

ENFA Activity Report 2015

ENFA's committee has met regularly through the use of Skype and between meetings made decisions by email. Each member has specific duties and has contributed to the running of the organisation. The General Assembly is the only time they all meet together face to face, although when representing ENFA at various events some members will meet up.

Membership

The Searching of organisations who represent people with fibromyalgia resulted in the finding of a new member. Because of this actions we remain on our level of 16 members from 13 different EU countries and Israel. Although many of the newly joined EU countries do not have a culture of patient support groups and any representing fibromyalgia have so far proved impossible to find, we did manage to find a new member from Serbia.

Awareness/attendance at events

ENFA committee members have continued to represent ENFA at meetings throughout Europe.

Publicity

In the year 2015 were no changes made on the appearance of the website. During the year the news items were updated with received news and articles provided by members, as well as the details of the members updated to date.

The website itself has had the same number of visitors as it had in previous years, with around 250 visitors a month. Because it is not increasing we should find a way to make the website more attractive to Fibromyalgia patients / healthcare professionals.

Individual board members did represent ENFA by filling out questionnaires or participated in P.R. activities aimed to raise more awareness for Fibromyalgia, patient involvement and attention for people with an invisible chronic condition.

Although various media sources have been contacted with press releases, no media interest to publish those has been shown thus far.

Umbrella organisations

ENFA representation was also present at the European League against Rheumatism (EULAR) congress in Rome. This was also a time to strengthen existing relations and make new ones. Also an opportunity to hear what is new on the fibromyalgia field.

ENFA as a full member of the patient arm of EULAR, People with Arthritis/Rheumatism in Europe (PARE), entitles us to attend conferences and have expenses paid. Two ENFA representatives did so at the PARE conference in Dublin .

Due to the participation of ENFA within Pain Alliance Europe (PAE), fibromyalgia is more mentioned now in occasion where representatives of ENFA are present. This happens when health professionals are together as well as policy makers and politicians. As the treasurer of ENFA is also the president of PAE, he has been asked several times to tell his life story or tell from his own experience how it is to deal with a chronic pain condition.

The other big advantage of participating in PAE is that there is more attention ever for chronic pain. The discussions within the European council meeting of the ministers of health during the Italian presidency opened ways to improve the situation. A lot of lobbying needs to be done as health care remains a national priority but the mere fact they discuss the subject means a big step forwards. ENFA was involved in the development of the strategy used.

We participated in the Working Group Patient Empowerment on April 28/29 and on November 6 /7. On May 19th we attended the Annual General Meeting of European Patients Forum (EPF). This meeting was followed the next two days (May 20 / 21) by the Patient Empowerment Conference. This was the start of the EPF Empowerment Campaign. All these meetings were in Brussels. EPF is a strong organisation representing 150 million patient in 64 patient organisations in 28 member states. We aim to be a full member of this organisation but need to represent more European countries. They have a strong voice in the European Parliament. Being part of EPF we could join in their programmes and in the meantime it will be fruitful for ENFA and for the Fibromyalgia community across Europe.

On November 18 we attended the Societal Impact of Pain (SIP) Symposium with interactive panel discussions. Important issues in the discussions were the actions needed in order to ensure that chronic pain will be a priority on the EU agenda in the member states as well as in the EU institutions. The discussions were open and very informative. However a lot of words and recommendations cannot guarantee the final results. We have to wait and see what positive effects and outcome should have at last.

ENFA is represented at European Medicine Agency (EMA) eligible associations meetings and has attended meetings discussing the wording and signage on patient information leaflets that are included in medicines, warning that it is under scrutiny.

This also means that should approval for a drug for fibromyalgia be sought we would be notified and be able to pass comment.

Finance

We still do not have any sponsorship, which means ENFA exists entirely through membership fees and the generosity of national organisations who pay the expenses for committee members to attend various events to represent ENFA. Please see separate financial report for full details.

Research

ENFA developed its own project proposal to engage more awareness for Fibromyalgia and submitted this to the EULAR for funding. However even after an additional review of the project it still didn't



receive funding from EULAR so the project is put on hold. At the moment we are looking for other options.

ENFA has produced a survey questionnaire which was launched early 2015, the resulting report was shown at the PARE meeting by means of a poster project.

EULAR has funded a team to update its guidelines for fibromyalgia and we have represented the patient voice in discussions about these. As a result the guidelines should be published in a patient version as well. This is scheduled for 2016.

Political

ENFA is on the transparency register of the European Parliament. This means we are informed when there is any mention of fibromyalgia within the parliament and invites us to comment on various health related issues.

The Board of ENFA