

~ Annual Report

0

2

Herer Europe Annual Report Alzheimer Europe Annual Report Al Europe Annual Report Alzheimer Europe Annual Report Al



# 2003 Annual Report









e i m e r

We acknowledge the financial support of Janssen-Cilag, Lundbeck, Merck Sharpe & Dohme and Pfizer which have made the publication of this Annual Report possible.

```
1. Preface
2. Executive summary
 3. Our core objectives
  4. The business plan programmes
   5. Networking
        10
     6. Other activities
         12
       7. Financial report
          8. Annex I: The member organisations of Alzheimer Europe
             9. Annex II: The Expert Advisory Panel of Alzheimer Europe
                 10. Alzheimer Europe
                      24
                     Board members
                           24
                          Secretariat
                                24
```

# 1. Preface

The adoption of the business plan in 2002 provided a new focus for Alzheimer Europe and our 2003 Annual Report logically follows the structure of the business plan to provide an update on the progress obtained in reaching its goals and priorities.



In many ways, the adoption of the business plan transformed our organisation and it has become possible for the first time to measure our achievements against the objectives we set ourselves. As the chairperson of Alzheimer Europe, I would therefore like to recall some of the objectives set out in our business plan and highlight the progress achieved in 2003.

Our business plan very clearly sets out the underlying philosophy for our organisation which is aimed at enhancing the dignity, respect and self-determination of the person with dementia and his/her family throughout the course of the disease.

Furthermore, the business plan defines the core objectives of our member organisations and provides the mission statement for our organisation, namely: Alzheimer Europe is an interface between national member organisations and European structures in order to represent the interests of people with dementia and their carers, to promote information exchange and to develop policy.

The first part of our Annual Report is therefore dedicated to presenting the activities we have carried out in furthering our core objectives and I would like to single out the complete and very successful overhaul of our Internet site, as well as the in-depth survey of our member organisations which give us a better understanding of the various services provided by them.

Also, Alzheimer Europe used last year to establish closer links with the medical and scientific community. Apart from strengthening its contacts with the European Alzheimer's Disease Consortium and Interdem for which Alzheimer Europe maintains the websites, the organisation also formalised its collaboration with a number of professionals with the creation of its Expert Advisory Panel. The organisation can now count on the advice of over 50 experts in four different areas, namely:

- Research and medical issues
- Care and social issues
- Legal issues
- Ethical issues

Our business plan was not only limited to a better definition of our core objectives, but also set out five

main objectives for Alzheimer Europe which it is worthwhile to recall:

- 1. Ensuring people with dementia and their carers are referred to Alzheimer associations
- 2. Promoting the autonomy of people with dementia through the right to an early diagnosis and the recognition of advance directives
- 3. Improving the support and counselling of carers of people with dementia at the onset of the disease
- 4. Promoting quality of care at home
- 5. Promoting the dignity and autonomy of people with dementia at the end of their lives Our timing for 2003 was targeted at identifying the funds for our activities, developing the first two programmes and establishing the working groups for the other programmes and I can confirm with deep satisfaction that we were successful in all three areas. A small delay made it impossible to organise the first meetings of our working groups in December 2003, but instead they took place in January and February 2004.

This success is clearly a result of the good collaboration between Alzheimer Europe and its member organisations, but is also due to the growing involvement of experts via our working groups and our Expert Advisory Panel. Without the support of these experts, we would have similarly have been unable to finish our European Commission funded project on the rarer forms of dementia which constituted another highlight of 2003.

Finally, our organisation is particularly grateful for the continued support of Janssen-Cilag, Lundbeck, Merck Sharpe & Dohme and Pfizer, who generously contributed to our business plan activities and without whom we would have been unable to look back on another year of growth for our organisation.

Jacques Selmes van den Bril Chairperson

# 2. Executive summary

### In 2003, Alzheimer Europe

- Strengthened its contacts with the scientific community through the establishment of an Expert Advisory Panel and through its continued collaboration with the European Alzheimer's Disease Consortium and Interdem
- Improved its information exchange through the publication of quarterly updates and a complete overhaul of its Internet site
- Contributed to the European discussions on the review of the pharmaceutical legislation, on animal research and stem cell research
- Carried out an extensive survey of the services provided by national Alzheimer associations and an inventory of the regional organisations of its members
- Surveyed its members on their views on whether to disclose a diagnosis of dementia to the person him/herself
- Established working groups and started the literature search for three of its business plan programmes
- Participated in two projects of the European Alzheimer's Disease Consortium

- Continued its collaboration with the European Federation of Neurological Associations and was represented by its Executive Director on the patient advisory group of the British Medical Journal and the working group with patient organisations of the European Medicines Evaluations Agency
- Supported the creation of the European Patients' Forum and was elected to its Executive at its inaugural meeting
- Finalised its European Commission funded project on "Rare forms of dementia"
- Organised a successful conference in Thessalonica (13-15 June 2003)



# 3. Our core objectives

As set out in its business plan, Alzheimer Europe is an interface between national member organisations and European structures in order to represent the interests of people with dementia and their carers, to promote information exchange and to develop policy.

