

ANNUAL REPORT

1996-1997

Alzheimer Europe

Annual Report (1996-1997)

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1 Preface

The Annual General Meeting in Helsinki, which took place on 1 October 1997, gave me the opportunity to look back on my first year as Chairperson of Alzheimer Europe.

Over this year, Alzheimer Europe has matured from a small, rather informal assembly of European carers associations into a fully functioning European organisation with a budget that has increased more than tenfold over the corresponding period.

It is with great satisfaction that I have noted the growing enthusiasm of Alzheimer associations for our common European platform and I would like to take this occasion to thank all of them for their active co-operation and support.

I would also like to pay tribute to the European Parliament for having introduced a specific budget-line for measures destined at improving the quality of life of Alzheimer sufferers and their family carers. This budget-line enabled Alzheimer Europe to introduce and fund the different European projects we are currently involved in: the Helpline and ERICA projects, as well as our European Carers' Manual. As a matter of fact, our thanks also go to the responsible services in the European Commission that supported the projects of Alzheimer Europe for its third consecutive year now and to Pfizer Pharmaceutical Group for their generous support of our Website.

A lot of work has been put into these different projects, yet at the same time Alzheimer Europe has also established a closer network with its member organisations and other institutes and associations active in the field of Alzheimer's disease and related disorders.

In this respect, I would like to pay a final tribute to the work of our Secretary General, Jean Georges and all his staff who largely contributed to the growing success of Alzheimer Europe.

Jeannot Krecké
Chairperson

2 Alzheimer Europe

Alzheimer Europe is a Non-Governmental Organisation aimed at raising awareness of all forms of dementia through co-ordination and co-operation between Alzheimer organisations in Europe, as well as organising support to the sufferers of the disease and their carers.

After the Annual General Meeting in Helsinki (1 October 1997), Alzheimer Europe now has members in all the countries of the European Union, as well as in Poland, Romania and Switzerland. All in all, 22 organisations from 18 countries participate in the activities of Alzheimer Europe. Close contacts have also been established with the Norwegian, Icelandic, Czech and Turkish Alzheimer associations.

As set out in the statutes, the aims of Alzheimer Europe are:

- ?? to promote by co-operation the support of patients suffering from Alzheimer's disease, or related disorders, and their carers;
- ?? to raise awareness of Alzheimer's disease by the medical profession, paramedical organisations, social services and the European Commission and European Parliament;
- ?? to exchange information between the national Alzheimer societies;
- ?? to develop models for improved care of Alzheimer patients;
- ?? to increase political advocacy in each of the member countries and centrally with the European Commission and Parliament;
- ?? to promote the training of personnel caring for Alzheimer patients;
- ?? to encourage and support research and the advance of knowledge into the cause, early diagnosis, treatment and prevention of Alzheimer's disease;
- ?? to promote world-wide co-operation with other organisations having the same or similar objectives and in particular Alzheimer's Disease International.

3 Introduction

The office of Alzheimer Europe became operational on 1 November, 1996 after the acceptance of the ERICA project by the European Commission.

This office situated at 145, route de Thionville, L-2611 Luxembourg was involved in the co-ordination of the general administrative tasks of Alzheimer Europe and the follow-up of the different European projects that Alzheimer Europe is involved in.

Currently the following people are employed by Alzheimer Europe:

- Jean Georges, project manager
- Dianne Gove, project assistant (Manual)
- Sandrine Lavallé, project assistant (ERICA)
- Marie-Laure Tortel, project assistant (EACH)
- Helena Hernberg, secretary
- Christiane Kummer, part-time secretary

4 Alzheimer Telephone Helpline

In the course of 1996, Alzheimer Europe was involved in the Telephone Helpline project, which was completed at the beginning of 1997. A manual with helpful organisational details has been elaborated. This manual will be presented at the Annual General Meeting in Helsinki and circulated to all Alzheimer Europe member organisations. Also, a version of the manual has been made available on Alzheimer Europe's Internet site.

The following AE member organisations were involved in the development of the manual:

Alzheimer Angehörige Austria (Austria)
Alzheimer Liga (Belgium)
Alzheimer Keskusliitto (Finland)
Federazione Alzheimer Italia (Italy)
Association Luxembourg Alzheimer (Luxembourg)
Alzheimerstichting (Netherlands)
Alzheimer Scotland – Action on Dementia (Scotland)
Fundación Alzheimer España (Spain)
Alzheimer’s Disease Society (United Kingdom)

5 ERICA

5.1 Objectives

5.1.1 Coordination

- ? The co-ordination of the setting up of organisations in countries and regions with limited facilities;
- ? The co-ordination of relations between countries of the European Economic Area and Eastern European countries;
- ? The role of intermediary between the different European associations in view of the setting up and coordination of common and transnational projects.

