts to involve these people in AE's work. The European Working Group of People with Dementia, which we launched in 2012, elected a new Board and also welcomed new members during 2014. The group members continue to be very active advisers to AE and advocates for people with dementia at our public events.

The European Dementia Ethics Network is another key component of AE's work. Ethical considerations are intrinsic to our activities and we have been able to address a number of issues over the years. In 2014, AE published "Ethical dilemmas faced by carers and people with dementia", a report that focuses on ethical dilemmas affecting informal carers and people with dementia. I heartily endorse the report for its straightforward depiction of ethical dilemmas in daily life and the vignettes depicting typical, everyday situations.

Our European Dementia Observatory continues to be a trusted source of information on scientific and policy developments in Europe. In 2014, our website attracted more unique visitors than the previous year and our newsletter subscribers read some 560 articles. AE also published three editions of the "Dementia in Europe" magazine that included interviews with EU and national policy makers, reports on the Global Dementia Legacy events and AE activities such as the European Parliament lunch debates and Annual Conference. Finally, we managed to increase AE's social media presence to 2,200+ Twitter followers and reach the maximum of 5,000 Facebook friends.

AE's research work also continued apace during the year. We published the 2014 Dementia in Europe Yearbook, an inventory of national policies and practices with a focus on the pathways to diagnosis of dementia and to post-diagnostic care and support in 30 countries. The Clinical Trial Watch, a project that will connect people with dementia and their families with high quality research, is proceeding on schedule and so is the Guideline Watch project. This is a database with national guidelines for the diagnosis, treatment and management of dementia in Europe.

I believe that these projects are unique in their genre, as they compare and contrast information about dementia care across many European countries. As always, our main sources are our member associations: none of this research would be possible without them, so we are very grateful for their enthusiastic cooperation in our work! We also thank SCA Global Hygiene for a successful two year partnership to develop guidelines for the promotion of continence care for people with dementia living at home.

Our member associations elected a new Board during the Annual General Meeting in October 2014 in Glasgow. I was very pleased to retain the position of Chair for another term, alongside my fellow Officers Iva Holmerová (Vice-Chair), Charles Scerri (Honorary Secretary) and Maria do Rosário Zincke dos Reis (Honorary Treasurer). We were also very glad to welcome several new Board members, namely Marie-Odile Desana, Sabine Henry, Gerry Martin, Jim Pearson, Jesús Rodrigo and Štefanija Lukič Zlobec. At this time I would like to thank the board members who ended their term: Patrick Maugard, Maurice O'Connell, Alicia Sadowska and Henry Simmons.

This was followed by the 2014 Annual Conference in Glasgow – another highlight of the year. The presence of over 830 delegates made this one of AE's most popular events ever – thanks largely to the excellent work of our colleagues from Alzheimer Scotland. Our overarching theme was “Dignity and autonomy in dementia” and the programme included some 190 speakers and 170 poster presentations. A notable highlight was the adoption of our Glasgow Declaration, which calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. We are very grateful for the financial support of the health programme of the European Union and also thank the Life Changes Trust for enabling numerous delegates with dementia to attend the conference.

In 2014, AE also received significant income from its participation in EU projects. These include IMPACT, NILVAD, PACE and PredictND, funded by the FP7 programme, and another three projects funded by IMI – the Innovative Medicines Initiative: AETIONOMY, EMIF and PharmaCog. The AFE-INNOVNET project is also partly funded by EU sources.

During the year, AE 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 European Parliament's Interest Group on Carers. I am very pleased to see that AE is in significant demand to participate in new Horizon2020 and IMI projects. Apart from the financial benefit, these are clear opportunities to increase our scientific knowledge and expand our network among researchers and scientists.

In the run-up to the May 2014 European elections, AE ran a European Dementia Pledge campaign that called on MEP candidates to support our work to make dementia a political priority. The results were very encouraging and we were able

to successfully relaunch the European Alzheimer's Alliance (EAA) in the European Parliament, with a total membership of 86 MEPs by the end of 2014. During the year, we also held two successful lunch debates in the Parliament that focused on the activities of the Innovative Medicines Initiative (IMI) and on dementia prevention. We are very grateful to MEPs Françoise Grossetête (France) and Keith Taylor (UK) for hosting these debates.

Meanwhile, on a national level, national dementia strategies were launched in Greece, Ireland and Italy. Once they are fully operational, these will provide much-needed services and relief to people with dementia and will also serve to raise awareness. The latter half of the year also saw the launch of the Neurodegenerative diseases plan in France. This plan contains many elements of the original Plan Alzheimer, but now covers all neurodegenerative afflictions.

All of AE's successes can be attributed to the outstanding team led by our Executive Director Jean Georges. My heartfelt thanks go to him and his colleagues in 2014: Ana Diaz, Annette Dumas, Kate Boor Ellis, Dianne Gove, Gwladys Guillore, Stefanie Peulen, Alex Teligadas and Grazia Tomasini.

Finally, I also wish to thank my colleagues on the AE Board who have freely given their experience and expertise to help carry out our ambitious work plan. We are also grateful for the cooperation of colleagues from our member associations as well as external experts in our activities and projects. I look forward to continuing this productive collaboration on behalf of people with dementia and their carers as Chairperson of Alzheimer Europe in 2015.

Heike von Lützu-Hohlbein,
Chairperson of Alzheimer Europe

Executive Summary

In 2014, Alzheimer Europe:

Campaigned

- launched a European Dementia Pledge campaign during the EU elections, calling on MEP candidates to support AE's work to make dementia a political priority
- welcomed the adoption of national dementia strategies in Greece, Ireland and Italy and the launch of the Neurodegenerative diseases plan in France

Communicated

- produced the 2014 Dementia in Europe Yearbook, an inventory of national policies and practices with a focus on the pathways to diagnosis of dementia and to post-diagnostic care and support in 30 countries
- published 558 articles in 11 editions of its email newsletter
- attracted 597,393 unique visitors to its website, an increase of 15.6% over the previous year. The website was updated in terms of content and visual presentation
- increased its social media presence to 2,200+ Twitter followers and the maximum of 5,000 Facebook friends
- produced a guide to the ethical dilemmas faced by people with dementia and carers on a day-to-day basis, in cooperation with the European Dementia Ethics Network

Worked in partnership with people with dementia

- actively consulted people with dementia on its activities through the European Working Group of People with Dementia (EWGPWD), which involved 12 people with dementia from 11 national organisations
- reconstituted the EWGPWD for a

second two-year term during the AE Conference in Glasgow

- involved the European Working Group of People with Dementia in the preparations and organisation of the 2014 Annual Conference in Glasgow, in various meetings and projects and through its Chairperson in the Board of the organisation

Held a major conference

- partnered with INTERDEM to organise the 24th Alzheimer Europe Conference in Glasgow
- organised its 24th Annual Conference on 20-22 October under the motto "Dignity and autonomy in dementia", attracting 800+ delegates, including 44 people with dementia

Worked in partnership with a range of organisations

- collaborated with the European Medicines Agency (EMA) as a full member of the Patients' and Consumers' Working Party (PCWP)
- followed the European Innovation Partnership on Active and Healthy Ageing and its campaign for the inclusion of dementia as a priority area
- reached out to the representatives of ALCOVE, the European Joint Action on Dementia and involved them in its analysis of national treatment and care pathways
- collaborated with the European Patients' Forum on a review of the EU clinical trial framework, data protection, patient safety and quality of care
- continued as an active member of the European Patients' Forum (EPF) by contributing to a number of consultation documents and participating in EPF's Public Affairs Group and Access to Healthcare Working Group

