

Annual activity report European Network of Fibromyalgia Associations. (ENFA)

During the year 2017 ENFA was involved in several activities related to fibromyalgia. The GA was organized in Malta during the SIP conference kindly funded by Grunenthal . Our members had the opportunity to attend the SIP conference, with all expenses covered by Grunenthal .

ENFA has organised the lunch meeting on April 12th 2017 hosted by the Cypriot Member of the European Parliament, Mr. Takis HADJIGEORGIOU with the main topic: “The position of the fibromyalgia patients in the society”. At this occasion ENFA presented the video “Monique fibromyalgie”, along with the presentations on social impact of fibromyalgia in relation to the Written declaration of Brain Mind and Pain Interest group. Special attention was given to Fibromyalgia patients and work.

Questions to the Commissioner

Fibromyalgia is a Rheumatic disease which affects mainly the muscles, the tendons and ligaments. It causes pain, bad quality of sleep, morning stiffness and fatigue, symptoms that oblige patients to leave their work and often leads to depression. Research shows that 1-3% of the general Public suffers with the disease.*In Europe 1-5 patients report unable to work and earn an income. **

In 2008, the written declaration 0069/2008 asking for the development of a strategy for recognizing Fibromyalgia as a disease was accepted by the EP.

ENFA represents patient Organizations in Europe. According to a questionnaire developed by ENFA in 2008 the percentage of patients not receiving appropriate care, amounts to 25%.

The Commission is asked:

If it has developed, and if not why, as a strategy for recognition of Fibromyalgia as a disease which is debilitating and can cause disability?

Which actions have been adopted in order to raise awareness amongst Health Professionals, patients and the public?

Why aren't the members States encouraged to promote early diagnosis and treatment?

At the meeting for all Eligible Organizations at the EMA Souzi Makri (President) represented the Organization.

Souzi Makri (President) represented ENFA at the EPF General Assembly in April 2017, in Brussels.

During the year 2016 we welcomed two more members as a Spanish member stepped in and a member from Serbia. This made a total on members of 17 from 13 different countries of which 10 are EU countries.

The board of PAE was made up by 5 board members.

Souzi Makri President

Mateja Kržan Vice-President

Jasmina Simic Secretary

Nick Steimpek treasurer

Gunilla Goran

The ENFA board received during the year support from different members of which they are grateful. We would like to thank the people who supported ENFA and sponsored them in any way for their generosity to make our work possible.