5.1.2 Information

- ? The setting up an inventory of existing European organisations operating in the field of Alzheimer’s disease and related disorders with regard to their structure, services and mode of financing;
- ? The collection of information and statistical data on projects and relevant models already available in Europe and other countries and this in collaboration with Alzheimer’s Disease International;
- ? Arrangements for the translation of texts of general interest in the field of Alzheimer’s disease and related problems.

5.1.3 Technical means

- ? The carrying out of preparatory work in view of the setting up of a computer network, which will, on the one hand, assemble the associations active in the field of Alzheimer’s disease and, on the other hand, be used to distribute the information via INTERNET to the general public, professionals, political and administrative bodies.

5.2 Work done so far

Alzheimer Europe has continued its work on establishing an inventory of the services and structure of its member organisations. At the same time, Alzheimer Europe has been in contact with a great number of other organisations that are active in the field.

A wide-ranging documentation centre has been established by contacting the different member organisations of Alzheimer Europe and other organisations active in the field.

Since the beginning of the project though, the main activities of Alzheimer Europe in this particular project centred on the setting up of the Alzheimer Europe Internet site. The site was first opened on a temporary basis in February 96 and after the suggestions of our member organisations were taken into account, it was officially launched at the beginning of June and registered in all the important search engines on the Net. Also we developed an extensive network of sites which refer surfers to the Alzheimer Europe website which can be consulted under: <http://www.alzheimer-europe.org>.

The Alzheimer Europe Internet site currently provides information on:

1. Alzheimer Europe, its objectives, statutes and Board members
2. Member organisations of Alzheimer Europe, their contact addresses and, where applicable, their e-mail addresses and Internet sites
3. European projects Alzheimer Europe is involved in
4. General information on Alzheimer's disease and related disorders
5. Information on upcoming conferences, symposia and other meetings
6. Links to other Internet resources dedicated to Alzheimer's disease and related disorders

Alzheimer Europe has contacted all its member organisations and offered to establish a rudimentary Internet site for them. So far, Alzheimer Europe has thus developed Internet sites for the Luxembourg and the Romanian association.

5.3 Future plans

The collected information will be made available to all member organisations of Alzheimer Europe, as the relevant information on all collected publications is foreseen to be disseminated on the computer network that will link all the different organisations.

Also a searchable database will be set up on Alzheimer Europe's Internet site in order to allow surfers to find the desired information and to be directed to the Alzheimer organisation which has published the relevant information.

Finally Alzheimer Europe plans to make its Internet site available in other languages, starting with French and German with other languages to follow.

6 Self-help Manual

6.1 Objectives

Preparation of a manual on Alzheimer's disease destined for members of the family and people taking care of a person with Alzheimer's disease or a related disorder. As the Manual is intended for a fairly wide audience, it will be written and presented in a style which will ensure that it is accessible and understandable to everyone. The aim of the project is to analyse all the existing information and data from the different national organisations and to produce a document summarising this information. The manual will provide general information about dementia and Alzheimer's disease as well as more specific details about symptoms and advice to carers on how to cope. The manual will be written in English and translated into the other eleven official languages of the European Union.

6.2 Participating organisations

Although most Alzheimer Europe member organisations participated at the first meeting organised by the European Commission, the final budget approved by the European Commission only allowed 6 member organisations to fully participate in the elaboration of the Manual.

The organisations that have been chosen represent the different regional and linguistic groups within Alzheimer Europe, whereas two more organisations have been included since their participation does not incur any substantial costs.

- Alzheimer Angehörige Austria (Austria)
- Alzheimer Liga (Belgium)
- Alzheimerforeningen (Denmark)
- Federazione Alzheimer Italia (Italy)
- Association Luxembourg Alzheimer (Luxembourg)
- Alzheimerstichting (Netherlands)
- Fundación Alzheimer España (Spain)
- Alzheimer's Disease Society (United Kingdom)

6.3 Work done so far and plans for the future

Alzheimer Europe has finished cataloguing the relevant information that already exists on the level of the different member organisations and has produced a first outline of the Manual. This outline was discussed and corrected at a first meeting that took place on 22 April in Luxembourg.

All AE member organisations have been sent the report of the meeting as well as the corrected first draft, in order to allow them to comment on the work done so far.

A second meeting was organised on 1 July, where a second draft of the Manual was presented. The more or less finalised version of the Carers Manual will be presented at the Annual Meeting of Alzheimer

Europe in Helsinki. Subsequently, the Manual will be translated into the other eleven official languages of the European Union.