- 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
- represented Alzheimer's Disease International (ADI) at the 64th session of the World Health Organisation Regional Committee for Europe
- collaborated with ADI on the Global Action against Dementia and the preparation of the Legacy event in London
- continued its collaboration with the AETIONOMY, AFE-INNOVNET, EMIF, NILVAD, PACE, PharmaCog and PREDICT-ND projects
- successfully concluded its two year partnership with SCA Global Hygiene to develop guidelines for the promotion of continence care for people with dementia living at home
- co-organised a European Parliament event "Hand in hand: fighting against Alzheimer's disease and other forms of dementia together" with Marina Yannakoudakis, MEP (UK)
- published three editions of the "Dementia in Europe" magazine that included interviews with EU and national policy makers and reports on the Global Dementia Legacy events and AE activities such as the European Parliament lunch debates and Annual Conference

Gathered and published research information

- continued the development of its Clinical Trial Watch, a project that will connect people with dementia and their families with high quality research
- continued to work on its Guideline Watch project, a database with national guidelines for the diagnosis, treatment and management of dementia in Europe

Helped raise the profile of dementia

- relaunched the European Alzheimer's Alliance (EAA) in the European Parliament after the EU elections, with a total membership of 86 MEPs at the end of 2014
- organised two public affairs meetings with its member associations to discuss EU policy developments and exchange national lobbying and campaigning activities
- brought together public affairs representatives of various national associations to exchange information and best practices on national dementia strategies and policies
- organised two successful lunch debates in the European Parliament that focused on the activities of the Innovative Medicines Initiative (IMI) and on dementia prevention

Received ongoing support from the European Commission

- received support from the European Commission in the form of an operating grant for the organisation's core activities

Expanded and consolidated our membership

- elected a new Board during its Annual General Meeting, where delegates also adopted the Glasgow Declaration and elevated Alzheimer Bulgaria to full member status

Introduction

Alzheimer Europe's Strategic Plan 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 2014 Annual Work Plan which was adopted at the Annual General Meeting in St. Julian's, Malta in 2013.

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.



AE Core Activities

In 2014, Alzheimer Europe received the support of the European Commission. The following core activities 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

Collaboration with EU Initiatives



Alzheimer Europe continued its collaboration with the European Medicines Agency (EMA) in 2014 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.

AE also followed the European Innovation Partnership on Active and Healthy Ageing and campaigned for the inclusion of dementia as a priority area in this initiative.

Finally, AE reached out the representatives of ALCOVE, the European Joint Action on Dementia and involved them in its analysis of national treatment and care pathways.

European Alzheimer's Alliance



The European elections in May were an opportunity for Alzheimer Europe and its members to further raise awareness about the challenges of dementia and revisit the political action started in 2007.

The organisation thus launched a European Dementia Pledge, calling upon all candidates to support Alzheimer Europe's policy campaign and contribute to making dementia a political priority if elected. By signing the Pledge, the candidates also committed to join the European Alzheimer's Alliance in the European Parliament. Among the 220 candidates who signed the Pledge, 40 were elected and 43 former Alliance members were re-elected. For the first time, all candidates from two countries (Ireland and Slovenia) became members of the Alliance. At the end of 2014, the Alliance could count on the support of 86 MEPs.

Françoise Grossetête (France, EPP) accepted to continue 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).

In the context of the European elections, 33 MEPs were keen to contribute to Alzheimer Europe's Dementia in Europe magazine "Election Supplement", highlight the past achievements in dementia and express their views on what priorities the new Commission and new Parliament should work on.



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

Alzheimer Europe gratefully acknowledges the support of the following Members of the European Parliament who were present or represented at the various meetings organised by Alzheimer Europe (lunch debates, annual conference), who 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: Martina Anderson (UK), Elena Oana Antonescu (Romania), Margrete Auken (Denmark), Lynn Boylan (Ireland), Biljan Borzan (Croatia), Hiltrud Breyer (Germany), Joseph Cuschieri (Malta), Maria Badiá i Cutchet (Spain), Heinz Becker (Austria), Maria da Graça Carvalho (Portugal), Nessa Childers (Ireland), Ole Christensen (Denmark), Deirdre Clune (Ireland), Brian Crowley (Ireland), Ian Duncan (UK-Scotland), Rosa Estaras Ferragut (Spain), Nathalie Griesbeck (France), Françoise Grossetête (France), Fiona Hall (UK), Marian Harkin (Ireland), Brian Hayes (Ireland), Ian Hudghton (UK), Anneli Jäätteenmäki (Finland), Mocija Kleva Kekus (Slovenia), Andrey Kovatchev (Bulgaria), Merja Kyllönen (Finland), Jean Lambert (UK), Liadh Ni Riada (Ireland), Matt McCarthy (Ireland), David Martin (UK), Marisa Matias (Portugal), Linda McAvan (UK), Mairead McGuinness (Ireland), Gay Mitchell (Ireland), Claude Moraes (UK), Angelika Niebler (Germany), Alojz Peterle (Slovenia), Sirpa Pietikäinen (Finland), Dagmar Roth-Behrendt (Germany), Brian Simpson (Ireland), Alyn Smith (UK), Catherine Stihler (UK), Lambert van Nistelrooij (Netherlands), Derek Vaughan (UK), Angelika Werthmann (Austria), Glenis Willmott (UK), Corien Wortmann-Kool (Netherlands), Marina Yannakoudakis (UK).

Jointly developing policy

Alzheimer Europe collaborated with the European Patients' Forum on a number of cross-disease policy issues, such as the review of the EU clinical trial framework, data protection, patient safety and quality of care.

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

Objective 2: Supporting policy with facts

Comparing national systems and identifying best practices

In collaboration with representatives of its national member organisations, Alzheimer Europe was able to carry out an extensive inventory of national policies and practices with a focus on the pathways to diagnosis of dementia and to post-diagnostic care and support. In addition, in countries where Alzheimer Europe has no member, relevant experts were identified and invited to participate. For the 2014 Dementia in Europe Yearbook, Alzheimer Europe has compiled information from 25 member states of the European Union as well as from Jersey, Norway, Monaco, Switzerland and Turkey.

More specifically, the 2014 Dementia in Europe Yearbook provides information about national policies and practices addressing the timely diagnosis of dementia, the pathways to get a diagnosis, the pharmacological treatment and ongoing assessment of dementia, disclosure of diagnosis, information pathways, assessment of psychosocial needs and development of care plans, and access to and transitions between the existing support and care services. Experts were asked to provide us with details of any relevant policy provisions (e.g. national dementia strategy, guidelines, laws and regulations) in the country and of current practices.

The national reports are supplemented by a comparative report in which the similarities and differences between the national care pathways in the individual countries are presented. In the comparative report, quantitative and qualitative information have been combined and used to provide a comprehensive picture of this complex topic. The comparative report also outlines the main barriers and current challenges to the timely diagnosis of dementia and to post-diagnostic care and support in Europe as perceived by the national experts.

The 2014 Yearbook enables readers to gain an impression of the complexities of the different dementia care pathways which currently exist in Europe and highlights the main gaps and challenges that people with dementia may experience. It is a useful tool for policy makers interested in monitoring progress or developing care pathways for people with dementia in these countries.

European Dementia Observatory

In recent years, Alzheimer Europe has continuously improved the information it provides to its members and external stakeholders on key developments. As a long-term objective, Alzheimer Europe would like to set up a European Dementia Observatory where all relevant developments in the dementia field will be monitored and reported on.

