

ANNUAL REPORT

1997-1998

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1 Preface

The period covered in this report has proved to be another year of outreach and growth for Alzheimer Europe.

Most importantly, the membership of Alzheimer Europe has grown considerably and we are glad to see that more and more organisations share the enthusiasm for our common European platform. 1998 has thus seen Alzheimer associations from the Czech Republic, Iceland, Norway, the Slovak Republic and Turkey join the 22 organisations from 18 European countries that were already members of Alzheimer Europe.

As a matter of fact, I would like to take this occasion to thank each and every one of our member organisations for their active co-operation and support over the past year. Without their dedication, the activities of Alzheimer Europe would have been greatly reduced.

In 1998, Alzheimer Europe also finalised its work on two different European projects, which culminated in the drafting of the first European Alzheimer Manual and the development of an Internet site, which will shortly be available in the 11 official languages of the European Union.

During the same period, Alzheimer Europe also undertook work on two new projects "Lawnet" and the "Alzheimer Europe Intranet" about which you will find further information in the following chapters.

Also, Alzheimer Europe was recognised by the European Commission as a representative European Co-ordination organisation active in the field of equal opportunities for disabled people and consequently received funding which allowed us to produce our newsletter and part-finance the running of our office.

Our heartfelt thanks go to the different services of the European Commission who generously supported the activities of the association.

Yet the activities of Alzheimer Europe were not limited to the co-ordination of European projects. A working group, consisting of Jens Bruder, Harry Cayton, Harry Crielaars, Jacques Selmes and Jean Georges worked on the development of a Strategy for the European Alzheimer movement for the third millennium which was discussed at the Annual General Meeting at our highly successful Conference in Lucerne (Switzerland). This document clearly sets out the priorities for the activities of Alzheimer Europe and its member organisation and will constitute a reference document for some years to come.

Finally, I do not want to finish this introduction without thanking our Secretary General, Jean Georges, and his staff, Dianne Gove, Sandrine Lavallé and Helena Hernberg whose hard work contributed largely to the growing success of the organisation. Their dedication allows me, as Chairperson of Alzheimer Europe, to envisage the coming years with a sense of confidence.

Jeannot Krecké

2 Alzheimer Europe Strategy for the third millennium

At the Alzheimer Europe Annual General meeting in Helsinki, a working group was set up which was charged with developing a long-term strategy for Alzheimer Europe. The group, consisting of Jacques Selmes, Franz Baro, Jens Bruder, Harry Cayton, Harry Crielaars and Jean Georges met several times and presented its recommendations to the Annual General Meeting in Lucerne.

There, the group presented a Draft Declaration of the needs and rights of people with dementia and their carers, which should serve as a focus point for the work of Alzheimer Europe and its member organisations.

Furthermore, the group presented an outline of specific priority areas for the future activities of the European Alzheimer movement. The objectives singled out by the group were:

1. The recognition of Alzheimer's disease
 - a) as a disease
 - b) as a handicap
 - c) as a major health scourge
2. The recognition of the principal caregiver
3. Information and training of health professionals
4. Improvement of the legal protection of people with dementia
5. The ethical dimension of dementia
6. Increasing awareness of all forms of dementia

The document which was presented at the Annual General Meeting will be further discussed by the member organisations of Alzheimer Europe and will be formally approved at the London Conference in July 1999.

3 Disability

As a first step towards the recognition of Alzheimer's disease as a disability, Alzheimer Europe received funding by the European Commission under its program for representative co-ordination organisations active in the field of equal opportunities for disabled people.

The funding made available in this way, allowed Alzheimer Europe to continue the financing of its Secretariat and the organisation of four Board meetings of the organisation, thus further developing the information exchange between its national member organisations.

Also, the publication of the present Annual Report would have been impossible without the support of the European Commission services.

Finally, the Commission support allowed Alzheimer Europe to start the publication of a quarterly newsletter dedicated to information on the organisation and important European developments of interest to national Alzheimer associations.

4 ERICA (Euro-réseau d'information et de coordination Alzheimer)

In the framework of its 1996 programme to support measures in favour of Alzheimer sufferers and their informal carers, the European Commission financed a project of Alzheimer Europe to carry out co-ordination and information activities with the help of the latest communication technologies.

As part of this project, which was finalised in 1998, Alzheimer Europe carried out extensive inventories of the organisations active in the field and the information material which these organisations have made available to the general public.

