

Alzheimer Europe

Annual Report 2023

Alzheimer Europe Annual Report 2023



2000 Annual Report

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We acknowledge the financial support of Janssen-Cilag which has made the publication of this Annual Report possible.

1. Preface

I ended my introduction to the 1999 annual report on a sombre note. At that time, we were confronted with financial difficulties due to a steady decline in European funding and a substantial budgetary deficit as a consequence.

For this reason, I am particularly glad to be able to present this year's report on a much more optimistic note. In 2000, we were able to identify new funding for the organisation and I would like to thank in particular our Luxembourg member organisation, Association Luxembourg Alzheimer, and through them, the Luxembourg Ministry for Family for their financial support.



Also, we were able to gather the representatives of four pharmaceutical companies (Aventis, Janssen-Cilag, Novartis and Pfizer) around one table and to convince them of the importance of a strong European organisation to defend the interests of people with dementia and their carers.

This combined financial support allowed us to improve the image of Alzheimer Europe and to raise the issue of dementia within the European institutions and the Council of Europe. The continuation of our quarterly newsletter further contributed to better inform decision makers about the activities of our organisation, as well as our member organisations about relevant European developments.

While work continued on our various European projects, such as our Intranet and our study on equality in

the provision of care at home (EPOCH), the highlight of last year was undoubtedly our work on the promotion of the legal rights and protection of people with dementia.

The work carried out under the two Lawnet projects is truly impressive. It is the first time, that all relevant legislation affecting people with dementia has been gathered and translated, allowing researchers and associations of people with disabilities to compare the various national systems.

Also, our attempt to develop recommendations on how to improve the rights of people with dementia proved highly successful. The consensus reached between national associations was truly astounding considering the differing legal systems, but also the different roles of doctors and families in the various countries involved.

For me, the adoption of the recommendations at the Annual General Meeting of the organisation proved how far Alzheimer Europe had matured beyond the simple exchange of information and experiences between national organisations. These recommendations will form the basis for effective and truly representative actions by Alzheimer Europe to make the views of people with dementia and their carers heard in Europe.

Jeannot Krecké
Chairperson

2. Alzheimer Europe's European projects

As in the past years, Alzheimer Europe has been active in developing projects, which could be carried out with the support of the European Commission. The projects which we worked on in 2000 fall under three different Commission programmes, namely:

- ▶ Actions in favour of people suffering from neurodegenerative diseases, more particularly Alzheimer type (DAT) and related disorders, and their (informal) carers;

- ▶ Preparatory measures combating and preventing discrimination;
- ▶ Measures to achieve equality between men and women.

2.1. Lawnet

The first Lawnet project was finalised in 1999 and consisted of an extensive inventory of all legislation affecting people with dementia and their carers. This project made us aware of the differences between the various national systems and the importance of developing recommendations on how to promote the legal rights and protection of people with dementia. Thanks to continued funding from the European Commission, an expert group was set up with representatives from our member organisations in Austria, Finland, Greece, Portugal, Spain and the United Kingdom (Scotland). In four meetings, they discussed at length possible recommendations and were able to reach a very broad consensus on most of the issues discussed. We were also happy to have a representative of the Council of Europe present at the various meetings organised by Alzheimer Europe.

On 23 September 2000, the 2nd Forum of Alzheimer Europe was dedicated to the presentation of the work carried out by the expert group. The three main round-table discussions focused on guardianship systems, restrictions of liberty of movement and bioethical issues, the main subjects studied by the expert group. The various presentations of the meeting were published and the proceedings can be ordered from the Alzheimer Europe office.

As a next step, the expert group presented its work at the Annual General Meeting of the organisation in Munich on 15 October 2000. After a discussion of the various recommendations, the represented organisations formally adopted the recommendations with Norway and Sweden abstaining and the Alzheimer's Society of the United Kingdom (England, Northern Ireland and Wales) expressing a reservation with regard to some of the recommendations. On the whole, the project proved highly successful, as it constitutes the first attempt by a European organisation to reach a consensus on much debated issues. As a result of the work, the following documents can be ordered from Alzheimer Europe:

- ▶ Recommendations on how to improve the legal rights and protection of adults with incapacity due to dementia;
- ▶ Guidelines on the use of various measures designed to restrict liberty of movement;
- ▶ Advance directive (living will).