In 2014, our monthly e-mail newsletters contained information on the latest activities of Alzheimer Europe and its member organisations and those of the European Alzheimer's Alliance, as well as information on interesting policy initiatives both on a national and European level. Alzheimer Europe also covered scientific developments in its monthly newsletter and provided updates concerning a number of ongoing European projects, some of which had direct involvement from Alzheimer Europe. We also included human interest stories of people living with Alzheimer's disease or another form of dementia and provided information on new resources and publications as well as listing occasional job opportunities for our contacts and partners.

In 2014, Alzheimer Europe published 11 editions of its newsletter with one newsletter covering December 2013 and January 2014 and another spanning August and September.

A total of 558 articles were featured in 2014 (484 in 2013) in Alzheimer Europe's monthly e-mail newsletters. This means there has been a steady increase in the number of articles each year since we began our newsletter statistics records in 2011. They can be broken down into categories, as follows:

Subject	Number of articles	
	2014	2013
Activities and projects of Alzheimer Europe	95	57
European policy developments in the field of dementia and European Alzheimer's Alliance	81	91
National policy developments	52	25
Activities and projects of AE member organisations	117	98
Scientific developments	117	130
Dementia in Society	46	24
New resources, publications and job opportunities	50	59

The information was also included on the Alzheimer Europe website which continued to receive a significant number of visitors throughout the year. Compared to 2013, the website attracted 15.6 % more visitors, as the number of unique visitors increased from 516,862 in 2013 to 597,393 in 2014. A number of updates were also made to the AE website in 2014, in terms of both the content and the visual presentation of the website. These updates will be ongoing in 2015, to ensure the website remains as current as possible.



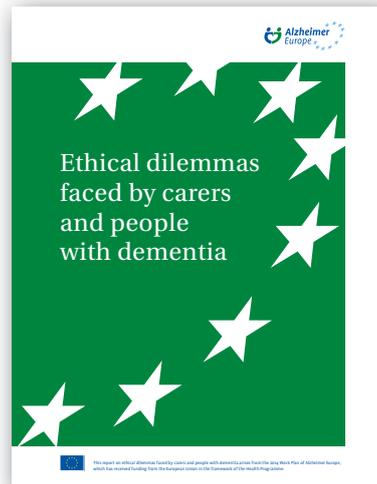
In recent years, Alzheimer Europe has continuously improved the information it provides to its members and external stakeholders on key developments.

Month	Visitors	
	2014	2013
January	44,600	41,995
February	50,902	44,191
March	60,736	42,700
April	57,019	44,725
May	51,784	42,271
June	49,992	49,382
July	37,423	38,384
August	37,788	33,741
September	49,015	44,896
October	55,666	56,221
November	64,008	53,741
December	56,623	38,775
Total:	597,393	516,862

In 2014, Alzheimer Europe continued to step up its social media presence on Twitter and Facebook. By the end of 2014, the association had reached over 2,200 Twitter followers (800 in 2013) and had also reached the maximum of 5,000 Facebook friends (4,000 in 2013). Social media channels Twitter and Facebook became a daily part of AE's activities in 2014 and played a major role in the communication activities for the AE Conference, as well as other events and projects. All AE team members who are involved in projects and attend AE events became active Twitter users in 2014 (if they were not already), tweeting from all events where they represented AE. AE also regularly tweeted giving AE website links (mainly individual news stories), to increase the website activity levels (increased number of "unique visitors").

Objective 3: Basing our actions on ethical principles

Ethical dilemmas faced by people with dementia and carers



As in previous operating grants, AE continued to focus on ethical issues. In 2014, AE worked on ethical dilemmas faced by people with dementia and carers on a day-to-day basis. This work was to be done in collaboration with experts identified through the European Dementia Ethics Network.

AE aimed at drafting vignettes based on a review of the literature and consultation with the expert group (including people with dementia and carers), to which experts in ethics would provide an ethical commentary. In addition, based on the review of the literature and discussion within the ethics working group, AE would develop guidance for people with dementia and carers on how to understand and address possible ethical dilemmas they might one day encounter.

An in-depth literature review was carried out to inform the development of the vignettes and the guidance on addressing ethical dilemmas. The choice of the ethical framework, upon which the guidance was based, was selected after discussion during two full-day workshops with the members of the ethics working group.

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. Jan Oyeboode, Bradford Dementia Group, University of Bradford (UK)
- Prof. Chris Gastmans, Catholic University of Leuven (Belgium)
- Prof. Julian Hughes, Newcastle University and Nuffield Council on Bioethics (UK)
- Dr Eila Okkonen, Muistiliitto/Alzheimer's Society of Finland (Finland)
- Mr Federico Palermi, AMPA/Alzheimer's Society of Monaco (Monaco)
- Mr Stig Atle Aavik, person with dementia (Norway)
- Ms Ranveig Andrea Hoff, carer (Norway)

Several additional experts provided ethical commentaries to the vignettes:

- Dr Anneli Sarvimäki, The Age Institute (Finland)
- Dr Louisa Jackman, Northumbria Healthcare Trust (UK)
- Dr Mark Schweda, University Medical Centre Göttingen (Germany)
- Dr Michael Dunn, Ethox Centre, University of Oxford (UK)
- Dr Ian James, Centre for the Health of the Elderly (UK)
- Ms Charlotte Emer, Northumbria University School of Law (UK)
- Ms Jana Kasparkova, Charles University in Prague (Czech Republic)
- Prof. Cees Hertogh, VU Medical Center (Netherlands)
- Prof. Guy Widdershoven, VU Medical Center (Netherlands)

The working group met twice in 2014. At these meetings, the experts discussed various ethical dilemmas that are experienced by people with dementia and their carers throughout the course of dementia. These were then organised into seven key sections which roughly presented different turning points or situations which often occur and result in difficulties deciding what would be the right or wrong thing to do or way to react.

1. The period of uncertainty or not knowing (pre-diagnosis)
2. The process of understanding/finding out (diagnosis),
3. The initial period of adaptation (shortly after diagnosis)
4. Living with dementia (getting on with routine life/adapting to challenges),
5. Caring for/receiving care (when increased levels of support are needed)
6. The possible transition into a care home (when continued care at home becomes problematic)
7. Care for a dignified end of life

Although certain ethical dilemmas were linked to different “stages” of dementia, this should not be understood as reflecting a strict chronological order but more as a means of structuring the report. As the progression of dementia differs from one person to the next and people's daily lives and characters are very different, the situations which arise and the different ethical dilemmas that people experience may occur at different times.

The meetings were also important in order to agree on the ethical framework and guidance for the future readers. The person with dementia and his carer played an important role in commenting on their experience with regard to various ethical dilemmas and sharing their approach to ethical dilemmas in general.



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 2014 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 from nominating organisations as well as that of a carer or other supporter.

Alzheimer Europe was able to involve 12 different people with dementia from 11 national organisations in Belgium, Czech Republic, Finland, Germany, Ireland, Jersey, Norway, Slovenia, Sweden and the UK (England and Scotland).

In 2014, the mandate of the group came to an end and AE issued a call for new members. The group was successfully reconstituted at the AE Conference in Glasgow and elected a new Executive comprised of Helga Rohra (Germany) as Chairperson and Hilary Doxford (UK-England), Agnes Houston (UK-Scotland) and Helen Rochford-Brennan (Ireland) as Vice-Chairpersons.