The main activities of Alzheimer Europe though have centred on the setting up of the Alzheimer Europe Internet site (www.alzheimer-europe.org). The site will shortly be available in all eleven official languages of the European Union and currently provides information on:

1. Alzheimer's disease and related disorders in general
2. Alzheimer Europe. Its objectives, statutes and Board members
3. The member organisations of Alzheimer Europe and their contact details
4. European projects of Alzheimer Europe
5. Activities of the European institutions in the field of Alzheimer's disease, disability and public health
6. Upcoming conferences, symposia and other meetings
7. Links to other Internet resources dedicated to Alzheimer's disease and related disorders

As part of the ERICA project, Alzheimer Europe also extended its co-operation with Alzheimer associations outside the European Union. Closer contacts were made possible, which culminated in the adoption of the Alzheimer organisations of Iceland, Norway, Turkey, the Czech and Slovak Republics as new full member organisations of Alzheimer Europe at the Annual General Meeting in Lucerne.

5 Care Manual

In the process of its Care Manual project, which received funding by the European Commission under its 1996 programme, Alzheimer Europe made an inventory of relevant information targeted at carers of people with dementia available at the level of all its member organisations.

On the basis of the collected information, Alzheimer Europe then proceeded to draft a European Manual taking into account all the advice and information already available and thus producing a Carers' Manual which is as complete as possible.

The drafting of the Manual in English was finalised in 1997 with the input and co-operation of all the member organisations of Alzheimer Europe and in 1998, the Manual was translated into the other official languages of the European Union.

Currently Alzheimer Europe is studying the possibility of having the Care Manual published and the German, Danish and Greek versions should be made available shortly. Nevertheless, Alzheimer Europe is continuing its discussions with other potential sponsors for the publication of the Manual in other languages.

6 Lawnet

In 1997, Alzheimer Europe also started work on a new project, supported by the European Commission. In its Lawnet project, Alzheimer Europe will carry out a survey of the different laws of the Member States of the European Union, which bear a relevance to the protection of the rights of people with dementia.

So far, Alzheimer Europe has carried out an extensive inventory of existing legislation in the following areas:

1. Restrictions in the person's private life (autonomy, self-determination)
2. Driving (e.g. withdrawal of the driving licence, obligatory medical visits and obligatory disclosure of the diagnosis of dementia to the relevant authorities)
3. Compulsory hospitalisation
4. Different systems of protection of the person and his or her possessions (e.g. guardianship, tutors, etc.)
5. Personal rights (e.g. to vote, marry, make a will, choose one's place of residence and treatment)
6. Violence or mistreatment (e.g. the use of restraint, excessive sedation, etc.)
7. Disclosure of the diagnosis to the person with dementia and/or his or her family
8. Consent to treatment and to take part in research
9. Living wills/advance directives
10. Euthanasia/assisted suicide

A substantial amount of these laws have been translated into English, in order to allow a comparison of the different existing systems.

In the next stages, Alzheimer Europe will draft country-specific reports describing the legal protection of people with dementia. This work will then be followed by singling out best practices in this important area and the development of European guidelines to improve the legal protection systems.

7 Intranet

In December 1998, Alzheimer Europe received funding from the European Commission to develop an Intranet linking the different national Alzheimer associations which are members of Alzheimer Europe. This computer network should serve as a “common memory” where all relevant data on Alzheimer’s disease and related disorders (services, publications, videos, organisations, etc...) will be collected and, at the same time, made accessible to all participants and eventually to the general public.

Easy to use E-mail, forums and chat possibilities will further increase the communication and the exchange of ideas and experiences between family organisations in Europe.

8 Co-operation with other European projects

8.1 Association Luxembourg Alzheimer

In 1997, Association Luxembourg Alzheimer presented a project proposal to the European Commission to develop an Alzheimer brochure for children. This brochure will be targeted at children from 9 to 11 years of age and is aimed at helping them to understand more about Alzheimer’s disease and to cope with the disease of a beloved grand-parent or relative.

Alzheimer Europe was closely associated with the co-ordination of this project which led to the drafting of a brochure “Dear Grandma” which is currently being translated into the other official languages of the European Union.

8.2 Institute of Psychiatry (The Maudsley)

In 1997 and 1998, the Institute of Psychiatry carried out a cross-national analysis of the carers of people with dementia of the Alzheimer’s type and the services they require, in which Alzheimer Europe was actively involved.

The project’s aims were:

1. to describe services available to carers of people with dementia of the Alzheimer’s type (DAT) in each Member State as represented by one health district

2. to explore the relevance of these services as experienced by carers
3. to collate data from each Member State and produce a collaborative report on services that are most responsive to the needs of carers of people with DAT

Alzheimer Europe contributed a country report on Luxembourg and took part in the different discussions which took place in the framework of this project.

