# Alzheimer Europe \*\*

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Annual Report

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# 2002 Annual Report









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

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# 1. Preface

In many ways, 2002 was a year of transition for Alzheimer Europe. It saw the completion of a number of successful European projects, a financial reorientation of the organisation, the development of a busi-



ness plan for the organisation and, last but not least, a number of personnel changes at the level of the Board of Directors.

As I am looking back on my first year as Chairperson of Alzheimer Europe, I would therefore like to start by paying a special tribute to my predecessor, Jeannot Krecké, who chaired the organisation from 1996 to 2002. His

achievements are manifold and I would like to take this opportunity to enumerate just a few of them.

During the six years under his excellent leadership, Alzheimer Europe grew from 20 to 31 member organisations and carried out eight successful European projects with a corresponding increase in its financial capabilities. Furthermore, Alzheimer Europe gained recognition as the representative of the interests of people with dementia and their carers in the European institutions, as well as in a large number of other European organisations. What better proof to this recognition than the fact that Alzheimer Europe was granted consultative status with the Council of Europe? I am particularly pleased that Jeannot agreed to stay on the Board of Alzheimer Europe where we will be able to draw on his vast experience for the future direction of our organisation.

2002 also constituted a hiatus for Alzheimer Europe with regard to European funding. It was the first time we started the year without any specific European funding. In this context, I find it worthwhile to point out that in 1997, the funding of our European projects constituted almost 70% of the overall income of the organisation. In comparison, European funding in 2002 amounted to less than 10% of Alzheimer Europe's revenue.

Despite this pronounced decrease in European funding, the financial situation of Alzheimer Europe is healthy and we have been able to diversify our income. Our member organisations contribute to a larger extent than before and I would like to single out in particular our Luxembourg association and the Luxembourg Ministry for Family for their substantial contribution. Finally, we were also able to count on the continued financial support of Janssen-Cilag, Pfizer and Merck Sharpe & Dohme for which I would like to thank them whole-heartedly.

2002 was also the year in which Alzheimer Europe redefined its priorities. After an extensive survey of our member organisations on their evaluation of past projects and their expectations for the future, Alzheimer Europe set up a working group consisting of Pekka Laine, Harry Cayton, Jean Georges and myself to define a business plan for the organisation setting out clear priorities and programmes for the organisation for the next five years.

The adoption of our new business plan at the Annual General Meeting in Maastricht was undoubtedly the highlight of 2002. The business plan clearly defines the working philosophy of 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.

This underlying philosophy, coupled with the definition of the priorities in the five-year business plan and the corresponding budgets will contribute to a clear vision of the organisation and I am confident that we will be able to achieve the goals set out in the business plan over the coming years.

Jacques Selmes van den Bril Chairperson

# 2. Executive summary

### In 2002, Alzheimer Europe

- started a European Commission funded project aimed at developing a database with specific information on "rare forms of dementia".
- participated in a survey on the conditions of the disclosure of a diagnosis of Alzheimer's disease highlighting the considerable delay between the appearance of symptoms and a diagnosis and the lack of information provided by health professional when disclosing a diagnosis,
- further developed its Intranet with the support of the Pfizer Foundation,
- contributed to the European Parliament discussions on the review of the pharmaceutical legislation by stressing the information needs of people with dementia and their carers on new and available treatment options.
- forwarded its formal position on the Draft Additional Protocol on Biomedical Research to the Council of Europe questioning the usefulness of allowing research with people with dementia without that research having a possible benefit for the research participant,
- developed its ties with the European Alzheimer's Disease Consortium and contributed to its proposal to create a Center of Excellence under the sixth research framework programme,

- continued as an active member of the European Federation of Neurological Associations (EFNA) and saw its Executive Director elected as the EFNA Secretary General,
- contributed actively to the preparatory meetings to create a European Patients' Forum,
- collaborated with other patient organisation in the think tank of the European Federation of Pharmaceutical Industries and Associations,
- organised with Stichting Alzheimer Nederland a successful conference on "Commitment to care" in Maastricht (2 to 4 June 2002),
- adopted a new business plan for the organisation providing a definition of the core objectives and underlying philosophy of the organisation, as well as clear priorities for the next five years.