Amongst their more notable contributions, we would like to highlight the following:

- Stig Atle Avik and his aunt/carer Ranveig Hofman (Norway) were active members of Alzheimer Europe's working group on the ethical dilemmas faced by people with dementia and their carers
- Helga Rohra (Germany) was an active member of the working group which developed the guidelines on improving the continence care of people with dementia living at home, which was launched at Alzheimer Europe's annual conference in Glasgow



In 2014, the EWGPWD and/or its members attended the following meetings:

1. 3-4 March 2014 meeting of the Executive of the EWGPWD in Luxembourg
2. 22-23 May 2014 meeting of the EWGPWD in Luxembourg
3. 19-22 October 2014 in Glasgow: meeting of the full group followed by a symposium organised by all members and a presentation by Helga Rohra in the plenary session of Alzheimer Europe's annual conference
4. The two meetings of Alzheimer Europe's working group on the day-to-day ethical issues faced by carers of people with dementia (Stig Atle Aavik)
5. The meetings and telephone conferences of Alzheimer Europe's working group for the project on good continence care for people with dementia living at home, in collaboration with SCA Global Hygiene (Helga Rohra)
6. Representation of the EWGPWD by Chairperson Helga Rohra at the Board meetings of Alzheimer Europe

24th Alzheimer Europe Conference in Glasgow

Alzheimer Europe held its 24th Annual Conference in Glasgow from 20-22 October 2014 under the motto "Dignity and autonomy in dementia". The conference was co-organised with Alzheimer Scotland and was attended by 830+ delegates, including 44 people with dementia.

The conference was attended by 830+ delegates.

The programme included some 190 speakers in plenary and parallel sessions, social symposia and workshops as well as 170 poster presentations. The first plenary session was entitled "Promoting a rights-based approach to dementia" and the second consisted of presentations and a round table discussion on dementia strategies and policies. At the end of the second plenary session, Alex Neil (Scotland's Cabinet Minister for Health and Wellbeing) became the first European minister to sign the Glasgow Declaration. Plenary session 3 focused on involving people with dementia while the last session concentrated on innovation and care.

The European Working Group of People with Dementia 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 organised a special symposium on the activities and advocacy efforts of people with dementia and operated an information booth throughout the conference.





The Annual General Meeting of Alzheimer Europe also took place in the framework of the 24th Alzheimer Europe Conference. At the meeting, the members of the organisation elected a new Board and re-elected Heike von Lützu-Hohlbein (Germany) as Chairperson, Iva Holmerová (Czech Republic) as Vice-Chairperson, Charles Scerri (Malta) as Honorary Secretary, Maria do Rosário Zinckedos Reis (Portugal) as Honorary Treasurer and Marie-Odile Desana (France), Sabine Henry (Belgium), Štefanija Lukic Zlobec (Slovenia), Gerry Martin (Ireland), Jim Pearson (UK – Scotland), Sirpa Pietikäinen (Finland) and Jesús Rodrigo (Spain) as Board members. Helga Rohra (Germany)

represents the European Working Group of People with Dementia on the AE Board.

The members also voted to upgrade Alzheimer Bulgaria to “full member” status, approved the annual and financial reports and adopted the organisation’s 2015 work plan and budget. AE’s member associations adopted the Glasgow Declaration, which 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.





Supporting and involving member organisations

Alzheimer Europe consistently involves its member organisations in meetings, projects and activities. In 2014, two successful meetings brought together the public affairs representatives of various national associations, with the February meeting organised at the same time as the European Parliament lunch debate.

These meetings were aimed at exchanging information on national dementia strategies and policies and the campaigning and advocacy activities of Alzheimer associations. In particular, the meetings focused on:

- updates on AE projects: Clinical Trial Watch, Policy Watch, Dementia Monitor and the Alzheimer's Association Academy
- AE's and members' participation in Global Dementia Legacy and OECD events
- drafting the Glasgow Declaration
- members' contributions to AE's Dementia in Europe Yearbook
- conducting the European Dementia Pledge campaign before the EU elections
- update on the composition of the new European Parliament after the EU elections

In addition, Alzheimer Europe's member associations presented activities from their countries, including awareness campaigns and lobbying work. These presentations serve to share best practices among the AE members.



Membership development

With the exception of Estonia, Hungary, Latvia and Lithuania, Alzheimer Europe currently has members in all of the EU Member States.

In 2014, the Annual General Meeting voted to grant full membership to Alzheimer Bulgaria (previously a provisional member) and decided to continue the provisional memberships of Foundation Compassion Bulgaria and Alzheimer Uniti (Italy).

Strategic partnerships



In 2014, Alzheimer Europe continued as an active member of the European Patients' Forum and contributed to a number of consultation documents, such as the EPF position on the EU reform of the clinical trial regulation, data protection and transparency. AE also participated in EPF's Public Affairs Group and Access to Healthcare Working Group.

Similarly, 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.



Alzheimer Europe was also represented at the Alzheimer's Disease International (ADI) Summer University in Geneva. Annette Dumas gave a presentation on "Building effective relationships with elected officials". Annette also represented ADI at the 64th session of the World Health Organisation Regional Committee for Europe. Alzheimer Europe also collaborated with ADI on the Global Action against Dementia and the preparation of the Legacy event in London.

Other activities and projects

EU Project participation

PharmaCog

Alzheimer Europe continued its involvement in the PharmaCog project. PharmaCog, or “Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development”, is an IMI project which started on 1 January 2010 and will run until the end of 2015.

Alzheimer Europe represents the interests of people with dementia and their carers in this consortium and helps with the dissemination of the research results to a lay audience. In 2014, the organisation updated the section of its website dedicated to the PharmaCog project.

Alzheimer Europe was represented by Alex Teligadas during a Steering Committee meeting on 27 January in Lille, France.



NILVAD



In 2014, Alzheimer Europe continued its collaboration with the NILVAD project, a phase III clinical trial of the drug nilvadipine on 510 people with mild to moderate Alzheimer's disease in nine European countries. Alzheimer Europe represents the views of people with dementia and their carers in the research consortium and disseminates results to a wider audience.

In May 2014, Alzheimer Europe proposed a new sub study on the experiences of the trial participants and their caregivers. This gained initial approval and was further developed by AE's Ana Diaz in cooperation with the University of Lille.

Alzheimer Europe was represented by Alex Teligadas at the General Assembly on 12-13 May in Lille, France and also by Ana Diaz at the Steering Committee meeting on 19 November in Munich, Germany.



EMIF



The five year European Medical Information Framework project began in 2013 with funding from IMI. EMIF aims to develop a framework for evaluating, enhancing and providing access to human health data across Europe. This framework will support various disease areas including dementia, where the project aims to identify predictors of Alzheimer's disease in the pre-clinical and prodromal phases.

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 18 March, 7 April, 30 April, 16-17 June, 22-23 September and 10-12 December. Jesús Rodrigo, member of the AE Board, gave a presentation on Alzheimer Europe activities during an EMIF press conference on 11 December in Barcelona, Spain.

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. The project will involve the collection of clinical data, imaging and genetic data and will create a new way to combine all of these together to look for patterns which could identify sub-groups of patients with similar causes of their disease.

Alzheimer Europe is a partner in work package 4 (Ethical and Legal Governance) that will initially provide input to ensure that patient perspectives and interests are considered in the project’s legal framework.

The organisation was represented by Alex Teligadas at the project launch meeting on 8-9 January in Anderlecht, Belgium and also by Ana Diaz at the project’s first General Assembly on 18-19 September in Biberach, Germany. Ana also attended a project meeting on 10 October in Hannover, Germany.