2.2. Intranet

In 2000, Alzheimer Europe also continued the development of its Intranet site. A steering group consisting of representatives of Alzheimer Europe's member organisations from Finland, Germany, Ireland, Luxembourg, the Netherlands, Romania and the United Kingdom (England, Northern Ireland and Wales) met on four occasions to test and improve the various sections of the Intranet. The Intranet attempts to increase the information exchange between Alzheimer Europe and its national associations, but also between national associations themselves. It has also been successfully used in co-

ordinating other European projects run by Alzheimer Europe.

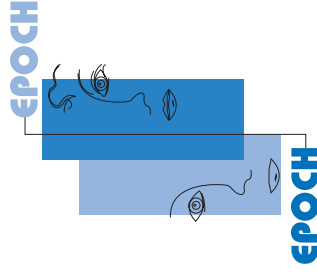
The various sections provide common databases on publications on dementia, on relevant conferences and meetings and on useful addresses, as well as communication tools, such as chat and discussion forums. Over the coming years, this tool will be further developed in order to provide national Alzheimer associations with an updated and easy-to-use information source.

2.3. Equality in the Provision of Care at Home (EPOCH)

In 2000, Alzheimer Europe also received funding from the Social Affairs and Employment DG of the European Commission to investigate the gender imbalance related to the task of caring for someone with dementia.

This project, which will be finalised in 2001, will be carried out in close collaboration with participants from our member organisations in Belgium, Denmark, Germany, Iceland, Ireland, Italy, Luxembourg, Norway and Spain.

In the course of 2000, an extensive survey was developed which will be distributed in the participating countries in order to discover in how far factors such as availability, perceived suitability, willingness, social pressure, support from others and sense of duty influence people to take on the task of caring. Particular attention will be paid to those areas, where men and women differ in their responses. The questionnaires will be evaluated in 2001. On the basis of those results, the organisation will produce a report and develop recommendations.



3. European developments

2000 proved to be another year of outreach for the organisation, as Alzheimer Europe succeeded in further strengthening its contacts with the European Commission and the European Parliament, as well as with the Council of Europe.

Thanks to the financial support of four companies

3.1. Contacts with the European Commission and European Parliament

In particular, Alzheimer Europe was able to meet with representatives of the Directorate Generals for Employment and Social Affairs, Education, Health and Consumer Protection and Research to discuss the existing funding possibilities and to inform the Commission officials about the activities and projects

of Alzheimer Europe. Similarly, Alzheimer Europe regularly informed the members of the European Parliament Committee on the Environment, Public Health and Consumer Policy of its actions and activities.



3.2. The European funding crisis and the public health programme

From a financial point of view, 2000 constituted a difficult moment, since the previous funding of specific Alzheimer projects came to an end. Despite continued support from the European Parliament, the Commission had reallocated the funds to the general health budget line.

Together with all its member organisations, Alzheimer Europe was able to raise awareness of this problem by writing to national health ministers as well as members of the European Parliament. This resulted in a meeting between representatives of Alzheimer Europe (J. Krecké and J. Georges) with Commissioner Byrne and we were particularly grateful for the support that we received from Karla Peijs, MEP and Dana Scallon, MEP at this meeting. We were also heartened by Commissioner Byrne's statement, in which he stated, "I understand and

recognise the valuable and honourable cause your organisation is working for, and the difficulty you have in fund-raising. The Commission is in agreement with you and the European Parliament on the need to improve the quality of life of the persons suffering from Alzheimer's and related diseases, and of the persons who care for them." Furthermore, our organisation was able to gather support from a great number of Members of the European Parliament who insisted that the issue of neuro-degenerative disorders should be more adequately addressed in the new programme of Community action in the field of public health.