8.3 University of Glamorgan

During the course of the year, Alzheimer Europe also actively participated in a project of the University of Glamorgan which brought together representatives of the main research projects in Europe in an attempt to synthesise the emerging data.

As part of the project, a report will be completed which will draw attention to the relative strengths and weaknesses in developments affecting Alzheimer sufferers and the areas where greater co-ordination may be required.

Alzheimer Europe was in charge of a specific chapter of this report looking into the legal and ethical issues of importance to Alzheimer sufferers and their carers.

8.4 European Institute of Women's Health

A final project that Alzheimer Europe participated in was the REMIND (Research effort to maximise information on neurodegenerative diseases) project of the European Institute of Women's Health in Dublin. The aims of the project were:

- To identify experts in the area from all Member States
- To examine the impact of strategies
- To provide an overview of current research and literature
- To carry out an in depth examination of current service provision

In the framework of this project so far, Alzheimer Europe contributed a national report on the service provision in Luxembourg.

9 Contacts with other organisations

9.1 Alzheimer's Disease International (ADI)

The Helsinki Conference (September 1997) was organised by the Alzheimer Society of Finland (Alzheimer Keskusliitto) and co-organised by Alzheimer Europe and Alzheimer's Disease International thus underlining

the close contacts that exist between the European and International umbrella organisations of the Alzheimer self-help movement.

Since this conference, these contacts have been maintained on a regular basis with representatives of the two organisations meeting at regular intervals and participating actively in each other's Annual Meetings. In 1998, both Nori Graham and Elizabeth Rimmer from ADI took part in the Annual General Meeting of Alzheimer Europe in Lucerne, while Jeannot Krecké and Jean Georges attended the International Conference of ADI in Cochin (India).

9.2 Council of Europe

During the course of 1997 and 1998, Alzheimer Europe also established closer contacts with different services of the Council of Europe and in particular with its Directorate of legal affairs, the Working party on psychiatry and human rights, the Working party on incapacitated and other vulnerable adults and the Steering Committee on bioethics.

A representative of the Council of Europe was present at the Annual General Meeting of Alzheimer Europe in Lucerne where the Convention on Human Rights and Medicine of the Council of Europe was presented and discussed.

Alzheimer Europe was also present at a hearing of the Working Group on Human Genetics of the Council of Europe in June 1998. At this meeting, Alzheimer Europe presented its views on such issues as genetic tests, genetic counselling and genetic research.

In 1998, Alzheimer Europe also applied for the status of consultative non-governmental organisation recognised by the Council of Europe.

9.3 European Disability Forum (EDF), Mental Health Europe

As in the past, Alzheimer Europe continued its co-operation in the activities carried out by the European Disability Forum and Mental Health Europe.

9.4 European Federation of Neurological Societies (EFNS)

In 1998, Alzheimer Europe was recognised as a collaborating society of the European Federation of Neurological Societies. In this capacity, the organisation was represented at the Annual Conference of EFNS in Seville and took part in the first meeting, which the EFNS organised with European patients' organisations.

9.5 European Public Health Alliance (EPHA)

In 1998, Alzheimer Europe became a member of the European Public Health Alliance and participated in the Annual General Meeting of EPHA as well as other events, such as the Summer School on the European Public Health Policy.

Alzheimer Europe is represented in the Board of EPHA by Professor Franz Baro.

9.6 EurolinkAge

Alzheimer Europe joined EurolinkAge as an associate member in 1998 and as such will participate in the organisation's policy sub-groups on technology and on care issues.

10 Other activities

10.1 Annual Conference

One of the highlights of the activities of Alzheimer Europe in 1998 was undoubtedly constituted by the Alzheimer Europe conference in Lucerne. Masterly organised by Association Alzheimer Suisse, the Conference "Keeping in touch" was attended by over 900 participants from 22 different countries.

Over two days, the Conference was a meeting place for family carers and professional caregivers with an intensive and fruitful exchange of information, ideas and experiences.

The excellent programme, the high quality of invited speakers, the overall impeccable organisation and the warm welcome that all participants received at the Conference made it a truly enjoyable meeting and set a very high example for other conference organisers to follow.

10.2 Public relations

Over the past two years, Alzheimer Europe has grown continually and extended its contacts with other organisations active in the field of Alzheimer's disease and related disorders. Members of the European Parliament and the European Commission have been informed on various occasions of the different activities Alzheimer Europe has carried out.

This growing recognition of the organisation has also become evident in the ever growing number of requests via mail and e-mail which Alzheimer Europe receives.