# 3. Alzheimer Europe's projects

## 3.1. Rare forms of dementia

In 2002, Alzheimer Europe was informed by the European Commission that its project on rare forms of dementia had been approved for funding. The project will consist in establishing a database which will include the following information on rare forms of dementia: disease name, synonyms, description of the disorder, symptoms, causes, epidemiological data, treatment, clinical trials, diagnostic procedures and sources for further information.

For this project, which started on 1st August 2002, Alzheimer Europe is happy to count on the expertise and advice of a working group consisting of:

- Marco Blom, Stichting Alzheimer Nederland, Bunnik, Netherlands
- ▶ André Delacourte, INSERM, Lille, France
- Clive Evers, Alzheimer's Society, London, United Kingdom
- Alexander Kurz, Psychiatrische Klinik der TU München, Munich, Germany
- Kurt Jellinger, Ludwig Boltzmann Institute of Clinical Neurobiology, Vienna, Austria
- Giuliano Binetti, Centro San Giovanni di Dio, Brescia, Italy

# 3.2. OPDAL – OPtimisation of the Diagnosis of Alzheimer's disease and related disorders

In 2002, Alzheimer Europe and ten of its member organisations took part in a survey on the conditions of the disclosure of a diagnosis of Alzheimer's disease which was supported by a grant from Janssen-Cilag. The findings were presented in a satellite symposium at the Alzheimer Europe Conference in Maastricht in which Gunhild Waldemar (Denmark), Micheline Selmes (Spain), Christian Derouesné (France) and Anthony Bayer (United Kingdom) took part.

The survey showed that a diagnosis is still made at a later stage of the disease. The delay between the moment when the family perceives that "something is wrong" and the confirmation of a diagnosis is reported to be over a year in 45% of the survey par-

ticipants. Furthermore, nearly half of the respondents said that the person with dementia would have been unable to understand the full implications of the diagnosis, which similarly suggests that the diagnosis was made at a later stage.

The survey also highlighted the lack of information provided by health professionals to carers and families. Carers clearly expressed their opinion that information on the disease provided by professionals was not sufficient and regretted in particular the small amount of time professionals dedicated to explanations.

# 3.3. Alzheimer Europe Intranet

Thanks to the support of the Pfizer Foundation, Alzheimer Europe was able to further develop its Intranet site, by:

- updating and linking the Intranet database on Alzheimer associations to the website of the organisation,
- updating and linking the Intranet database on events to the website of the organisation,
- developing a new access database for all publications, documents and videos of relevance to the member organisations, which can be linked and searched on the Intranet.
- allowing the organisation to share all internal documents (such as minutes, rules and regulations

- and other documents) directly with all the member organisations,
- developing a project database allowing member organisations to share information on relevant projects they have carried out,
- developing a links database with information on other websites of interest for people with dementia and their carers, which can be consulted on the Internet and Intranet sites of the organisation,
- developing a user-friendly chat and discussion forum for use by members of Alzheimer Europe.

# 4. European developments

# 4.1. Pharmaceutical review – Information to patients

Alzheimer Europe closely followed the discussions within the European Commission and the European Parliament on the proposed changes of the European Union's pharmaceutical review.

In May 2002, Alzheimer Europe joined a number of other organisations in signing a declaration outlining the views of patients on the proposed changes.

The declaration stated the following principles:

"European patient groups believe that ALL patients, no matter their condition, background or nationality, have a fundamental and legitimate human right of access to all kinds of information about their health, medical conditions and the availability of treatments including knowledge of the best available management for their disease. It is a question of solidarity, equity and patients' rights.

We would like to draw attention to, and agree with the assertion in the Commission's legal text that patients have a 'legitimate need' for information.

From our perspective, EU patients/citizens need factually accurate, reliable, easily understandable information to be able to make informed decisions. They need to understand their condition and do want to receive information on treatments available.

