

A BRIEF PRESENTATION TO OUR INTERNATIONAL COUNTERPARTS, CONTACTS AND FRIENDS

Contents

1. Letter from the President.
 2. The Foundation itself.
 3. The Foundation's goals.
 4. The Foundation's current projects.
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1. Letter from the President

Barcelona, Spain, March '04

Dear colleagues and friends,

In the next few pages you will find information on Spain's "Fundación para la Fibromiálgia y el Síndrome de Fatiga Crónica" (**Foundation for Fibromiálgia and Chronic Fatigue Syndrom**).

Like that of your own associations and foundations around the world, **our mission is to face these tough enemies**, CFS and Fibro. They need to be fought with weapons like generous scientific cooperation, permanent action for public and media awareness, tenacious political lobbying and private fundraising, and, above all, with true dedication to our enemy's victims.

CFS and Fibro patients deserve to be listened to, to be properly diagnosed and treated, to be understood by society and helped to endure their suffering and to fight their illness. Most unfortunately, the widespread presence of these pathologies in modern societies has **not been considered important enough** by most governments or even by the public. Because they aren't contagious, or because the visible effects are often less alarming than the ones caused by other illnesses, society has seldom taken them as what they are: **a serious, threatening and ubiquitous health problem** that forces millions to live in pain while it also consumes vast medical resources and patients' working time at a macro-economic level.

Therefore we believe that in most countries, **efforts have so far been smaller than necessary** to tackle with this problem. The pharmaceutical industry, the medical community, the health authorities, the mass media and even ourselves, the non-profit foundations and patients' organizations, we all need to rethink our strategies.

Ours is possibly one of the youngest organizations in this global battle, but we have started with resolve and momentum. One of our ambitions is to help organize a platform of CFS and Fibro associations and foundations throughout Europe and internationally. In an increasingly globalized world, our efforts will be more productive if we can coordinate ourselves to act on a supra-national level too. There are **countless transnational entities that can't be addressed just nationally**, from large pharmaceutical industries and medical research companies to global media, as well as European and other regional and worldwide decision-making bodies where our voices should be heard.

We welcome any suggestions as to how we could build a flexible, unbureaucratic and effective network together. In the meantime, we shall ourselves put forward initiatives in this way. **A yearly international congress on CFS and Fibro** could perhaps be a worthy effort. If this idea gathers support, we volunteer to host the first congress in our country.

May I also take this opportunity to invite you to Spain's first **Specialized Course on CFS and Fibromialgia**, jointly organized by us and the International University of Catalonia. It will take place in Barcelona next May, with Spanish and prestigious international experts confirmed. You will find further information on our website: **www.fundacionfatiga.org**.

I most eagerly look forward to **hearing from you** and to establish ways of further cooperation, both on a bilateral basis and toward a functioning network.

Best regards,

Anna Cuscó,
Foundation President.

2. The Foundation itself

The Foundation's main data

- **Incorporated** in 2002 as a non-profit organization under the Foundations Law (Reg. No. 1724).
- **Formally recognised** by the Government as a "Socially Beneficial Scientific Entity".
- **Officially declared** by the Health and Social Security authority as one of its civil "scientific research partners" (Parliament resolution No. 290-01317/06).
- **Tax-deductible** donation recipient under Spanish law.

The Foundation's contact data

Address: Joan Güell 128, E-08028 Barcelona, Spain.

Phone: +34.93.4190833.

E-mail: info@fundacionfatiga.org

Website: www.fundacionfatiga.org

The Foundation's Honorary President

Ms. Montserrat Caballé. A world famous opera singer, Ms. Caballé is one of Spain's most prominent and prestigious public figures. It is indeed an honour for the Foundation that Ms. Caballé has accepted our honorary presidency and keeps a permanent interest in obtaining information on our cause and progress. Her help has been crucial in the Foundation's public and media relations. Ms. Caballé is an Ambassador for UNESCO and an Honorary Ambassador for the UNO (1974). She is a

doctor honoris causa by Moscow and Valencia universities, among countless other titles and honours.