PACE



The aim of PACE is to compare the effectiveness of palliative care for elderly people in long term care facilities in Europe. This FP7 funded project which is coordinated by the Vrije Universiteit Brussels (Belgium) has the following key objectives:

- to map and classify existing palliative care systems
- to compare effectiveness of health care systems with and without formal palliative care structures
- to compare the impact of a health service intervention
- to consider differences between population groups and to investigate the effects of gender, age, socio-economic status, dementia and functional status
- to develop products/tools for policy and decision-makers based on the study results

In 2014, the mapping exercise was completed and a report produced. The ethical approval process in all participating countries was initiated. Throughout the year, the partners worked on developing the materials to be used in the planned intervention and agreeing on the recruitment strategy to be adopted. Alzheimer Europe ensured work on the dissemination of information about the project.

AFE-INNOVNET

Another successful project application in 2013 was AFE-INNOVNET (Innovation for age-friendly environments in the European Union).

The overarching goal of this thematic network (TN) coordinated by AGE Platform Europe is to set up a large EU wide community of local and regional authorities (LRAs) and other relevant stakeholders across the EU who want to work together to find smart and innovative evidence-based solutions to support active and healthy ageing and develop age-friendly environments (AFE) across the EU.

In 2014, Alzheimer Europe contributed towards the development of a participatory approach to the involvement of older people in the creation and promotion of age-friendly societies, to the covenant and to the identification of dementia-friendly initiatives for the repository.



PredictND



In 2013, the European Commission also provided funding to the PredictND project – “From patient data to clinical diagnosis in neurodegenerative diseases”.

Coordinated by VTT Technical Research of Finland, PredictND aims to provide an objective and systematic ICT-based approach for the diagnosis of neurodegenerative diseases. One of the main objectives is to show that a clinical protocol based on the use of modern computer-based models enables objective earlier diagnostics compared to current clinical procedures. The second main objective of PredictND is to improve cost-efficiency of early diagnostics by developing a low-cost and simple-to-use battery of measurements that could be used to detect persons at high risk for dementia. These persons could then be scheduled for more accurate but more expensive clinical diagnostic methods. PredictND develops and studies approaches that could be used by general practitioners or even by citizens themselves.

Alzheimer Europe carried out a survey at its annual conference in Glasgow of participants' attitudes and preferences with regard to a hypothetical website which would eventually contain information and the low-cost games and tests. The results of this survey provided valuable information about the readiness of the participants regarding such a system, their likely motivation to do the tests and games and some important concerns about the whole concept of low-cost monitoring/detection of dementia.

Corporate Affairs

European Parliament lunch debates

In 2014, Alzheimer Europe organised two successful lunch debates in the European Parliament which were well attended by MEPs.

On 18 February, Françoise Grossetête, MEP (France) and Chair of the European Alzheimer's Alliance, hosted a lunch debate on the current and future activities of IMI. These were presented by IMI Executive Director, Michel Goldman. He explained what IMI was and the place of brain disorders in the IMI budget. He also gave an overview of the four IMI projects that address the complexity of brain pathology, patient heterogeneity and the lack of validated makers for disease activity.



On 2 December, Keith Taylor, MEP (UK) and Vice-Chair of the European Alzheimer's Alliance hosted a lunch debate on dementia prevention. Dr Miia Kivipelto, Karolinka Institutet, Sweden, showed how cognitive decline could be controlled by addressing multiple risk factors simultaneously.



In addition, Alzheimer Europe co-organised the European Parliament event “Hand in hand: fighting against Alzheimer’s disease and other forms of dementia together” with Marina Yannakoudakis, MEP (UK) and Vice-Chair of the Alliance. The meeting explored how the EU’s 2009 European Initiative on Alzheimer’s disease has supported progress in the field of dementia across Europe.



Jean Georges (Alzheimer Europe) presented Alzheimer Europe’s work to make dementia a European public health priority, Matthew Norton (Alzheimer’s Research UK) explained the organisation’s strategy to find treatments and cures for dementia through world-class biomedical research, Alison Cook (Alzheimer’s Society) presented the organisation’s campaign “One million Dementia Friends”. The European Commission was represented by Joanna Darmanin (Health) who gave an overview of the EU activities that followed the Communication and Catherine Berens (Research) presented an overview of EU funding programmes.

Dementia in Europe Magazine

In 2014, 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:

- José Manuel Barroso, European Commission President
- Adonis Georgiades, Greek Minister of Health
- Giuseppe Ruocco, General Director of Prevention at the Italian Ministry of Health
- Bent Høie, Norwegian Minister of Health
- Alex Neil, Scotland’s Cabinet Secretary for Health and Wellbeing
- Pascal Strupler, Switzerland’s Director of Public Health

The Global Action Against Dementia was also featured in the magazine, with a report on the first Global Dementia Legacy event in London in June 2014. At this event, the participants explored the financial and social impact of investing in dementia and identified a set of priorities to tackle dementia at a global level. In the wake of this event, Dennis Gillings, World Dementia Envoy, gave an interview for the magazine, talking about his role in coordinating the Global Action Against Dementia.

The magazines also contain detailed accounts on AE projects and meetings, such as the European Parliament lunch debates and the organisation’s Annual Conference. In addition, the magazines feature a section on “Living with dementia” where people with dementia and carers provided insightful accounts of their own experiences of dementia.

Issue 16 (February 2014) included coverage of AE’s 2013 conference in Malta, while issue 18 was launched in October 2014 at the 24th Alzheimer Europe Conference in Glasgow. This issue featured a special supplement dedicated to Scotland, including interviews with Alex Neil (Cabinet Minister for Health and Wellbeing) and five MEPs, a profile of Alzheimer Scotland and an article by a Scottish man with dementia.



Clinical Trial and Guideline Watch

As part of the Clinical Trial Watch, AE looked at existing European resources where people with dementia and their families could obtain information about ongoing clinical trials that are conducted in Europe. The result of this exercise showed the multiple challenges that people with dementia and their families would have to face to access such information. AE, in close collaboration with the EWGPWD, has worked during 2014 on a project aimed at connecting people with dementia and their families with high-quality research. This involves developing a database containing updated information, from relevant existing registries, that is adapted to the needs of people with dementia and their families. Four members of the EWGPWD have been actively involved in this work, and during 2014 a dementia-friendly format for the report that will be used in the database has been developed.

As part of the Guideline Watch, AE intends to develop a database with national guidelines for the diagnosis, treatment and management of dementia in Europe. In 2014, AE contacted 63 organisations and experts (e.g. Alzheimer associations, professional bodies, Ministries, first author of existing guidelines) that could provide information about guidelines in their country. This strategy has helped AE to update the information about national guidelines that had been collected in previous years and to find new guidelines. In total, in 2014, AE has compiled information about 71 national guidelines from 26 different European countries. 47 guidelines that were available in English or that were translated by AE to English have been inputted into the database. The remaining guidelines need to be translated to English.

Promoting continence care

Between January 2013 and December 2014 Alzheimer Europe partnered with SCA Global Hygiene to develop guidelines for the promotion of continence care for people with dementia living at home.

Due to the lack of research on this topic, an approach based on expert consensus was adopted. A steering group and expert working group were set up comprised of experts in both dementia and continence care, as well as a person with dementia from the European Working Group of People with Dementia and an informal carer with experience providing continence care to a person with dementia. An integrative review of relevant literature was carried out, including peer-reviewed research articles as well as grey literature in the two domains.

The expert working group agreed on the target audience and the scope of the guidelines and accompanying report. A brainstorming session was held to determine the overall content of the guidelines and a final draft version, produced by means of an iterative process, was presented at the plenary session of the Global Forum on Incontinence held in Madrid in April 2014. This marked the beginning of a wider consultation involving international experts in continence care and continence research as well as purposively selected individuals and groups, including people with dementia and informal carers in Europe.