# 3.1. Representing views

As set out in the business plan, Alzheimer Europe carried out a survey of its member organisations in which 26 of the 31 member organisations participated. The first results of the study were presented at the Annual General Meeting and the Annual Conference in Thessalonica (June 2003), as well as the Annual Meetings of the French and Irish Alzheimer's associations. A report is currently being drafted presenting the results of the survey and giving an overview of the contributions of the various Alzheimer associations. It is hoped that the report will be adopted by the Board of Alzheimer Europe in 2004 and published shortly afterwards.

Contacts with the European institutions continued in 2003 and Alzheimer Europe was actively involved in various activities of the European Patients' Forum, as well as the European Federation of Neurological Associations and the Executive Director of Alzheimer Europe chaired a meeting in the European Parliament on stroke.

In order to strengthen its contacts with the scientific and medical community, Alzheimer Europe set up an Expert Advisory Panel with experts in four areas. For this, Alzheimer Europe has secured the participation of renowned experts in these fields who will be able to advise the organisation including to provide input in discussions with the European institutions.

Alzheimer Europe also continues its collaboration with the European Alzheimer's Disease Consortium and has recently established contacts with Interdem. Alzheimer Europe develops the Internet sites of both these organisations of professionals in the field of dementia research and care.

Finally, Alzheimer Europe has continued its collaboration with Alzheimer's Disease International and aims at establishing a formal co-operation with ADI through a partnership agreement. Similar partnership agreements will be drawn up with European professional organisations, such as the European Federation of Neurological Societies or the International Psychogeriatrics Association.

# 3.2. Information exchange

Alzheimer Europe produced quarterly updates focusing on the activities of Alzheimer Europe and its member organisations, relevant European developments and information on scientific news about Alzheimer's disease.

The Internet site (www.alzheimer-europe.org) was completely overhauled using a content management system allowing easier updates of the Internet site. All information previously collected in Alzheimer Europe projects is now available and can be downloaded from the English Internet site. Furthermore, the English Internet site includes all news which is included in the quarterly updates. The other language versions do not contain the same depth of information, as not all information is available in all other European languages. Nevertheless, the information collected through the

Care Manual project has been made available in other languages, as well as the recommendations of Alzheimer Europe with regard to the legal rights of people with dementia. The Internet sites in Spanish, Portuguese, French, Italian and Dutch thus provide general information on Alzheimer's disease, as well as useful tips for carers on how to deal with or, where possible prevent, certain situations.

The Alzheimer Europe Intranet was integrated into the Internet site and can be accessed via this site. Furthermore, the databases on conferences, members and useful links have been connected to the Internet site, ensuring that the information is always up-to-date and takes into account the latest changes.

# 3.3. Developing policy

Alzheimer Europe set up a Public Affairs Working Group to follow relevant European developments. The working group is made up of the policy officers of the various member organisations and will advise the organisation in the development of policy positions.

With regard to the development of policies on legislative proposals discussed within the European institutions, Alzheimer Europe was actively involved in the drafting of positions by the European Patients' Forum and the European Federation of Neurological Associations on the Commission review of the pharmaceutical legislation. Since the chapter on information to patients was rejected by both Parliament and the Council of Ministers, Alzheimer Europe will devel-

op a position on this issue in order to influence a new round of discussions at a very early stage.

Alzheimer Europe was also in charge of coordinating a campaign of the European Patients' Forum which resulted in the European Parliament adopting an amendment to the 2004 budget granting core funding for the Forum.

Currently, the organisation is also following the discussions on animal research and will develop a position. Furthermore, the organisation has started a consultation process on stem cell research and will attempt to develop a position in 2004.

# 4. The business plan programmes

# 4.1. BP 1 – Alzheimer associations

The first business plan priority aims at ensuring that people with dementia and their carers are referred to Alzheimer associations.

In order to show the variety of services that are provided by Alzheimer associations, Alzheimer Europe carried out an inventory of its member organisations as indicated above. The initial findings of the survey indicate that the 28 national Alzheimer association who took part in the survey:

- Represent 1.132 regional branches
- Have 108,421 members
- ▶ Employ 2,911 staff members
- Run 698 support groups for carers of people with dementia, 85 support groups for people with dementia and 565 training sessions
- Operate 169 day care centres, 107 home care services and 3 long-term care services
- Contributed 69,125.266 Euro for the support of people with dementia and their carers in 2001

At the same time, Alzheimer Europe also carried out an inventory of the regional organisations of the national organisations and in 2004, Alzheimer Europe will look into how best to present these addresses on the Alzheimer Europe Internet.

