

CONFESQ

SPANISH NATIONAL COALITION OF FIBROMYALGIA, MYALGIC ENCEPHALOMYELITIS /CFS MULTIPLE CHEMICAL SENSITIVITY AND ELECTROHYPERSENSITIVITY

1

PRESENTATION



- 1 INTRODUCTION
- 2 ME+COVID19
- 3 EUROPEAN UNION

INTRODUCTION SPAIN DATA





- FIBROMYALGIA
- CHRONIC FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS (ME)
- MULTIPLE CHEMICAL SENSITIVITY
- ELECTROHYPERSENSITIVITY

- ❖ 2004 2009: Coordinator of Fibromyalgia and Chronic Fatigue Associations
- ❖ 2009 2017: National Confederation of Fibromyalgia and Chronic Fatigue Syndrome
- 2018-present: National Coalition of Fibromyalgia, FCS/ME, Multiple Chemical Sensitivity and Electrohypersensitivity
- ❖ Member of:
 - ➤ State COCEMFE (disable people)
 - ➤ Plataforma de Organizaciones de Pacientes (POP)
 - ➤ Pain Alliance European (PAE)
 - ➤ European Network Of Fibromyalgia Associations (ENFA)
 - ▶Pain Euro-Mediterranean Coalition (PEC)

INTRODUCTION **SPAIN REPRESENTATION**



We represent 57 organizations:

- 17 Associations
- 5 Federations
- 10.000 patients associated

Agrupación de Asociaciones de Fibromialgia y Fatiga Crónica de Extremadura "Virgen de Guadalupe" (AGRAFIFEX)



níndrome

atiga

rónica-SOM

Comunidad Valenciana

fexaf

















CENTRAL DE ASTURIAS















Federación Aragonesa de Fibromialgia y Fatiga Crónica

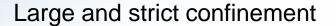




ME+COVID19







Present: de-escalated

Negative aspects

- Cancellation and delay of consultations with specialists and surgical interventions
- Stop in hospital treatments, physiotherapy and osteopathy, injections, walking...
- ME is not recognized as a risk subject
- There has not been special measures for our group, because is not been considered a risk patients

Positive aspects

Telephone medical consultations



EUROPEAN UNION



Parliamentary Committee on Petitions

(with the favorable vote of all the members of the different political groups that integrate it)

APPROVES



the resolution presented requesting additional European funding for ME/FCS research

Next step - Voting this resolution in the plenary session of the European Parliament

CONFESQ requested a meeting with MEP Jordi Cañas, Spanish spokesman for the liberal group in this petition

(LINK)

Target



Knowing what we can do to get that favorable vote

PROPOSAL FOR THE EUROPEAN UNION



MEETING RESULTS

The meeting was very interesting and, as a result, we have proposed 3 courses of action



- National campaign with politicians of the Congress and the Senate and the MEPs, to get their favorable vote
- Proposal for joint actions to the European ME/FCS Association
- Contact with researchers in order to strengthen EUROMENE (or another network) and create a strong, coherent, coordinated, participatory research network.



THANK YOU VERY MUCH!

We are going to keep in touch next week

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