As patients, we welcome information from different

sources including the pharmaceutical industry, provided they meet the above-mentioned criteria, the ownership of the source is clearly identified and agreed safeguards are in place."

In October 2002, before the first reading of the review in the European Parliament, Alzheimer Europe joined the call of the European Federation of Neurological Associations warning against further restrictions on access to information for patients. In this call, EFNA expressed its concern that some amendments proposed by MEPs would introduce a new definition for advertising of medicinal products that would ultimately threaten the information campaigns run by patient organisations. In addition, such steps would further widen the information gap between those people who have already access to the Internet and are able to read English and those for whom no information is available in their mother tongue and who have no access to the Internet.

# 4.2. Council of Europe Draft Protocol on Biomedical Research

In October 2001, Alzheimer Europe was consulted by the Council of Europe on the Draft Additional Protocol of the Council of Europe on Biomedical Research.

On 14 January 2002, Alzheimer Europe forwarded its provisional position on the participation of people with dementia in research to the Council of Europe. While welcoming most of the clauses of the draft protocol, Alzheimer Europe questioned the usefulness of allowing research with people with dementia without that

research having a possible benefit for the research participant.

The organisation stressed that such research should be possible in the early stages of the disease when people with dementia may still be able to express their consent and also in the presence of advance directives in which people with dementia had expressed their willingness to take part in such research.

# 5. Networking

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



In April 2002, Jean Georges, Executive Director of Alzheimer Europe met with Professors Bruno Vellas and Bengt Winblad and Emma Renish MD from the European Alzheimer's Disease Consortium (EADC). This meeting took place at the fringe of the Geneva Springfield Symposium and was dedicated to exploring ways of establishing closer links between the European umbrella organisation of Alzheimer associ-

ations and the European research community. The idea that Alzheimer Europe could be an important actor for the dissemination of research results to people with dementia and carers was welcomed and the researchers of the EADC accepted the possibility of acting as a scientific advisory board to Alzheimer Europe.

Furthermore, the possibility of jointly presenting an interest for a center of excellence under the sixth research framework programme was also discussed.

# 5.2. European Federation of Neurological Associations (EFNA)



Alzheimer Europe continued to be an active member of the European

Federation of Neurological Associations and took part in a number of initiatives organised by the association, such as its public relations workshop on 13 June 2003.

A new EFNA Board was elected at the Annual General Meeting of the organisation in Vienna on 27 October

2002. At the first meeting of the new Board, Jean Georges, Executive Director of Alzheimer Europe, was elected as Secretary General of EFNA. The other positions were filled as follows:

Chairperson: Mary Baker Vice-Chairperson: Audrey Craven Treasurer: Alistair Newton

Member at Large: Hilkka Karkkainen

# 5.3. European Patients' Forum

Alzheimer Europe was actively involved in a number of initiatives dedicated to creating a common voice for patients' and carers' organisations in Europe.

Thus, the organisation was represented at a meeting organised by the European Commission on 18 July 2002, at which the organisations agreed on principle to the creation of a European Patients' Forum and set out the following objectives:

- ▶ To facilitate an open and inclusive Patients Forum enabling ALL Pan-European patient groups to exchange information and points of view 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 Patients' Organisations,
- To offer external stakeholder views in the European health care debate an independent patient group resource,

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

The organisations present also discussed a number of criteria that patients' organisations should fulfil in order to become full members of the Forum. By and large, the organisations accepted the criteria that had been developed by

Alzheimer Europe and that were presented at the meeting by its Executive Director, Jean Georges, namely:

- ▶ Legitimacy: European patients' organisations should have statutes registered in one of the member states of the European Union. In case the organisation is not registered in an EU Member State, additional information needs to be provided demonstrating EU focus and activities,
- As regards representation: European patients' organisations should have members in more than half of the member states of the European Union.
- Democracy: European patients' organisations should have governing bodies which are elected by their members,
- Accountability: Statements and opinions of European patients' organisations should reflect the views and opinions of its membership and consultation procedures with the membership should be put in place,

Transparency: European patients' organisations should disclose their recourses of funding and publish their audited financial accounts.