A report on best practices in the field of communication and collaboration between Alzheimer associations and national scientific societies will be completed in 2004. Further financial support for this programme was secured from the Pfizer

Foundation.

## 4.2. BP 2 – Advance directives

The second business plan programme is dedicated to the promotion of the autonomy of people with dementia through the right to an early diagnosis and the recognition of advance directives,

In 2003, Alzheimer Europe carried out a survey of its member organisations to discover their views on the disclosure of a diagnosis of dementia to the person. When analysing the responses, it was clear that the vast majority (over 80%) of the 28 participating associations felt that a diagnosis should either always be given to the person or should only be withheld under exceptional circumstances. Among those exceptional circumstances, the associations mentioned the possibility of the person explicitly refusing to know the diagnosis or being unable to understand the diagnosis due to the advanced stage of the disease. The survey constituted the first time that carers' associations were asked to develop their views on this topic which is much debated by professionals in the field.

In 2003, Alzheimer Europe started a literature search, as well as a legal update on the subject of advance directives and disclosure of diagnosis. Finally, the

Board also set up the working group for the programme which consists of the following members:

- Peter ASHLEY (United Kingdom)
- Holger BAUMGARTNER (Austria)
- ▶ Dorthe BUSS, (Denmark)
- ▶ Elaine GADD (United Kingdom)
- Alan JACQUES (United Kingdom)
- ▶ Nicole KERSCHEN (Luxembourg)
- Anna MÄKI-PETÄJÄ (Finland)

A further representative will be included to represent the Latin legal and cultural tradition and the working group shall be chaired by Alan JACQUES; the representative of the Board of Alzheimer Europe.

Further funding for this programme was secured from Fondation Médéric Alzheimer and though the start of the project was slightly delayed, the production of the legal update as well as the position paper on advance directives should be finalised by the end of 2004 as planned.

# 4.3. BP 3 – Counselling and support

The third business plan programme focuses on improving the support and counselling of carers of people with dementia at the onset of the disease.

As foreseen in the initial timing, the activities for this programme were limited to the setting up of a working group consisting of the following representatives of the member organisations of Alzheimer Europe:

- Patrice ALLARD (France)
- Antonia CROY (Austria)
- ▶ Pierluigi DE BASTIANI (Italy)

- Sabine JANSEN (Germany)
- Mireille ELSEN (Luxembourg)
- Alicja SADOWSKA (Poland)
- Micheline SELMES (Spain)

A first meeting of the working group will be scheduled at the beginning of 2004, where the working method and time table will be agreed upon. The production of the deliverables is expected for 2005 and 2006 as initially planned.

# 4.4. BP 4 - Care at home

With its fourth business plan programme, Alzheimer Europe aims at promoting quality of care at home. As with the third programme, the activities were limited, as planned, to the establishment of the working group and the start of the literature search. The following representatives of the member organisations of Alzheimer Europe are included in the working group:

- Marco BLOM (Netherlands)
- Sirkkaliissa HEIMONEN (Finland)
- Sabine HENRY (Belgium)
- Angela KEEGAN (Ireland)
- Majken PLOBY (Sweden)
- Eugen STEFANUT (Romania)

Mary MARSHALL, Director of the Dementia Services Development Centre at the University of Stirling has also agreed to take part in the working group, which will be chaired by Angela KEEGAN.

A first meeting of the working group will be programmed for the beginning of 2004, where a working method and time table will be agreed upon. The production of the deliverables is expected for 2006 as initially planned.

# 5. Networking

# 5.1. European Alzheimer's Disease Consortium (EADC)



Alzheimer Europe continued its participation in the European Alzheimer's Disease Consortium alongside a number of highly respected research centres active in the dementia field and took part in the two 2003 meetings organised by EADC in Liège and Stockholm.

In particular, Alzheimer Europe is involved in two EADC projects to represent the views of people with dementia and their carers:

▶ ICTUS: The impact of treatment with anticholinesterase inhibitors on Europeans with Alzheimer's disease, which is a prospective two year observational study which coordinates the centralisation of patient data available within the study's individual centres. Its primary objective is to determine whether treatment changes the pattern of institutionalisation.

▶ DESCRIPA: Development of screening guidelines and diagnostic criteria for pre-dementia Alzheimer's disease. The primary goal of the project is to reach an evidence-based European consensus on the identification of subjects with Alzheimer's disease in the pre-dementia stage.

# 5.2. European Federation of Neurological Associations (EFNA)



Alzheimer Europe continued its collaboration with the European Federation

of Neurological Association and at EFNA's Annual General Meeting in Brussels, the Executive Director of Alzheimer Europe was re-elected as its Secretary General.