7 Co-operation with other European projects

7.1 European Alzheimer Clearing House (EACH)

Alzheimer Europe was represented at all meetings of the EACH Consortium and was in charge of Workpackage 3 the objectives of which were the following:

- ? Translation and updating of workbook on the available information and documentation in different associations
- ? Feasibility study of a computer software programme for the exchange of information obtained at the different national Alzheimer helplines
- ? Report on younger Alzheimer sufferers
- ? Report on Alzheimer patients in rural areas

Currently the workbook has been finalised and EACH will take over the responsibility of having it translated.

With regard to the software programme, there has been an agreement between Alzheimer Europe and EACH that Alzheimer Europe is free to co-operate with Alzheimer's Disease Society on the development of such a programme. A first version of this programme will be presented at the Helsinki conference and could be made accessible to all Alzheimer Europe member organisations.

Finally a literature and resources study has been done in the field of young Alzheimer patients and AD sufferers in rural areas. Reports will be published giving an overview of the existing problems and the solutions or services available in different EU member states.

8 New EU-Projects

Alzheimer Europe consistently informed all member organisations about the adoption of a new budget line in the field of Alzheimer's disease and on the new call for proposals under this budget line. Organisations received this information in their national language and Alzheimer Europe offered to help organisations in filling out their application and in finding prospective partners.

In this field, Alzheimer Europe was also contacted by a large number of other associations or institutes wishing to apply for funding. In order to reply to these requests, Alzheimer Europe referred these organisations to the national associations of Alzheimer Europe, as well as to other associations active in the field.

8.1 Alzheimer Europe projects

The development of new EU-projects was one of the main tasks of the Alzheimer Europe office, as the continuation of the office to a large extent depended on this.

Before the final deadline set by the European Commission, we submitted four projects, namely:

1. Lucerne Conference
2. Lawnet
3. Helpline data sharing
4. Database on European projects

The experts committee chose only two of these projects (1 + 2) that have since been forwarded to the budgetary authority of the European Commission. A final decision on these projects is nevertheless still pending.

8.2 Association Luxembourg Alzheimer

Alzheimer Europe will also collaborate on a project developed by the Luxembourg Alzheimer association. This project consists in drafting a publication on Alzheimer's disease dedicated to a younger audience. It will be particularly directed at the children and grandchildren of Alzheimer sufferers.

8.3 University of Glamorgan

Alzheimer Europe has been invited to participate in the new project submitted by the University of Glamorgan which aims at bringing together the main projects that received funding under last year's budget-line.

The objectives of the project are as follows:

1. To examine both the policy and technical components which together have a bearing on Alzheimer's and neuro-degenerative (ND) disease sufferers and their carers.
2. Specifically, to bring together representatives of major research projects in Europe to attempt to synthesise data which is emerging on: the epidemiology of Alzheimer's and ND across Europe; social and health policy relating to sufferers and their carers; the financing of services; service delivery; and consumer viewpoints.
3. Completion of a report for the European Union which draws attention to relative strengths and weaknesses in Alzheimer's and ND developments and the areas where greater co-ordination may be required.

9 Other activities

9.1 Statutory changes

An important aspect of the work carried out by Alzheimer Europe in 1997 was the amendment of the statutes of the organisation. A complex procedure was adopted by the Board in Limerick in order to allow all organisations to participate in the discussions. Thus, a first draft was circulated with the different proposals of the Board giving the organisations the opportunity to comment on the proposed changes. At a meeting of the Management Team, these comments were taken into account and included in the second draft, which was circulated to all organisations for further amendments. The Board met a final time in Luxembourg to discuss the amendments with the organisations that had responded to the statutory changes. A final draft was then circulated for a last round of amendments. The final documents lists all received amendments and will be presented at the Annual General Meeting in Helsinki for adoption.

9.2 Public relations

One of the priorities of the Alzheimer Europe office was to improve the public image of the association. In this field further progress is needed, but so far, the following initiatives have been taken:

1. A reception for MEPs was hosted in Brussels
2. The Internet site of Alzheimer Europe was inaugurated in the presence of MEPs, representatives of the European Commission and the Luxembourg government
3. A leaflet presenting Alzheimer Europe, its members, its objectives and its projects has been produced and will be presented in Helsinki.
4. A poster presenting Alzheimer Europe has equally been produced and will also be presented in Helsinki.