The Foundation's Board of Trustees

President:

Ms. Anna María Cuscó. Medical Doctor and Psychologist

Trustees:

Mr. Jorge Albareda. Engineer.

Dr. José Corominas. Psychiatrist.

Ms. Pilar Diaz. Lawyer.

Dr. Ferran J. García. Rheumatologist.

Dr. Joaquín Fernández. Internal Medicine MD.

Mr. Antonio Magaldi. Lawyer.

Ms. Lídia Monterde. Professor.

Dr. Violant Poca. Rheumatologist.

Mr. Xavier Roig. Economist.

Ms. Marta Rosselló. Entrepreneur.

Ms. Teresa Sol. Lawyer.

Mr. Francisco Javier Tulla. Economist.

Mr. Lluís Viguera. Economist.

3. The Foundation's goals

Scientific research

- **Advanced basic research.**
- **Clinic research.**
- **Research on diagnosis methodology.**
- **Funding of other institutions' research.**

Medical community

- **Support to Spain's first medical unit on CFS & Fibromyalgia, at a prestigious private clinic in Barcelona.**
- **Diagnosis support to discard or confirm CFS.**
- **Treatment support and second opinion.**
- **Courses and seminars.**
- **Online advanced self-course for MDs.**
- **Medical journal contributions.**
- **Fast obtention, translation and spreading of information on foreign advances in research and treatment.**
- **International dissemination of research and treatment breakthroughs produced in Spain.**

Public & mass media

- **Dissemination of facts on CFS & Fibromyalgia.**
- **Differentiation of each of these pathologies.**
- **Generation of public awareness on the cause.**

- **Generation of public solidarity with the patients.**
- **Fight against CFS social stigmatization.**
- **Intense participation in the mass media.**

Patients & families

- **Direct funding and other support to local patients' organizations.**
- **Creation and operation of systems allowing the patients' organizations to raise funds efficiently.**
- **National networking coordination for patients' organizations.**

Government

- **Strong, professionalized political lobbying in favour of adequate resources for these pathologies within the public healthcare system.**
- **Pushing for recognition of these pathologies' importance, the suffering involved and patients' rights and needs.**

4. The Foundation's current projects

Academic projects

- **Barcelona, May '04. Specialization Course on CFS & Fibromialgia jointly organized with the International University of Catalonia. Prominent specialists confirmed.**
- **Medical support website (in Spanish).**
- **Internet, April '04. Launching of the first online advanced self-course for MDs (in Spanish). For further information write to:
*curso_sfc@fundacionfatiga.org***

Public awareness and lobbying projects

- **May 12th, 2004. International Fibromialgia Day. Strong media action. Event in Barcelona.**
- **Permanent presence in the media.**
- **Preparation of a literary prize for essays by patients.**
- **Several meetings with top healthcare system politicians, both in office and shadowing.**

Direct care projects

- **Support to the country's first specialized unit assisting CFS and Fibromialgia patients, located in one of Spain's top-level private clinics, in Barcelona.**
- **Creation and operation of volunteers network to help patients.**

- **(Limited) funding for resourceless patients.**
- **Meetings with over a hundred local patients' organizations. First assembly with most of them was organized by the Foundation in October '03.**

Fund-raising projects

- **In cooperation with a prominent global bank, dissemination of FibroCARD[®], a credit card oriented to patients, relatives and friends. It generates funds for research and for each of the local patients' associations involved. The contract has been signed and the bank is starting to distribute cards. The demand from the patients' associations is overwhelming. We have negotiated that 1 % of all expenses made with the cards be secured for our cause without any additional expenses to the cardholder.**
- **Intensive conversations with various potential donors.**
- **Intensive study of Spanish and EU funds available for application.**
- **Current preparation of a business-targeted Cause-Related Marketing project including co-advertising and other inexpensive but efficient ways of support for companies willing to associate with the cause.**

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