The final version of the guidelines was launched at Alzheimer Europe's annual conference in Glasgow and a shorter, more dementia-friendly version, solely for people with dementia, was made available on Alzheimer Europe's website.



Meetings attended by AE representatives

Meetings organised by Alzheimer Europe in the framework of the 2014 Operating Grant

Date	Meeting	Location
17-18 February	AE Board meeting	Brussels, Belgium
19 February	Public Affairs Meeting	Brussels, Belgium
3-4 March	Meeting of the Executive of the European Working Group of People with Dementia (EWGPWD)	Luxembourg, Luxembourg
31 March–1 April	1 st meeting of AE ethics working group	Luxembourg, Luxembourg
22-23 May	Meeting of EWGPWD	Luxembourg, Luxembourg
7-8 July	AE Board meeting	Luxembourg, Luxembourg
9 July	AE public affairs meeting with members	Luxembourg, Luxembourg
21-22 July	2 nd meeting of AE ethics working group	Brussels, Belgium
19 October	EWGPWD meeting	Glasgow, UK
20 October	AE Board meeting and AGM	Glasgow, UK
1 December	AE Board meeting	Brussels Belgium

Meetings attended by AE representatives in the framework of the 2014 Operating Grant

Date	Meeting	Location
14 January	Meeting with European Personalised Medicine Association	Luxembourg, Luxembourg
16-17 January	Kick-off meeting of ACTIFCare project	Maastricht, Netherlands
27 January	JPND-AAL Conference	Amsterdam, Netherlands
30 January	Conference on “Impact of Ageing on Mental Health and Well-being”	Barcelona, Spain
4-5 February	Consensus Panel: “Improving assessment in early Alzheimer’s disease”	London, UK
4-5 February	European Commission meeting of government experts in dementia	Luxembourg, Luxembourg
19 February	EFNA European Parliament lunch debate “Out of office”	Brussels, Belgium
20 February	European Parliament breakfast meeting: “Paving the way to equitable access to treatment in Europe”	Brussels, Belgium
25-26 February	Patients’ and Consumers’ Working Party of European Medicines Agency	London, UK

Date	Meeting	Location
27 February	Workshop “Whether and how to integrate ethical issues in clinical practice guidelines”	Hannover, Germany
18 March	European Commission conference on “Health in Europe – Making it Fairer”	Brussels, Belgium
25 March	EFID Awards Ceremony	Brussels, Belgium
26-29 March	Geneva/Springfield symposium	Geneva, Switzerland
27 March	Organisation meeting for MEP M. Yannakoudakis’ “Hand in hand” event	Brussels, Belgium
1 April	MEP M. Yannakoudakis’ “Hand in hand” event	Brussels, Belgium
3-4 April	European Commission summit on chronic diseases	Brussels, Belgium
8 April	Meeting organised by MEP A. Kovatchev on “Universal access to health: your voice in the European union”	Brussels, Belgium
8-9 April	Global Forum on Incontinence	Madrid, Spain
9 April	Carers Interest Group meeting in the European Parliament	Brussels, Belgium
10 April	Meeting with the European Association for Homes and Services for the Ageing	Luxembourg, Luxembourg
24 April	22 nd annual conference of the Ligue Alzheimer	Huy, Belgium
30 April	Meeting with Association Luxembourg Alzheimer	Luxembourg, Luxembourg
12-13 May	EPF AGM and related working sessions	Brussels, Belgium
12-14 May	EIP AHA synergies meeting and conference	Athens, Greece
19 May	Dementia briefing during World Health Assembly of WHO	Geneva, Switzerland
23 May	Symposium on Dementia and Caregiving organised by Trinity College Dublin and the Irish centre for Social Gerontology	Dublin, Ireland
3 June	EMA Human Scientific Committees’ Working Parties with PCWP and HCPWP joint meeting	London, UK
4 June	IMPACT project meeting	Lleida, Spain
9-10 June	Scottish government’s 1 st International Dementia Conference	Edinburgh, UK
10 June	EPF Public Affairs meeting	Brussels, Belgium
11 June	EFPIA webinar on “Patient Understanding of Benefit Risk”	Brussels, Belgium
12 June	Meeting with MEP M. Yannakoudakis to discuss further collaboration on dementia	Brussels, Belgium
18 June	DG Sanco conference on “Frailty in old age, identifying priorities for EU policy”	Brussels, Belgium
19 June	1 st Global Dementia Legacy event	London, UK
23-26 June	ADI Alzheimer University on “Campaigning for change”	Geneva, Switzerland
25 June	JPND palliative care expert workshop	Amsterdam, Netherlands

Date	Meeting	Location
2 July	Meeting with AARP and EU stakeholders	Brussels, Belgium
18 July	Meeting with World Dementia Envoy, Dr Gillings and UK Department of Health	Brussels, Belgium
22 July	Meeting with AGE	Brussels, Belgium
24-25 July	Consortium meeting for IMI-funded EPAD project	London, UK
2 September	Meeting with representatives from the European Commission's DG Sanco	Luxembourg, Luxembourg
10 September	EFPIA Think Tank with patient organisations	Brussels, Belgium
10 September	German-Swedish seminar on "Care planning and quality of life of older people with dementia"	Berlin, Germany
11-12 September	2 nd Global Dementia Legacy event	Ottawa, Canada
15 September	Launch meeting of German "Alzheimer Agenda"	Berlin, Germany
16-18 September	64 th session of the WHO Regional Committee for Europe	Copenhagen, Denmark
26 September	European Patients Forum Public Affairs meeting	Brussels, Belgium
26 September	Luxembourg Health Ministry conference on the "Programme Demenz Prävention-PDP"	Luxembourg, Luxembourg
29-30 September	Meeting with Alzheimer Slovenia (Spominčica) in preparation for 25 th AE conference in 2015	Ljubljana, Slovenia
1-2 October	14 th Croatian Congress on Alzheimer's Disease (CROCAD-14)	Brela, Croatia
3 October	Meeting with MEPs' assistants to discuss EAA	Brussels, Belgium
2-3 October	Project proposal meeting organised by Tampere University of Applied Sciences and Tampere Unit for Computer-Human Interaction University	Tampere, Finland
3 October	Symposium on ethical challenges of future Alzheimer's disease clinical research organised by Pasqual Maragall Foundation	Barcelona, Spain
8-9 October	Expert seminar on "Future Medicine in the Human Brain Project"	Copenhagen, Denmark
14 October	Meeting with MEP Keith Taylor (EAA Vice-Chair) to discuss his role in EAA, plan lunch debate of 2 December	Brussels, Belgium
15 October	Carers Interest Group meeting in the European Parliament	Brussels, Belgium
15 October	Meeting of EP Intergroup on Ageing and Solidarity	Brussels, Belgium
17 October	Meeting with representatives of General Direction for local powers, social action and health of the Wallonia Public Service	Jambes, Belgium
21 October	INTERDEM workshop "Dementia Outcome Measures: Charting new territories"	Glasgow, UK
23 October	Meeting on Scotland's National Dementia Strategy	Glasgow, UK
23-24 October	Ideas Lab and meeting of International Advisory Board of the Dementia Services Development Centre	Stirling, UK