4. Networking

3.3. Council of Europe

As an NGO with consultative status at the Council of Europe, Alzheimer Europe actively participated in the quarterly NGO meetings which were held in Strasbourg and in particular the "Health" sub-grouping. Furthermore, the organisation is involved in the special working group, which deals with "palliative care".

The organisation also contributed a written response to the Council of Europe's "White paper on the protection of the human rights and dignity of people suffering from mental disorders, especially those placed as involuntary patients in a psychiatric establishment".

In the framework of its Lawnet project, representatives of the Legal Rights Department of the Council of Europe were able to play an active role, inform the project participants about the work of their organisation, as well as contribute to a better understanding of the various subjects under discussion.

Finally, we were particularly pleased that the 2nd Alzheimer Europe Forum on "The legal rights of people with dementia" in Luxembourg on 23 September 2000 was held under the auspices of Mr. Walter Schwimmer, the Secretary General of the Council of Europe.

2000



As in the previous years, we were active in strengthening our contacts with other European organisations, such as the Platform of European Social NGOs, EuroLinkAge and the European Public Health Alliance, of which Alzheimer Europe is a member.

The organisation also took part in various activities organised by the European Federation of Pharmaceutical Industries (EFPIA) and the European Federation of Neurological Societies (EFNS).

4.1. European Disability Forum

Alzheimer Europe also continued its involvement within the European Disability Forum, which underwent considerable changes in 2000. Thus, the organisation redefined its membership criteria by insisting that member organisations should be administered by

people with disabilities or by parents of people with disabilities. We were particularly pleased that we complied with all the new requirements and that we were able to continue as a full member organisation.

4.2. European Federation of Neurological Association (EFNA)

Another important development in 2000 was the creation of the European Federation of Neurological Associations. Aware that most people with neurological disorders face similar problems, such as stigma, lack of awareness and limited treatment possibilities, a number of associations met on several occasions in order to create a European platform to defend these interests and to raise awareness of the prevalence of neurological disorders in our societies.

Alzheimer Europe was involved in these discussions from the beginning and we were pleased to be among the founding members of a new organisation, the objectives of which are:

- ▶ To improve the quality of life of those affected by neurological disorders;
- ▶ To promote rapid and accurate diagnosis, appropriate treatment, rehabilitation and care for people with neurological illness;
- ▶ To promote better access to information which is accurate and understandable;
- ▶ To promote public awareness and understanding of neurological conditions;
- ▶ To eliminate prejudice and stigma associated with neurological diseases;
- ▶ To increase priority given to neurology by policy and decision makers and by health care providers.



5. Other activities

5.1. Annual Conference: “Bridges into the Future”

The 10th Anniversary Meeting of Alzheimer Europe “Bridges into the Future” took place in Munich from 12 to 15 October 2000 and presented a great opportunity for the 600 participants to look back on 10 years of activities of the European Alzheimer movement, to learn of the latest research in care and treatment and to gain insight into what the future might



hold for the management of Alzheimer's disease.

The success of the meeting would have been impossible without the dedication and organisational skills of the "Deutsche Alzheimer Gesellschaft" which we would like to pay a special tribute to.

5.2. Workshop on Quality of Life in Madrid

In the framework of its co-operation with the pharmaceutical industry, Alzheimer Europe organised a multidisciplinary workshop on "The quality of life of people with dementia" in Madrid on 4 September 2000. During the one-day meeting, various experts presented their views on the concept of quality of life and the application of this concept to people with dementia. During the ensuing workshop, participants from

Alzheimer associations, policy makers, scientists and representatives of the pharmaceutical industry reached a high degree of consensus and agreed on the usefulness of the concept, as an adequate measurement of quality of life would allow for better evaluation of service provision and treatment efficacy in the field of dementia.

6. Financial report



MAZARS & GUERARD (LUXEMBOURG)
Réviseurs d'entreprises

To the Board of Directors
ALZHEIMER EUROPE a.s.b.l.
LUXEMBOURG

REPORT OF THE INDEPENDENT AUDITOR

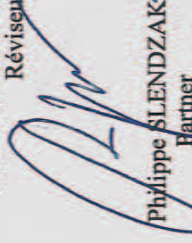
We have audited the accompanying balance sheet and profit and loss account of **ALZHEIMER EUROPE a.s.b.l.**, association internationale sans but lucratif, for the year ended December 31, 2000. These balance sheet and profit and loss account are the responsibility of the Board of Directors. Our responsibility is to express an opinion on these accounts based on our audit.