9.3 Contacts with other organisations

9.3.1 Alzheimer's Disease International

Alzheimer Europe has established regular contacts with Alzheimer's Disease International (ADI) and representatives of both organisations met on several occasions. Equally both organisations keep one another informed on developments in their respective fields. As a token of this strengthened co-operation, the Annual General Meeting of Alzheimer Europe coincides this year with the International Conference of ADI. Finally, Alzheimer Europe participated in the activities which ADI organised on the occasion of World Alzheimer's Day. The ADI-Charter was sent to the chairpersons of all the political groups in the European Parliament, as well as to the members of the Public Health Committee of the European Parliament. The Charter thus received the backing of the Chairs of the Socialist and Green groups, as well as of a large number of other MEPs.

9.3.2 European Alzheimer Clearing House (EACH)

As mentioned above, Alzheimer Europe continued its co-operation in the framework of this year's EACH project. Discussions arose on the continued relationship with regard to the new project submitted by EACH.

Both organisations agreed on the need to clearly define their respective fundamental missions. The main aims of Alzheimer Europe were defined as being advocacy, the representation of AD associations on a European level and the exchange of information between these associations. The main functions of EACH are the clearing and dissemination of scientific findings in the field of Alzheimer's disease.

Alzheimer Europe is called upon to play an important role in the dissemination of EACH's findings to the national Alzheimer associations. Finally, both organisations recognised the need to keep their representative structures separate and agreed upon setting up a liaison committee between the two organisations.

9.3.3 European Disability Forum and European Regional Council

Alzheimer Europe is a member of the European Disability Forum (EDF) and is represented in the mental health sector through the European Regional Council of the World Federation for Mental Health (ERC). Therefore closer contacts have been established with both the EDF and the ERC and representatives of Alzheimer Europe participated at the annual conferences of both platforms.

10 Meetings

10.1 Statutory Meetings

20 November 1996	Board Meeting in Limerick
22 November 1996	Extraordinary Annual General Meeting in Limerick
12 December 1996	Management Team in Brussels
28 January 1997	Management Team in Brussels
30 June 1996	Board meeting in Luxembourg
27 September 1997	Board meeting in Helsinki
1 October 1997	Annual general Meeting in Helsinki

10.2 Workshops and seminars

13 December 1996	Helpline Workshop in Brussels
21 February 1997	Workshop on WP 3 (EACH) in Brussels

22 April 1997	Care Manual Workshop in Luxembourg
1 July 1997	Care Manual Workshop in Luxembourg
28 September 1997	Care Manual Workshop in Helsinki
28 September 1997	Helpline Workshop in Helsinki
28 September 1997	Workshop on Information technology in Helsinki
30 September 1997	Workshop on EU Projects in Helsinki
30 September 1997	Workshop on AD patients in rural areas (EACH) in Helsinki

10.3 Other meetings

19-20 December 1996	EACH-Consortium in Brussels
8 January 1997	Meeting with representatives from the European Disability Forum and the European Regional Council of the World Federation for Mental Health in Brussels
13-14 January 1997	Meeting with Pfizer in Rome
24 January 1997	Meeting with ADI in London
27-28 January 1997	Meeting with ADS in London
29 January 1997	Reception for MEPs in Brussels
29-30 January 1997	EACH-Consortium in Brussels
6-7 March 1997	Partners in the Healthcare Journey in Paris
8-9 March 1997	Annual Meeting of European Disability Forum in Brussels
10 March 1997	Meeting with Pfizer in Paris
13 March 1997	Meeting with Nicole Delpérée in Luxembourg
19 March 1997	Meeting with Louis Becerra in Luxembourg
20 March 1997	CJD conference in Warwick (UK)
24-25 March 1997	EACH-Consortium in Brussels
18 April 1997	Meeting of German-speaking AD associations in Stuttgart

21 April 1997	Presentation of the Alzheimer Europe Internet Site in Luxembourg
28-29 April 1997	Meeting with Alzheimerstichting in Bunnik (NL)
29-30 May 1997	EACH-Consortium in Louvain (B)
28 June 1997	Meeting with Greek representatives in Athens
7-8 July 1997	Meeting with Alzheimer Keskusliitto in Helsinki
9-10 July 1997	Congress of the World Federation for Mental Health in Lahti (SF)
14 July 1997	Meeting with Karla Peijs in the European Parliament in Strasbourg
23 July 1997	Meeting with Ligue Alzheimer in Luxembourg
11 August 1997	Meeting with ADI in London
12 August 1997	Meeting with ADS in London
4 September 1997	First Congress of the Deutsche Alzheimer Gesellschaft in Stuttgart
8 September 1997	Meeting with ADI in Brussels
9-10 September 1997	EACH-Consortium in Brussels
18 September 1997	Participation at the European Carers Study organised by the Institute of Psychiatry (The Maudsley) in Dublin
19 September 1997	World Alzheimer's Day Conference of Fundación Alzheimer España in Madrid