Alzheimer Europe participated in a number of EFNA's initiatives, such as the study day on "informed patients" dedicated to examining the Commission review of the pharmaceutical legislation and its provisions on information to patients and a Commission organised conference on "Brain Research in Europe". Through his collaboration on the EFNA Board, Jean

Georges was also appointed to the patient advisory group of the British Medical Journal and the working group with patient organisations of the European Medicines Evaluations Agency (EMEA).

The EMEA group addresses patient-specific questions such as:

- Pharmacovigilance and reporting of adverse drug reactions
- Accessibility and readability of patient information leaflets
- Transparency and dissemination of information on prescription medicines to patients

# 5.3. European Patients' Forum



Alzheimer Europe actively supported the creation of the European Patients' Forum and was one of the 12 patient associ-

ations which formally joined the organisation at its inaugural meeting on 31 January 2003.

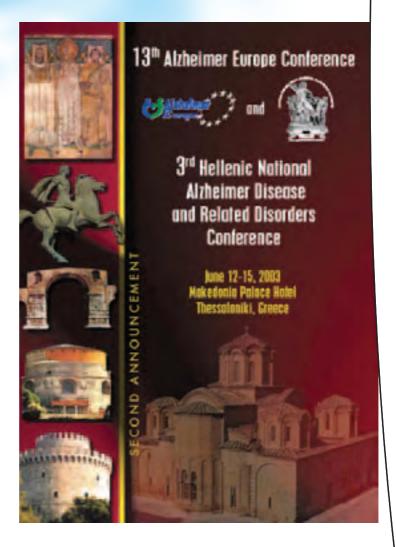
The main objectives of the Forum are:

▶ To facilitate an open and inclusive Patients' Forum enabling ALL pan-European patients' groups to exchange information and points of views in the area of EU Health Policy and all other EU initiatives of interest or concern to patients

- ▶ To share health experiences and examples of good practice in order to strengthen the role and voice of European patient organisations
- To offer the views of patients, as stakeholders in the European healthcare debate, by means of a broad, truly representative and independent patient group resource

- ▶ To provide a forum for patients' organisations to develop common positions on European health policy issues and to lobby on behalf of those organisations, giving them a central position in the provision of healthcare in Europe
- To become the natural first point of reference for the European Commission and other European institutions when seeking the opinions of patients and/or when seeking to consult patient groups
- To co-operate in the formation and execution of joint projects aimed at improving health outcomes and the quality of life of European patients

At the inaugural meeting, the founding members of the Forum also elected an Executive to lead the organisation for two years and Jean Georges, the Executive Director of Alzheimer Europe, was amongst those elected to the EPF Executive together with Rodney Elgie, President, Arjen Broekhuizen, Vice-President, Christoph Thalheim, Treasurer, Bernd Arents, Deidre O'Connell, Anders Olauson and Colin Webb, members.



# 6. Other activities

# 6.1. Project on Rare forms of dementia

In 2002, Alzheimer Europe received funding from the European Commission programme for rare diseases to carry out a project on "Rare forms of dementia". Although the literature search had already started in 2002, most of the work was carried out in 2003, with two workshops held in Luxembourg bringing together a number of European experts, namely:

- ▶ BINETTI Giuliano, Memory Clinic, Brescia, Italy
- ▶ DELACOURTE André, INSERM, Lille, France
- EVERS Clive, Alzheimer's Society, London, United Kingdom
- JELLINGER Kurt, Institute of Clinical Neurobiology, Vienna, Austria)
- KURZ Alexander, Psychiatrische Klinik der TU München, Munich, Germany
- POEL Jos van der, Alzheimer Nederland, Bunnik, Netherlands

The experts found some 30 diseases or disease groups which are rare forms of dementia or which lead to dementia in rare cases. Each of these diseases is presented on the Alzheimer Europe Internet site with a general outline of the disease, its symptoms and course, the causes and risk factors, the genetics and frequency, the diagnostic procedures, as well as

information on care and treatment, ongoing research and available services.

The expert group discussed possible ways to present these diseases, and the group ultimately opted for a classification system based on the causes of dementia, as such a system had the advantage of grouping related diseases.

The biggest group of diseases is made up of degenerative diseases, which are characterised by a progressive loss of nerve cells and synapses. For most of these diseases, the causes of this nerve loss are unknown and knowledge about possible treatment or prevention remains limited. At the same time, the group also provided information on infectious, metabolic, traumatic, toxic and cerebro-vascular diseases.

The final report on the project was submitted on time to the European Commission and Alzheimer Europe would like to take this opportunity to thank the participating experts for their contributions to the success of this project.