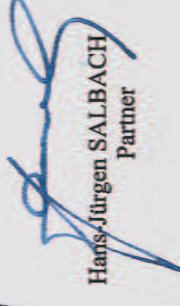
We conducted our audit in accordance with International Standards on Auditing. Those Standards require that we plan and perform the audit to obtain reasonable assurance about whether the balance sheet and profit and loss account are free of material misstatement. An audit includes examining, on a test 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, 2000 and of the results of its operations for the year then ended.

Luxembourg, June 8, 2001

MAZARS & GUERARD (LUXEMBOURG)
Réviseurs d'entreprises


Philippe SLENDZAK
Partner


Hans-Jürgen SALBACH
Partner

Enclosed : balance sheet as of December 31, 2000
Profit and loss account as of December 31, 2000

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6.2. Balance sheet as of 31 December 2000

	2000 EUR	1999 EUR
ASSETS		
Current assets		
Subsidies due (EC)	30.000	13.382
Other debtors	4.820	32.610
Cash at bank and on deposit	134.856	35.603
	169.676	81.595
Accruals	-	2.717
	169.676	84.312
LIABILITIES		
Capital and reserves		
Results brought forward	59.833	125.021
Result of the year	2.184	(65.188)
	62.017	59.833
Creditors		
Payments received on account	33.175	-
Trade creditors	72.599	20.294
Other liabilities	1.855	2.934
	107.659	23.228
Accruals	-	1.251
	169.676	84.312

6.3. Profit and loss account

	2000 EUR	1999 EUR
Subsidies from the European Commission	196.143	237.574
Other operating income		
Sponsorship	125.402	27.953
Sponsorship received on account	(33.175)	-
Co-financing in kind	67.523	-
Membership fees	22.200	18.300
Donations	15.481	1.726
Publication sales and royalties	2.663	74.270
Internet services	1.487	4.462
Project participation	-	5.882
Other operating income	17.066	9.542
External charges		
External experts	(67.688)	-
Publication and information material	(64.659)	(82.719)
Travel expenses	(40.088)	(50.690)
Communication costs	(34.958)	(50.237)
Accommodation expenses	(27.974)	(34.539)
Office rent and associated costs	(19.521)	(20.908)
Office stationary and related costs	(9.614)	(6.452)
Interpretation / Translation	(8.594)	(19.426)
Leasing	(2.282)	(2.080)
Membership fees	(1.303)	(1.357)
Other costs	(1.208)	(1.376)
Staff costs		
Wages and salaries	(110.104)	(139.082)
Social security costs	(26.213)	(37.463)
Interest receivable and similar income	2.240	2.020
Interest payable and similar charges	(640)	(588)
	2.184	(65.188)

7. Meetings

Annex 1:

7.1. Statutory Meetings

10-12 March	2000:	Executive meeting in Luxembourg
17 June	2000:	Board Meeting in Luxembourg
3 September	2000:	Board meeting in Madrid
12 October	2000:	Executive meeting in Munich
13-14 October	2000:	Alzheimer Europe Conference "Bridges into the future" in Munich
15 October	2000:	Annual General Meeting in Munich
17 December	2000:	Executive Meeting in Luxembourg

7.2. Workshops and Seminars

1-2 March	2000:	Lawnet workshop in Luxembourg
9-11 June	2000:	Lawnet workshop in Luxembourg
7-9 July	2000:	Intranet workshop in Delft/Bunnik (Netherlands)
3 September	2000:	Multidisciplinary workshop on "The quality of people with dementia" in Madrid
23 September	2000:	2nd Alzheimer Europe Forum "The legal rights of people with dementia" in Luxembourg
11 October	2000:	EPOCH workshop in Munich
14 October	2000:	Intranet workshop in Munich

