

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

The year 2016 was a refreshing year for ENFA as for different reasons it was involved in several activities related to fibromyalgia.

Thanks to a grant of Grunenthal ENFA was able to undertake three actions to raise more awareness on fibromyalgia. First we were able to organize the General Assembly on May 22 in the Thon Hotel EU. We were glad to see so many member representatives over there.



On May 23 ( in the European Parliament ) and 24 ( Concert Noble ) we were involved in the Societal Impact of Pain where the ENFA representatives were able to get the attention of several other guests. During the plenary day (May 24 ) we have been given the opportunity to present ENFA to all the guests during the patient market. It was in Brussels, Belgium.

The next thing was the finalizing of the new EULAR guidelines on fibromyalgia as done by a working group of EULAR. The fibromyalgia patients input was done by our president Souzi Makri. These new guidelines were presented during the EULAR symposia in June in London. The president and the treasurer were both present there. The treasurer was also invited to be co-chair in a combined Pare-professional meeting of EULAR on the Friday where fibromyalgia was one of the subjects.



Thanks to the contacts of the treasurer contact was made to a filter that had made a documentary on chronic pain. One of the subjects involved in that video was a fibromyalgia patient. The filmmaker was able to combine the several parts into a video only of the fibromyalgia patient. This was made possible by a grant of Grunenthal for the preparation and the translation into different languages. Most of these activities took place in 2016 but the finishing will be in 2017. The preparations for a first presentation in the European Parliament has been started in 2016 and are also waiting to be finished in 2017.

ENFA was this year involved in specific PARE activities. ENFA was represented by Jasmina Simic at the PARE conference 2016 in Sofia, Bulgaria

Beside the activities specific on fibromyalgia, ENFA was also involved in activities at the EMA the European Patients Forum (EPF)

With regard to the EMA activities, Ms Gunilla Goran attended the workshop for patients in November 2016. At the meeting for all Eligible Organizations, Gunilla Goran (member of the Board) and Souzi Makri (President) represented the Organization.

Souzi Makri (President) represented ENFA at the EPF General Assembly in April 2016, 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

Ella Vine Secretary

Joop van Griensven Treasurer

Lizi Sommer member.

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.