# 6.2. Annual Conference: "Science and Care"

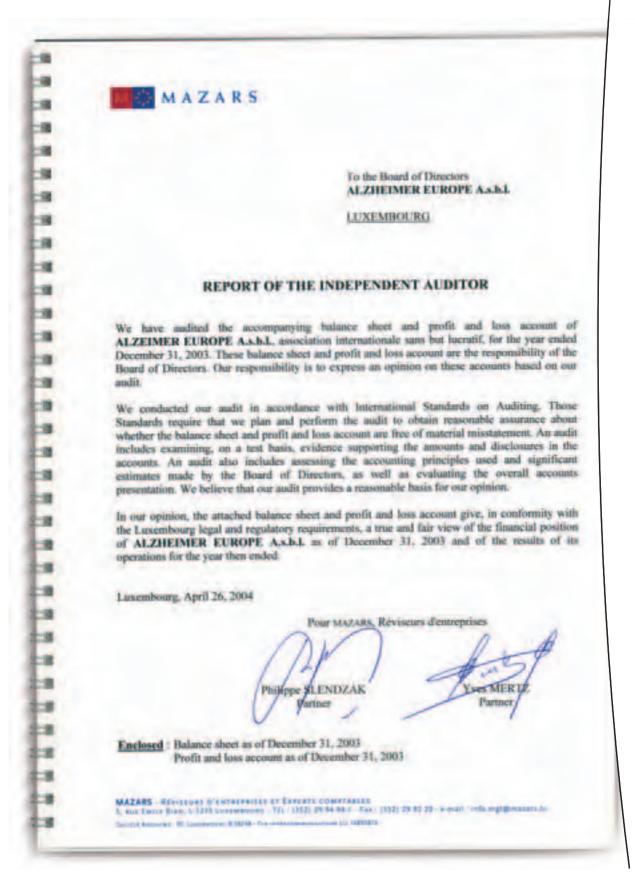
The 13th Alzheimer Europe conference took place in Thessalonica from 13 to 15 June 2003. Some 800 participants from a great number of countries and professional backgrounds took part to discuss the latest research news on the diagnosis and treatment of dementia, as well as the latest trends in the care and management of dementia.

The conference also gave an opportunity to the representatives of national Alzheimer associations to give information and updates on their activities and to exchange their experiences.

The Annual General Meeting which took place in the framework of the conference, constituted an ideal opportunity to discuss the progress of the Alzheimer Europe business plan. At the same time, the organisation adopted some statutory changes which will allow for a direct election of the Honorary Officers by the Alzheimer Europe members.

# 7. Financial report

# 7.1. Report of the independent auditor



# 7.2. Balance sheet as of December 31, 2003

	2003 EUR	2002 EUR
ASSETS		
Current assets		
Subsidies due (EC)	24,948	
Debtors	20,107	17,372
Cash at bank and on deposit	_106,044_	87,692
	151,099	105,064
Accruals	5,184	40
	156,283	105,104
LIABILITIES		
Capital and reserves		
Results brought forward	72,783	71,058
Result of the year	4,696	1,725
	77,479	72,783
Creditors		
Payments received on account	70,221	19,894
Trade creditors	8,583	10,759
Other liabilities	0	1,668
	78,804	32,321
Accruals	156,283	105,104

# 7.3. Profit and loss account – Year ended December 31, 2003

	2003 EUR	2002 EUR
Support and revenue Subsidies from the EC	62,844	20,316
Other operating income Sponsorship Sponsorship received on account Co-financing in kind Membership fees AE Conference Publication sales and royalties Donations Internet services Project participation Other operating revenue	152,172 - 70,221 110,140 40,875 10,303 4,920 4,523 3,480 1,622 11,230	132,204 - 15,260 94,014 44,375 1,048 1,100 1,437 2,775 14,479
External charges External experts Equipment & Leasing Travel expenses Accommodation expenses Office rent and associated costs Communication costs Publication and Information material Office stationery and related costs Other costs Membership fees	- 116,160 - 28,243 - 26,177 - 23,775 - 20,317 - 17,870 - 7,816 - 4,637 - 2,916 - 925	- 105,085 - 5,511 - 20,347 - 15,132 - 19,798 - 27,377 - 17,176 - 3,679 - 1,337 - 640
Staff costs Wages and salaries Social security costs	- 61,756 - 16,838	- 62,755 - 17,309
Interest receivable and similar income	1,060	1,969
Interest payable and similar charges	- 822	
	4,696	1,725

# 7.4. Acknowledgements

Alzheimer Europe would like to thanks the following individuals, organisations and companies for their invaluable support in 2003.

### PLATINUM DONORS AND SPONSORS (Donations and sponsorship from 50,000 €)

Alzheimer Europe is grateful to **Association Luxembourg Alzheimer** and the **Luxembourg Ministry for Family** for the secondment of the Executive Director of Alzheimer Europe and the office space they make available to the organisation free of charge.