With the support of the European Commission, Alzheimer Europe has started the publication of a quarterly newsletter, which has further enhanced the public image of the organisation. Over 1,200 individuals and organisations from various backgrounds currently receive the newsletter directly. The interest generated by

this newsletter has been tremendous and a large number of other organisations have asked to be included on the mailing list for this publication.

11 Meetings

11.1 Statutory meetings

1 October 1997	Annual General Meeting in Helsinki
14 January 1998	Board Meeting in Luxembourg
6 May 1998	Board Meeting in Lucerne
9 May 1998	Annual General Meeting in Lucerne
9 May 1998	Board Meeting in Lucerne
9 November 1998	Executive meeting in Brussels
26 November 1998	Board meeting in Madrid

11.2 Workshops and seminars

6 May 1998	Workshop on European projects in Lucerne
6 May 1998	Workshop on "Lawnet" in Lucerne
3 December 1997	Strategy Meeting in Brussels
13 January 1998	Strategy Meeting in Luxembourg
26 February 1998	Strategy Meeting in London
2 April 1998	Strategy Meeting in Madrid

11.3 Other meetings

14 October 1997	EACH Seminar in Stockholm
20 October 1997	Meeting with Dementia Services Development Centre (Striling)
21 October 1997	Commonwealth Meeting in Edinburgh (Alzheimer Scotland - Action on dementia)
22 October 1997	Alzheimer Forum in Neuss (Germany)

5-6 November 1997	EACH Meeting in Brussels
8 November 1997	Meeting with Institute of Psychiatry in Dublin
9 November 1997	Forum of Fundación Alzheimer España in Madrid
17 November 1997	Meeting with Association Luxembourg Alzheimer and Pfizer in Luxembourg
27 November 1997	Alzheimer Forum in Teruel (Spain)
8-9 December 1997	Meeting of German-speaking Alzheimer associations in Vienna
25 February 1998	Meeting with Alzheimer's Disease International in London
27 May 1998	Meeting with Institut démographique de Louvain in Luxembourg
8 June 1998	Hearing of Council of Europe in Strasbourg Human Rights and Biomedicine
25 June 1998	Annual General Meeting of Federazione Alzheimer Italia (Milan)
29 June-2 July 1998	Dementia Care Conference in Loughborough (UK)
29 June 1998- 2 July 1999	Summer School of European Public Health Alliance in Luxembourg
8 July 1998	Meeting with European Patients' Voice in Brussels
10 July 1998	Meeting with Association Alzheimer Suisse in Luxembourg
21 July 1998	Meeting with University of Middlesex in Luxembourg
24 July 1998	Meeting with Association France Alzheimer in Paris
28 July 1998	Meeting with Alzheimer's Disease Society (UK) in Luxembourg
29 July 1998	Meeting with European Commission and EISAI in Luxembourg
3 September 1998	Meeting with Alzheimer's Disease Society (UK) in London
4-5 September 1998	Annual General Meeting of Alzheimer's Disease Society (UK) in Belfast
11-12 September 1998	Meeting with Alzheimer Angehörige Austria in Vienna
19-25 September 1998	Annual Conference of the European Federation of Neurological Societies in Seville

21 September 1998	Meeting with European Federation of Pharmaceutical Industries and Associations (EFPIA) in Brussels
24-26 September 1998	Annual Conference of Alzheimer's Disease International in Cochin (India)
31 September- 2 October 1998	Children's brochure Meeting in Luxembourg
1 October 1998	Meeting with Ligue Alzheimer (Belgium) in Luxembourg
20 October 1998	Meeting with European Commission in Luxembourg
22-23 October 1998	Annual General Meeting of Czech Alzheimer's Society in Prague
28 October 1998	Public Hearings of the European Parliament on the future of the public health policy in the European Community
3 November 1998	"Elderly care and the Law" in Glasgow
10 November 1998	Meeting with EISAI and Association France Alzheimer in Paris
14-15 November 1998	Annual General Meeting of Alzheimer Scotland – Action on dementia in Edinburgh
13-15 November 1998	Meeting with University of Glamorgan in Cardiff
14-15 November 1998	"Remembering yesterday, caring today" in Vienna
19 November 1998	Seminar of Fundación Alzheimer España and Escuela Nacional de Sanidad in Madrid
20-21 November 1998	Media Forum "Mass longevity – a good story" in Vienna
3-4 December 1998	Children's brochure Meeting in Luxembourg
9 December 1998	Meeting with Hoechst Marion Roussel in Paris
10 December 1998	Meeting with Université Paris-Dauphine in Paris