Date	Meeting	Location
1 November	European Commission workshop on “Health, Demographic Change and Wellbeing”	Brussels, Belgium
5-7 November	3 rd Global Dementia Legacy event	Tokyo, Japan
11-12 November	APFADA and AMPA conference on “Alzheimer and the Mediterranean: Working together...”	Lisbon, Portugal
11-12 November	OECD workshop on AD research	Lausanne, Switzerland
13 November	2 nd EC Working Group meeting of government experts on dementia	Rome, Italy
14 November	Italian EU Presidency dementia conference	Rome, Italy
25 November	EMA Patient and Consumer training session	London, UK
28-29 November	Integrated Care Workshop by Prof. Alexander Kurz	Munich, Germany
1 December	EIP AHA 3 rd conference of partners: “Taking stock and focusing on delivery”	Brussels, Belgium
8-9 December	International workshop on “The diagnosis of Alzheimer’s disease with biomarkers”	Geneva, Switzerland
10 December	Last EFPIA Think Tank meeting of 2014	Brussels, Belgium
10 December	Workshop to develop the AAL challenge-led call for proposals 2015	Brussels, Belgium

Other meetings organised by AE or attended by AE representatives in 2014

Date	Meeting	Location
9-10 January	AETIONOMY launch meeting	Brussels, Belgium
27 January	PharmaCog Steering Committee Meeting	Lille, France
11 February	Meeting with Sandoz	Luxembourg, Luxembourg
18 February	European Parliament lunch debate on Innovative Medicines Initiative	Brussels, Belgium
18 February	Company Round Table meeting	Brussels, Belgium
24-25 February	PACE kick-off meeting	Brussels, Belgium
5 March	Skype conference for Improving Continence Care of People with Dementia Living at Home project	Luxembourg, Luxembourg
10 March	EFPIA Think Tank meeting	Brussels, Belgium
13-14 March	Launch of Predict ND project	Espoo, Finland
18 March	Meeting of EMIF WP16	Brussels, Belgium
25 March	Meeting with Roche	Luxembourg, Luxembourg
7 April	Meeting of EMIF WP15	Diegem, Belgium

Date	Meeting	Location
8 April	"Twitter Academy" – social media training sponsored by Lilly	Brussels, Belgium
25 April	Meeting with Novartis and Lundbeck	Brussels, Belgium
30 April	Meeting of EMIF WP15	Diegem, Belgium
9 May	Meeting with Lilly	Brussels, Belgium
12-13 May	3 rd NILVAD General Assembly	Lille, France
20-21 May	Kick-off meeting of AFE-Innovnet project	Brussels, Belgium
3-4 June	Lilly Advisory Board meeting	Stockholm, Sweden
6 June	Lilly Working Group meeting	Erl Wood, UK
17 June	2 nd EMIF Business Modelling Workshop	Barcelona, Spain
18-19 June	Meeting with Alzheimer Scotland re conference	Glasgow, UK
27 June	Patient advocacy meeting organised by Lundbeck	Copenhagen, Denmark
1 July	EFPIA/Patients Think Tank	Brussels, Belgium
8 July	Round Table discussion with AE's corporate sponsors	Luxembourg, Luxembourg
11 July	Meeting with Servier and EFPIA	Brussels, Belgium
18-19 September	1 st General Assembly of the AETIONOMY project	Biberach, Germany
22 September	Meeting with Alzheimer Scotland re conference	Glasgow, Scotland
22 September	Roche Dementia forum	Amsterdam, Netherlands
22-23 September	EMIF communications task force meeting	Barcelona, Spain
23-24 September	2 nd meeting of the Predict ND project	Amsterdam, Netherlands
1-3 October	AFE-Innovnet consortium meeting and "dementia friendly cities" workshop	Brussels, Belgium
10 October	1 st AETIONOMY External Legal and Ethical Advisory Board Meeting	Hannover, Germany
20-22 October	Alzheimer Europe 24 th annual conference	Glasgow, UK
17-18 November	Consortium meeting of PACE project	Manchester, UK
19 November	4 th NILVAD Steering Committee meeting	Munich, Germany
2 December	AE Lunch Debate on dementia prevention	Brussels, Belgium
5 December	Working day: "People with dementia experiences of participating in the NILVAD clinical trial"	Lille, France
9-12 December	EMIF project meetings and EMIF colloquium	Barcelona, Spain
18 December	Meeting with Roche	Luxembourg, Luxembourg

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, 2014



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

R.C.S. Luxembourg F 2773

14, rue Dicks
L-1417 LUXEMBOUR

REPORT OF THE REVISEUR D'ENTREPRISES AGREE

Following our appointment by the General Meeting of the Shareholders dated October 20, 2014, we have audited the accompanying annual accounts of **ALZHEIMER EUROPE**, which comprise the balance sheet as at December 31, 2014 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, 2014, 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 23rd, 2015

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



Philippe SLENDZAK
Partner

Appendix:

- Annual accounts as at December 31st, 2014

Balance sheet as of December 31, 2014

Agenda Item 7d

	2014 (Euro)	2013 (Euro)
ASSETS		
Fixed assets		
Other fixed assets	28.597	16.055
Current assets		
Debtors European Commission	123.382	108.181
Other debtors	31.653	76.193
Cash at bank and on deposit	167.130	466.279
	322.165	650.653
Prepayments	2.589	3.417
	353.350	670.125
LIABILITIES		
Capital and reserves		
Results brought forward	183.738	178.446
Result of the year	14.060	5.292
	197.798	183.738
Creditors		
Amounts owed to credit institutions		
EU Subsidies received on account	55.596	276.606
Tax and social security	19.456	10.547
Payments received on account		40.000
Trade creditors	51.149	88.722
Other liabilities	20.291	64.521
	146.492	480.396
Deferred income	9.060	5.991
	353.350	670.125

Deferred income represents a part of income received in 2014 which will be used in 2015.

As at December 31, 2014, the total of untaken holidays represents KEUR 21.6 and has not been recorded in the accounts. Moreover, the non-profit organisation has 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, 2014

	2014 (Euro)	2013 (Euro)
Support and revenue		
Other operating income		
Corporate sponsorship	296.608	332.255
EU Subsidy	465.297	300.905
Deferred income	5.991	79.317
Sponsorship received on account	- 9.060	- 5.991
Co-financing in kind	56.700	56.700
Project participation and other subsidies	109.915	113.192
AE Conference registration fees	164.362	115.447
Membership fees and contributions	57.790	56.305
Donations	498	1.400
Publication sales and royalties	5.693	2.389
Other operating income	9.248	11.106
External charges		
External experts	- 142.542	- 211.243
Accommodation expenses	- 172.543	- 187.050
Alzheimer Europe Foundation	- 29.422	- 34.094
Publication and Information material	- 95.053	- 97.148
Travel expenses	- 59.274	- 64.257
Office rent and associated costs	- 47.646	- 28.283
Equipment and Leasing	- 33.561	- 24.064
Communication costs	- 31.572	- 25.023
Office stationery and related costs	- 7.486	- 2.740
Membership fees	- 1.000	- 1.120
Other costs	- 4.270	- 4.171
Irrecoverable EU subsidy		
Staff costs		
Wages and salaries	- 448.171	- 329.084
Social security costs	- 67.532	- 48.409
Depreciation	- 9.469	- 1.784
Interest receivable and similar income	558	737
Interest payable and similar charges		
	14.060	5.292

Breakdown of income

In 2014, Alzheimer Europe had an audited income of EUR 1,163,599.24 of which EUR 618,472.58 (53.15%) were for the organisation's core activities (including the organisation's Dementia Ethics Network) and EUR 545,126.66 (46.85%) were for the organisation's annual conference, corporate affairs activities and other projects.