Alzheimer Europe gratefully acknowledges the financial support of the **European Commission** under its programme for rare diseases for the 2003 activities of Alzheimer Europe for its project on "rare forms of dementia".

# GOLD DONORS AND SPONSORS (Donations and sponsorship between 20,000 € and 49,999 €)

Alzheimer Europe is grateful to **Janssen-Cilag** and **Lundbeck** which generously agreed to support the activities Alzheimer Europe will carry out in the framework of its business plan in 2003.





Alzheimer Europe gratefully acknowledges the support of the **Pfizer Foundation** which generously agreed to support Alzheimer Europe in the setting up of an inventory gathering the addresses of all national and local Alzheimer associations. This project is the first priority of the Alzheimer Europe business plan.



### SILVER DONORS AND SPONSORS (Donations and sponsorship between 5,000 € and 19,999 €)

Alzheimer Europe is grateful to **Merck Sharpe & Dohme** and **Pfizer Europe** which generously agreed to support the activities Alzheimer Europe will carry out in the framework of its business plan in 2003.





### BRONZE DONORS AND SPONSORS (Donations and sponsorship between 1,000 € and 4,999 €)

Alzheimer Europe is grateful to **Mazars** for having carried out the audit of the 2002 financial accounts of the organisation free of charge.



Alzheimer Europe gratefully acknowledges a generous donation of the **European Investment Bank**.



### OTHER DONORS (Donations under 1,000 €)

Alzheimer Europe is grateful to the following individuals and companies who have donated to the organisation in 2003:

- Ms. Alison Hazel (USA), in loving memory of Mrs. Geets, Merksem, Belgium
- ▶ Dexia Banque Internationale à Luxembourg
- Lombard International Assurance S.A.
- SNS Bank
- ▶ Thompson Finance S.A.

# 8. Annex I: The member organisations of Alzheimer Europe

# 8.1. Full member organisations



### **Austria**

Alzheimer Angehörige Austria Obere Augartenstraße 26-28 A-1020 WIEN

Tel: +43-1-332 51 66 Fax: +43-1-334 21 41 alzheimeraustria@via.at www.alzheimer-selbsthilfe.at



### Belaium

For the Flemish-speaking part:
 Vlaamse Alzheimer Liga
 Stationstraat 60-62
 B-2300 TURNHOUT

 Tel: +32-14-43 50 60
 Fax: +32-14-43 76 54
 vlaamsealzheimerliga@skynet.be
 www.alzheimer.be

► For the French- and German-speaking parts:
Ligue Alzheimer
Clinique le Perî
4bis, Montagne Ste. Walburge
B-4000 LIEGE
Tel: +32-4-225 87 93
Fax: +32-4-225 86 93
henry.sabine@skynet.be



www.alzheimer.be

### Bulgaria

Alzheimer Bulgaria 14, Paisii Hilendarsky Str. BG-6100 KAZANLAK Nadia Azmanova@hotmail.com



### Cyprus

Pancyprian Alzheimer Association Stadiou Street 31A CY-6020 LARNACA Tel: +357-4-62 71 04 Fax: +357-4-62 71 06 alzhcyprus@yahoo.com



### **Czech Republic**

Česká alzheimerovská spolecnost Centre of Gerontology Šimùnkova 1600 CZ-182 0 0 PRAGUE 8

Tel: +420-2-86 88 36 76 Fax: +420-2-86 88 27 88 Petr.Veleta@gerontocentrum.cz www.gerontocentrum.cz



### **Denmark**

Alzheimerforeningen Sankt Lukas Vej 6,1 DK-2900 HELLERUP Tel: +45-39-40 04 88 Fax: +45-39-61 66 69 post@alzheimer.dk www.alzheimer.dk



### **Finland**

Alzheimer-keskusliitto Luotsikatu 4 E FIN-00160 HELSINKI Tel: +358-9-622 62 00 Fax: +358-9-62 26 20 20 varpu.kettunen@alzheimer.fi www.alzheimer.fi



### France

Association France Alzheimer 21, Boulevard Montmartre F-75002 PARIS

Tel: +33-1-42 97 52 41
Fax: +33-1-42 96 04 70
directeur@francealzheimer.org
www.francealzheimer.org



### Germany

Deutsche Alzheimer Gesellschaft e.V. Friedrichstr. 236 D-10969 BERLIN

Tel: +49-30-25 93 79 50 Fax: +49-30-31 50 57 35 info@deutsche-alzheimer.de www.deutsche-alzheimer.de



### Greece

Greek Association of Alzheimer's Disease and Related Disorders (GAADRD) Charisio Old People's Home Terma Dimitriou Charisi – Ano Toumba GR-543 52 THESSALONIKI