In November 2002, a second meeting of patients' organisations (including Alzheimer Europe) was organised to continue the discussions on the creation of a European Patients' Forum.

The organisations present reiterated their commitment towards the creation of such a Forum, which would allow patient organisations to share their experiences and to develop joint positions towards the European institutions.

Furthermore, draft statutes and rules and regulations were discussed which should be formally adopted at the launch meeting of the European Patients' Forum in January 2003.

# 5.4. European Federation of Pharmaceutical Industries and Associations (EFPIA)

Alzheimer Europe continued its active involvement in the EFPIA think tank which brings together representatives of pharmaceutical companies and of patients' organisations to discuss European issues of interest to these two stakeholders in the health care debate. In particular, the think tank discussed the respective views of patients and industry on the proposed

Commission review of the EU pharmaceutical legislation and in particular the provisions with regard to information to patients.

# 6. Other activities

# 6.1. Annual conference: "Commitment to care"

From 2 to 4 June 2002, Stichting Alzheimer Nederland hosted the 12th Alzheimer Europe Conference in Maastricht under the title "Commitment to care".

Researchers and representatives of Alzheimer associations from a great number of European countries used the opportunity to exchange ideas and experiences. The first day was dedicated to the Annual General Meeting of Alzheimer Europe and useful workshops for staff and volunteers of Alzheimer associations. While this meeting served mainly to discuss and adopt the new business plan of the organisation, it was also the occasion for the elections of the new Board of the organisation.

The Annual General Meeting unanimously adopted the proposal of the newly elected Board and nominated Jacques Selmes (Spain) as its new Chairperson,

Gabriella Salvini (Italy) as Vice-Chairperson, Maurice O'Connell (Ireland) as Honorary Secretary and Pekka Laine (Finland) as Honorary Treasurer.

Other members of the Board are: Ad Adriaansen (Netherlands), Huguette Drera (France), Gülay Gürvit (Turkey), Sabine Henry (Belgium), Alan Jacques (United Kingdom), Jeannot Krecké (Luxembourg), Alexander Kurz (Germany) and Naja Skovgaard (Denmark).

The Annual General Meeting was followed by the main conference and the next two days gave an overview of interesting research developments in the treatment and care of people with dementia.



An undoubted highlight of the instructive conference was a contribution by Peter Ashley from the United Kingdom, who shared his personal experience of having been diagnosed and living with Lewy Body Dementia. His presentation reminded all present of the need to listen to and include people with dementia in the activities of Alzheimer associations, as well as in policy and service development.





# 6.2. The Alzheimer Europe business plan

In 2001, a working group (consisting of Jacques Selmes, Harry Cayton, Pekka Laine, Jean Georges) was set up to develop a business plan for the organisation. This group met several times in 2002 and consulted with the members to ensure that the proposed priorities of the business plan coincide with their expectations.

At its Annual General Meeting in Maastricht on 2 June 2002, Alzheimer Europe adopted the business plan developed by the working group. This business plan, which covers the activities of the organisation from 2002 to 2006, sets out three main core objectives for Alzheimer Europe, namely:

- to improve the information exchange between Alzheimer Europe, its member organisations and European structures,
- to develop policy statements and
- to represent the views of people with dementia and their carers.

The mission statement resulting from these three core objectives defines the role of Alzheimer Europe as 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 business plan also clearly sets out the main aim of the organisation which is "to enhance the dignity, respect and self-determination of the person with dementia and his/her family throughout the course of the disease".

Based on this main claim, the business plan sets out five programmes:

- To ensure that people with dementia and their carers are referred to Alzheimer associations when receiving a diagnosis (No diagnosis of Alzheimer's disease should be disclosed without the address of an Alzheimer or dementia association).
- ➤ To promote the autonomy of people with dementia through the right to an early diagnosis and the recognition of advance directives (Every person with Alzheimer's disease in an early stage should be informed about the possibility of legally expressing his/her wills for the future).
- To improve the support and counselling of people with dementia at the onset of the disease (No diagnosis of Alzheimer's disease without access for the fanily to information, support and counselling),
- To promote quality of care at home (People with dementia and their carers have the right to lead their lives as normally as possible) and
- To promote the dignity and autonomy of people with dementia at the end of their lives (A consensual approach to end-oflife issues is clearly needed).