7.3. Meetings with member organisations

24-25 January	2000:	Meeting with Alzheimer Society of Ireland in Dublin
26-27 January	2000:	Meeting with Alzheimer's Society in London
14 February	2000:	Meeting with Association France Alzheimer in Strasbourg
9 March	2000:	Visit by Gabriella Salvini, Chairperson of Federazione Alzheimer Italia
21 March	2000:	Meeting with French-speaking organisations in Paris
23 March	2000:	Meeting with Czech Alzheimer's Society in Prague
5 April	2000:	Visit by Marc Wortmann, Executive Director of Stichting Alzheimer Nederland
10-12 April	2000:	Meeting with Fundación Alzheimer España in Madrid
16 May	2000:	Meeting with French speaking organisations in Paris
2-4 June	2000:	Meeting with German speaking organisations in Berlin
11 September	2000:	Visit by Radka Arnold of the Bulgarian Alzheimer association
30 September	2000:	Meeting with Greek Association for Alzheimer's Disease and Related Disorders in Thessaloniki

7.4. Meetings with European officials

9 February	2000:	Meeting with DG Research in Brussels
10 February	2000:	Meeting with DG Employment and Social Affairs in Brussels
10 February	2000:	Meeting with DG Education in Brussels
11 February	2000:	Meeting with DG Health and Consumer Protection in Luxembourg
15 February	2000:	Hearing on non discrimination in Brussels

6.4. Acknowledgements

Alzheimer Europe would like to thank the following individuals, organisations and companies for their invaluable financial support in 2000.

BRONZE DONORS AND SPONSORS

(Donations between 100 € and 5,000 € and sponsorship between 1,000 € and 10,000 €)

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(Donations between 5,001 € and 10,000 € and sponsorship between 10,001 € and 20,000 €)

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- Sponsors:
 - Association Luxembourg Alzheimer
 - Ministère de la Famille, de la Solidarité Sociale et de la Jeunesse



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(Donations between 10,001 € and 25,000 € and sponsorship between 20,001 € and 50,000 €)

- Sponsors:
 - Aventis (USA)
 - Janssen-Cilag (B)
 - Novartis (CH)
 - Pfizer (B)



PLATINUM DONORS AND SPONSORS

(Donations over 25,000 € and sponsorship over 50,000 €)

- Sponsor:
 - European Commission



8. Annex 2: Alzheimer Europe's member organisations

16	February	2000:	Meeting with European Agency for Special Education Needs in Brussels
29	February	2000:	Meeting with DG Research
11	May	2000:	Conference of European Agency for the Evaluation of Medicinal Products (EMA) in London
6	September	2000:	Meeting with Commissioner David Byrne
7.5. Other meetings			
17	January	2000:	Meeting with PanEuroLife in Luxembourg
21	January	2000:	Meeting with Centre de Recherche Public-Santé in Luxembourg
7	February	2000:	Meeting with Janssen-Cilag in Brussels
8	March	2000:	Pfizer Workshop in Brussels
16-19	March	2000:	Meeting of Platform of European Social NGOs in Lisbon
27	April	2000:	Meeting with Luxembourg Ministry of Health in Luxembourg
5-7	May	2000:	Meeting of European Multiple Sclerosis Platform in Lisbon
10	May	2000:	Meeting of European Federation of Pharmaceutical Industries and Associations (EFPIA) in London
15	May	2000:	Meeting of European Federation of Neurological Associations (EFNA) in London
15	June	2000:	Presentation of ASTRID Guide in Northampton (UK)
16	June	2000:	Meeting with Aventis, Janssen-Cilag, Novartis and Pfizer in Luxembourg
15-18	July	2000:	ADI Conference in Washington (USA)
13-14	September	2000:	EFPIA Meeting in Brussels
25	September	2000:	Meeting with PanEuroLife in Luxembourg
1	October	2000:	Meeting on Psychiatry in South-Eastern Europe in Thessaloniki
5-6	October	2000:	Janssen-Cilag Workshop in Antwerp
24	November	2000:	Meeting with Fondation Médéric Alzheimer in Paris



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