Tel: +30-2310-92 58 02 Fax: +30-2310-90 90 00 info@alzheimer-hellas.gr www.alzheimer-hellas.gr



### Hungary

Memory Foundation Pf. 105 H-1277 BUDAPEST Tel: +36-1-325 62 99

Fax: +36-1-325 62 99 memoryfound@freemail.hu



### **Iceland**

F.A.A.S. Austurbrún 31 IS-104 REYKJAVÍK Tel: +354-533-10 88 Fax: +354-533-10 86 faas@alzheimer.is www.alzheimer.is



### Ireland

The Alzheimer Society of Ireland Alzheimer House 43, Northumberland Avenue IRL-DÚN LAOGHAIRE, CO. DUBLIN Tel: +353-1-284 66 16 Fax: +353-1-284 60 30 info@alzheimer.ie

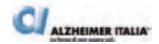


www.alzheimer.ie

### Italy

Associazione Italiana Malattia di Alzheimer Ripa di Porta Ticinese 21 I-20143 MILANO

Tel: +39-02-89 40 62 54 Fax: +39-02-89 40 41 92 aimanaz@tin.it www.alzheimer-aima.it



Federazione Alzheimer Italia Via Tommaso Marino, 7 I-20121 MILANO Tel: +39-02-80 97 67 Fax: +39-02-87 57 81 info@alzheimer.it

www.alzheimer.it



### alzheimer

### Luxembourg

Association Luxembourg Alzheimer B.P. 5021 L-1050 LUXEMBOURG Tel: +352-42 16 76-1 Fax: +352-42 16 76-30 info@alzheimer.lu

www.alzheimer.lu



### **Netherlands**

Alzheimer Nederland Kosterijland 3 Postbus 183 NL-3980 CD BUNNIK Tel: +31-30-659 69 00 Fax: +31-30-659 69 01 info@alzheimer-ned.nl www.alzheimer-ned.nl



### Norway

Nasjonalforeningen Demensforbundet Oscargt. 36 A Postboks 7139 Majorstua N-0370 OSLO Tel: +47-23 12 00 00

Fax: +47-23 12 00 00 Fax: +47-23 12 00 01 post@nasjonalforeningen.no www.nasjonalforeningen.no/demens



### Poland

Polskie Stowarzysszenie Pomocy Osobom z Chorobą Alzheimera ul. Hoza 54/1 PL-00-682 WARSAW Tel: +48-22-622 11 22 Fax: +48-22-622 11 22 alzheimer\_pl@hotmail.com www.alzheimer.pl



### **Portugal**

Associação Portuguesa de Familiares e Amigos dos Doentes de Alzheimer Av. Ceuta Norte, Quinta do Loureiro, Lote 1, lojas 1 e 2 P-1350-410 LISBOA Tel: +351-21-61 04 60 Fax: +351-21-61 04 69 alzheimer@oninet.pt www.alzheimerportugal.org



### Romania

Societatea Alzheimer Bd. Mihail Kogalniceanu 49 Sc. A, Et. 1, Apt. 8, Sector 5 RO-70603 BUCHAREST

Tel.: +40-21-334 89 40 Fax: +40-21-334 89 40 contact@alz.ro www.alz.ro



### **Slovak Republic**

Slovenská Alzheimerova spolocnost Dúbravská cesta 9 SK-842 45 BRATISLAVA Tel.: +421-2- 62 41 41 43

Tel.: +421-2- 62 41 41 43 Fax: +421-2- 62 41 41 43 alzheimer@alzheimer.sk www.alzheimer.sk



### Spain

Confederación Española de Familiares de Enfermos de Alzheimer y otras demencias c/ Pedro Alcatarena N° 3 E-31014 PAMPLONA (Navarra)

Tel: +34-948-17 45 17 Fax: +34-948-26 57 39 alzheimer@cin.es www.ceafa.org



Fundación Alzheimer España c/ Pedro Muguruza, 1, 6C E-28036 MADRID Tel: +34-91-343 11 65 Fax: +34-91-359 54 50 alzheuro@yahoo.es www.alzheimer.rediris.es



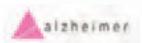
### Sweden

Alzheimerföreningen i Sverige Sunnanväg 14 S Box 4109 S-227 22 LUND Tel: +46-46-14 73 18 Fax: +46-46-18 89 76

Fax: +46-46-18 89 76 info@alzheimerforeningen.se www.alzheimerforeningen.se



Demensförbundet
Drakenbergsgatan 13 nb
S-117 41 STOCKHOLM
Tel: +46-8-658 52 22
Fax: +46-8-658 60 68
rdr@demensforbundet.se
www.demensforbundet.se



### **Switzerland**

Association Alzheimer Suisse 8, rue des Pêcheurs CH-1400 YVERDON-LES-BAINS Tel: +41-24-426 20 00 Fax: +41-24-426 21 67 alz@bluewin.ch www.alz.ch