# 7. Financial report

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# 7.1. Report of the independent auditor



To the Board of Directors
ALZHEIMER EUROPE A.s.b.l.

LUXEMBOURG

### REPORT OF THE INDEPENDENT AUDITOR

We have audited the accompanying balance sheet and profit and loss account of ALZEIMER EUROPE A.s.b.l., association internationale sans but lucratif, for the year ended December 31, 2002. These balance sheet and profit and loss account are the responsibility of the Board of Directors. Our responsibility is to express an opinion on these accounts based on our audit.

We conducted our audit in accordance with International Standards on Auditing. Those Standards require that we plan and perform the audit to obtain reasonable assurance about whether the balance sheet and profit and loss account are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the accounts. An audit also includes assessing the accounting principles used and significant estimates made by the Board of Directors, as well as evaluating the overall accounts presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the attached balance sheet and profit and loss account give, in conformity with the Luxembourg legal and regulatory requirements, a true and fair view of the financial position of **ALZHEIMER EUROPE A.s.b.l.** as of December 31, 2002 and of the results of its operations for the year then ended.

Luxembourg, May 23, 2003

Pour MAZARS, Réviseurs d'entreprises

Philippe SLENDZAK Partner ves MERT Partner

Enclosed: Balance sheet as of December 31, 2002

Profit and loss account as of December 31, 2002

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SOCIÉTÉ ANONYME - RC LUXEMBOURG B 56248 - TVA INTRACOMMUNAUTAIRE LU 16893816

	2002 EUR	2001 EUR
ASSETS	2011	2011
Current assets		
Debtors	17,372	38,426
Subsidies due (EC)		36,000
Cash at bank and on deposit	87,692	50,029
	105,064	124,455
Accruals	40	80
	405 404	404 505
	105,104	124,535
LIABILITIES		
Capital and reserves		
Results brought forward	71,058	62,017
Result of the year	1,725	9,041
	72,783	71,058
Creditors		
Payments received on account	19,894	32,982
Trade creditors	10,759	19,012
Other liabilities	1,668_	1,483
	32,321	53,477
Accruals	105,104	124,535

	2002 EUR	2001 EUR
Support and revenue Subsidies from the EC	20,316	90,000
Other operating income Sponsorship Sponsorship received on account Co-financing in kind Membership fees Donations Publication sales and royalties Internet services Project participation AE Conference Other operating revenue  External charges External experts Publication and Information material Travel expenses	132,204 - 15,260 94,014 44,375 1,100 1,048 1,437 2,775 14,479 - 105,085 - 17,176 - 20,347	91,345 33,175 122,283 44,500 9,753 102,458 1,575 10,000 5,000 4,369 - 162,483 - 90,445 - 37,693
Communication costs Accommodation expenses Office rent and associated costs Interpretation/Translation Office stationery and related costs Leasing Membership fees Other costs Alzheimer Europe Award	- 27,377 - 15,132 - 19,798 - - 3,679 - 5,511 - 640 - 1,337	- 24,124 - 19,830 - 19,340 - 1,881 - 9,681 - 4,705 - 845 - 3,094 - 4,878
Staff costs Wages and salaries Social security costs	- 62,755 - 17,309	- 100,671 - 26,888
Interest receivable and similar income	1,969	2,629
Interest payable and similar charges	- 586	- 1,487
	1,725	9,041
Income Expenses	298,457 - 296,732	517,086 - 508,045

# 7.4. Acknowledgements

Alzheimer Europe would like to thank the following individuals, organisations and companies for their invaluable financial support in 2001.