Funding of core activities (EUR 618,472.58)

In 2014, the core funding of Alzheimer Europe was composed as follows:

- EUR 365,986.09 (59.18%) from public funding
- EUR 118,500.00 (19.16%) from foundations and other non-profit organisations
- EUR 77,289.74 (12.50%) from member organisations
- EUR 40,700 (6.58%) from corporate sources
- EUR 998.56 (0.16%) from private individuals
- EUR 558.22 (0.09%) from bank interest and similar
- EUR 14,439.97 (2.33%) from other sources

Public funding

In 2014, the breakdown of public funding totalling EUR 365,986.09 can be broken down as follows:

- Alzheimer Europe received EUR 285,168 as an operating grant from the European Commission, EUR 24,652.79 for its participation in the PredictND project, EUR 14,709.92 for its participation in the EMIF project, EUR 10,630.07 for its participation in the NILVAD project, EUR 10,162.51 for its participation in the Aetionomy project, EUR 9,124.50 for its participation in the PACE project, EUR 6,544.98 for its participation in the PharmaCog project, and EUR 4,993.32 for its participation in the AFE-Innovnet project

Foundations and organisations

The EUR 118,500 which Alzheimer Europe received in 2014 from foundations and other non-profit organisations can be broken down as follows:

- EUR 87,000 as direct support from Fondation Alzheimer, Luxembourg
- EUR 31,500 in donated time by experts involved in the ethical work and comparison of national dementia strategies of Alzheimer Europe (at EUR 300 per day)

Funding from member organisations

In 2014, the EUR 77,289.74 funding from member organisations can be broken down as follows:

- EUR 57,789.74 in membership fees and contributions
- EUR 19,500 in co-financing from Board members and time donated to the organisation by representatives of member organisations (at EUR 300 per day)

Corporate support

In 2014, Alzheimer Europe received EUR 40,700 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 5,700 from Newsweaver which provided an e-mail facility free of charge

Private individuals

In 2014, AE received EUR 998.56 from individuals which can be broken down as follows:

- EUR 500.50 in publication sales and
- EUR 498.06 in donations

Bank interest and similar

In 2014, Alzheimer Europe had an income of EUR 558.22 from bank interest and similar income.

Other income

In 2014, EUR 14,439.97 came from other sources not mentioned above.

Funding of project activities (EUR 545,126.66)

In 2014, Alzheimer Europe received EUR 545,126.66 for its various projects, including its Annual Conference in Glasgow, Scotland, a project on good incontinence care and its corporate affairs activities, of which:

- EUR 261,607.70 (47.99%) came from corporate sponsors
- EUR 164,362.24 (30.15%) from private individuals,
- EUR 112,876.31 (20.71%) from public sources and
- EUR 9,349.29 (1.72%) from foundations and other non-profit organisations
- EUR 5,991.13 (1.10%) from deferred income from 2013
- EUR -9,060.19 (-1.66%) was income deferred to 2015

Corporate support

The corporate support received by Alzheimer Europe for its activities in 2014 (EUR 261,607.70) can be broken down as follows:

- Lilly contributed EUR 51,891.33 as a gold sponsor of AE's corporate programme and AE's Annual Conference in Glasgow, and as travel support
- SCA Global Hygiene contributed EUR 41,500 as a bronze sponsor of AE's corporate programme, as a silver sponsor of AE's Annual Conference and towards the AE/SCA joint project on good incontinence care
- Hoffmann-LaRoche contributed EUR 20,283.92 as a bronze sponsor of AE's corporate programme, as a silver sponsor of AE's Annual Conference in Glasgow and as travel support
- Piramal provided EUR 15,000 as a bronze sponsor of AE's corporate programme and AE's Annual Conference in Glasgow
- Lundbeck provided EUR 10,432.45 as a bronze sponsor of AE's corporate programme and as travel support
- Janssen and Danone contributed EUR 20,000 each as silver sponsors of AE's corporate programme
- Pfizer, Novartis, GE Healthcare and Merz contributed EUR 10,000 as bronze sponsors of AE's corporate programme
- Nestlé provided EUR 7,500 as a sponsor of AE's corporate programme
- Sandoz provided EUR 5,000 as a sponsor of AE's corporate programme
- Kaizo contributed EUR 20,000 as a sponsor of a networking event at AE's Annual Conference in Glasgow
- Bupa contributed EUR 10,000 as a sponsor of a networking event at AE's Annual Conference in Glasgow

Private individuals

In 2014, Alzheimer Europe received EUR 164,362.24 in registration fees for the Alzheimer Europe Conference in Glasgow.

Public funding

In 2014, Alzheimer Europe received EUR 99,310.76 as a grant from the European Commission and EUR 13,565.55 from the Scottish Government for its Annual Conference in Glasgow.

Foundations and organisations

In 2014, Alzheimer Europe received EUR 9,349.29 from the Life Changes Trust in Glasgow.

Deferred income

In 2014, Alzheimer Europe was able to contribute EUR 5,991.31 to its project activities which came from deferred income in 2013 and reported EUR 9,060.19 of its project income to 2015.

Overall funding

The following table lists all sources of income received in 2014.

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 (2014)	As % of AE income)	
		2014	2013
Lilly	51,891.33	4.46%	4.67%
GlaxoSmithKline	35,000.00	3.01%	3.45%
Hoffmann-LaRoche	20,283.92	1.74%	
Janssen	20,000.00	1.72%	2.64%
Piramal	15,000.00	1.29%	1.40%
Lundbeck	10,432.45	0.90%	0.93%
Pfizer	10,000.00	0.86%	3.74%
GE Healthcare	10,000.00	0.86%	2.22%
Merz	10,000.00	0.86%	0.93%
Novartis	10,000.00	0.86%	0.93%

Funding source	Funding received (2014)	As % of AE income)	
		2014	2013
Sandoz	5,000.00	0.43%	
Sanofi			1.87%
Avanir			0.93%
Baxter			0.93%
Sub-total: Pharmaceutical funding	197,607.70	16.98%	24.66%
SCA Global Hygiene	41,500.00	3.57%	4.52%
Nutricia	20,000.00	1.72%	1.87%
Kaizo	20,000.00	1.72%	
Bupa	10,000.00	0.86%	
Nestlé	7,500.00	0.64%	
Newsweaver	5,700.00	0.49%	0.50%
Mazars			0.28%
Sub-total: Other corporate sources	104,700.00	9.00%	7.18%
Total: Corporate funding	302,307.70	25.98%	31.84%
European Commission	465,296.85	39.99%	28.13%
Scottish Government	13,565.55	1.17%	
Maltese Ministry of Finance			1.17%
Total: Public funding	478,862.40	41.15%	29.30%
Fondation Alzheimer, Luxembourg	87,000.00	7.48%	8.13%
Other organisations (donated time)	31,500.00	2.71%	1.96%
Life Changes Trust	9,349.29	0.80%	
Fondation Roger de Spoelberch			0.63%
Fondation Médéric Alzheimer			0.47%
Malta Tourism Authority			0.19%
Total: Foundations and organisations	127,849.29	10.99%	11.38%
Individuals (Conference fees, donations, publications)	165,360.80	14.21%	11.15%
Total: Individuals	165,360.80	14.21%	11.15%
AE member organisations	77,289.74	6.64%	7.82%
Total: Member organisations	77,289.74	6.64%	7.82%
Deferred income	-3,068.88	-0.26%	7.41%
Total: Deferred income	-3,068.88	-0.26%	7.41%
Bank interest and similar	558.22	0.05%	0.07%
Total: Bank interest and similar	558.22	0.05%	0.07%
Other income	14,439.97	1.24%	1.04%
Total: Other income	14,439.97	1.24%	1.04%
Total Income	1,163,599.24	100.00%	100.00%



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