

ENFA report 2014

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

Despite searching out organisations who represent people with fibromyalgia, we have been unable to increase membership of ENFA during the last year. 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.

Awareness/attendance at events

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

In May ENFA was by invitation present at the 10th anniversary of the Slovenian Fibromyalgia Associations. We were very grateful with this invitation and we were surprised by the efforts they made to make this anniversary such a success. We hope they will have success in the future in managing the organisation and the communication with the health professionals.

Publicity

In the year 2014 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.

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

Umbrella organisations

ENFA representation was also present at the European League against Rheumatism (EULAR) congress in Paris. 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 is now a full member of the patient arm of EULAR, People with Arthritis/Rheumatism in Europe (PARE), which entitles us to attend conferences and have expenses paid.

Due to the participation of ENFA within Pain Alliance Europe (PAE), fibromyalgia is more mentioned now. As the treasurer 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. Of course fibromyalgia is mentioned at these times.

In April we attended an exhibition and cocktail with different stakeholders in chronic pain in the European Parliament organised by PAE. We saw a pain experiment (Pain Box) developed by the Montescano Pain School.

On November 17th we were present at the PAE General Meeting and participated in a workshop. The purpose of this workshop was “What can PAE do for the individual member and what can the member do for PAE?” Also what issue are important for members. An interesting question and it resulted in a lot of information.

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.

On May 12th and 13th we attended the Annual General Meeting of European Patients Forum (EPF), where the EPF Workplan 2014 was presented and we participated for the first time in the Working Group Patient Empowerment. 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 fruitfull for ENFA.

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 can not 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) patient meetings and has attended meetigns 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 has been involved in a bid for funding from the EU Horizon 2020 project. The XPres project, a coalition made up from researchers from different countries / universities to write a research project to come to the recognition of mechanisms within the DNA structure of Fibromyalgia patients. A couple of meetings were attended and involved some writing of the project proposal, especially those chapters where patients involvement was mentioned and those chapters where the presentation of the project to the outside world was proposed.

It was in the race until the final round of about 20 projects. As budget was limited to 50 million Euro and the average costs of the projects were 6 million only 8 or 9 projects were awarded. Unfortunately ours was one of the rejected ones.

Other projects we had agreed to participate on were rejected at an earlier stage.

Although disappointed the project was refused it did however allow us to make contact with different professionals which may have its positive effect for the future.



ENFA has produced a survey questionnaire to be launched early 2015, with the resulting report to be published ready for 12th May 2015 international awareness day.

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.

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.