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

- ► Association Luxembourg Alzheimer (L)
- Ministère de la Famille, de la Solidarité Sociale et de la Jeunesse (L)



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

- ► European Commission (EU)
- Janssen-Cilag (B)
- Pfizer Europe (B)
- Pfizer Foundation (US)
- ▶ Weber Shandwick Adamson (B)









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

▶ Merck Sharpe & Dohme (B)



### BRONZE DONORS AND SPONSORS (Donations and sponsorship between 100 € and 4,999 €)

- Bank of Bermuda (L)
- ▶ San Paolo Bank (L)
- ► Mazars (L)

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

# 8.1. Full member organisations



### Austria

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### Germany

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### Greece

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www.ceafa.org

### Spain

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alzheimer@cin.es



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### Turkey

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muratemre@superonline.com



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► 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:

www.alzscot.org

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

# Associate member organisations

### 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

### Ireland

European Institute of Women's Health 33 Pearse Street IRL-DUBLIN 2

Tel: +353-1-67 15 69 1 Fax: +353-1-67 15 66 2 info@eurohealth.ie www.eurohealth.ie

# 9. Annex II: Alzheimer Europe publications

# Annual report

The annual reports of the organisation can be ordered free of charge from Alzheimer Europe:

- Annual report 2001
- Annual report 2000
- Annual report 1999
- Annual report 1998
- ▶ Annual report 1997/96

### Care manual

The Care manuals are destined for family members and people taking care of a person with Alzheimer's disease or a related dementia. The manual provides general information on dementia and Alzheimer's disease, as well as more specific information about symptoms and how to cope. Currently, the following language editions are available: Danish, French, German, Greek, Italian, Portuguese, Turkish.

All these Care manuals can be ordered from Alzheimer Europe or from the concerned member organisations. They are sold for  $\leq 10$ , but please allow for  $\leq 2.5$  postage costs, if you are living in Europe and  $\leq 5.5$  postage costs if you are living outside Europe.

### Children's book

The Children's book relates a story of the daily life of a family in which the grandmother is suffering from Alzheimer's disease. The story is portrayed through the eyes of one of the grandchildren. It is targeted at children from 9 to 11 years of age.

Currently, the following language editions are available: Danish, Dutch, French, German, Greek and Italian

All these books can be ordered from Alzheimer Europe or from the concerned member organisations. They are sold for  $\leqslant 5$ , but please allow for  $\leqslant 2.5$  postage costs, if you are living in Europe and  $\leqslant 5.5$  postage costs if you are living outside Europe.

# Conference proceedings

### 1st Alzheimer Europe Forum Proceedings

"The future of Alzheimer's disease and dementia in Europe: Hopes and fears about the development of anti-dementia drugs", Brussels, BELGIUM – 1999, 54 pages

### 2nd Alzheimer Europe Forum Proceedings

"The legal rights of people with dementia", Luxembourg, LUXEMBOURG - 2000, 80 pages

### **3rd Alzheimer Europe Forum Proceedings**

"Equality of access to care and treatment", Brussels, BELGIUM – 2001, 50 pages

These proceedings can be obtained from Alzheimer Europe for  $\leq$  5 per copy. Please allow for  $\leq$  2.5 postage costs, if you are living in Europe and  $\leq$  5.5 postage costs if you are living outside Europe.

# Position papers

### Position paper 1

Recommendations on how to improve the legal rights and protection of adults with incapacity due to dementia – 2001, 12 pages

### Position paper 2

Guidelines on the use of various measures designed to restrict liberty of movement – 2001, 8 pages

### **Position paper 3**

Advance directive (living will) - 2001, 8 pages

These three position papers are available in the following languages: Danish, Dutch, English, Finnish, French, German, Greek, Portuguese, Spanish and Swedish.

They can be obtained from Alzheimer Europe for  $\in$  1.5 per copy. Please allow for  $\in$  1 postage costs, if you are living in Europe and  $\in$  1.5 postage costs if you are living outside Europe. If you are ordering multiple copies, please contact the Alzheimer Europe secretariat for the postage costs.

# 10. Alzheimer Europe

# 10.1. 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 Stichting 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)

# 10.2. Secretariat

### **Alzheimer Europe**

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

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