### **Turkey**

Alzheimer Vakfi
Halaskargazi Caddesi No:115/4
HARBIYE-ISTANBUL
Tel.: +90-212-224 41 89
Fax: +90-212-296 05 79
alzheimervakfi@ttnet.net.tr
www.alz.org.tr



### **United Kingdom**

► For England, Northern Ireland and Wales:
Alzheimer's Society
Gordon House
10 Greencoat Place
UK-LONDON SW1P 1PH
Tel: +44-20-73 06 06 06
Fax: +44-20-73 06 08 08
enquiries@alzheimers.org.uk
www.alzheimers.org.uk



For Scotland:

Alzheimer Scotland – Action on Dementia 22 Drumsheugh Gardens UK-EDINBURGH EH3 7RN

Tel: +44-131-243 14 53 Fax: +44-131-243 14 50 alzheimer@alzscot.org www.alzscot.org

# 8.2. Associate organisation



### Belgium

Alzheimer Belgique a.s.b.l. Place Reine Fabiola 8 b2 B-1083 BRUSSELS

> Tel: +32-2-428 28 19 Fax: +32-2-428 28 19 alzheimer.belgique@swing.be

# 9. Annex II: The Expert Advisory Panel of Alzheimer Europe

# 9.1. Medical and research issues

Belgium: VAN BROECKHOVEN Christine

**Denmark:** WALDEMAR Gunhild

Finland: ERKINJUNTTI Timo

France: ALLAIN Hervé

DEROUESNE Christian FORETTE Françoise MOULIAS Robert ROBERT Philippe VELLAS Bruno

Italy: BRUNI Amalia Cecilia

LUCCA Ugo

Irland: LAWLOR Brian

**Germany:** STOPPE Gabriela

Netherlands: HOFMAN Albert

JOLLES Jelle SCHELTENS Philip

Romania: TARATU Nicoletta

**Switzerland:** SARTORIUS Norman

Sweden: WIMO Anders

WINBALD Bengt

Turkey: EMRE Murat

United Kingdom: BAYER Antony

BURNS Alistair McKEITH Ian

# 9.2. Care and social issues

Belgium: WUNSCH Guillaume

France: BOURIN Michel

Italy: GUAITA Antonio

**NOBILI** Alessandro

**Germany:** NEUMANN Eva Maria

**Sweden:** BECK-FRIIS Barbo

United Kingdom: BANERJEE Sube

DOWNS Murna JACKSON Jim MELZER David NOLAN Mike WOODS Bob

# 9.3. Ethical issues

France: RIGAUD Anne-Sophie

Denmark: WALDEMAR Gunhild

Italy: DEFANTI Carlo

**Germany:** MIETH Dietmar

Netherlands: BERGHMANS Ron

**OLDE RIKKERT Marcel** 

Norway: SPARR Sigurd

Sweden: NORBERG Astrid

Turkey: EMRE Murat

# 9.4. Legal issues

Austria: JAQUEMAR Susanne

**Denmark:** BUSS Dorthe

Finland: MÄKI-PETÄJÄ Anna

**Germany:** MIETH Dietmar

Ireland: COSTELLO John

Greece: LECCA MARCATI Elenie

LEKKAS Paul

# 10. Alzheimer Europe

# **Board members**

**Chairperson:** Jacques Selmes,

Fundación Alzheimer España (Spain)

**Vice-Chairperson:** Gabriella Salvini, Federazione Alzheimer Italia (Italy) **Honorary Secretary:** Maurice O'Connell, Alzheimer Society of Ireland (Ireland)

**Honorary Treasurer**: Pekka Laine, Alzheimer Keskusliitto (Finland)

**Members** 

Ad Adriaansen Alzheimer Nederland (Netherlands)

Huguette Drera France Alzheimer (France)
Gülay Gürvit Alzheimer Dernegi (Turkey)
Sabine Henry Ligue Alzheimer (Belgium)

Alan Jacques Alzheimer Scotland – Action on Dementia (United Kingdom)

Jeannot Krecké Association Luxembourg Alzheimer (Luxembourg)
Alexander Kurz Deutsche Alzheimer Gesellschaft (Germany)

Naja Skovgaard Alzheimerforeningen (Denmark)

# Secretariat

### **Alzheimer Europe**

145, route de Thionville L-2611 Luxembourg

Tel: +352-29 79 70 Fax: +352-29 79 72 info@alzheimer-europe.org www.alzheimer-europe.org

Executive Director: Jean Georges
Communication Officer: Sandrine Lavallé
Office Manager: Claire Haigh

# 

Annual Report

IA trope Annual Report Alzheimer Europe Annual Re heimer Europe Annual Report Alzheimer Europe Annual Re

