

Overview of ENFA activities to be presented to the general meeting of December 12<sup>th</sup> 2009.

## In the beginning.

At the end of 2007 the first contact was made between Pfizer and the president of ENFA for exploring the possibilities of joining together to get more attention for Fibromyalgia in Europe.

As ENFA at that stage was almost dead the president asked for some support of the Dutch association in order to get some support. The Dutch association agreed with this and the secretary was obliged to accompany the president on his way through Europe.

The first actual contact was made in the Netherlands in January 2008 and was followed by meetings in Brussels and telephone conferences. At that stage other European associations were asked to join ENFA and work together to get ENFA's re birthing on more solid ground.

## 2008

All that work resulted firstly with the start of the global survey, secondly in a general meeting on May 6<sup>th</sup> 2008 and thirdly in a round table discussion with members of parliament and the start of producing a written declaration about fibromyalgia.

This information was given at the general meeting on May 6<sup>th</sup> in Brussels.

Soon after this first result followed a second highlight with the official presentation and press conference on the 12<sup>th</sup> of June 2008 in Paris of the survey called: Fibromyalgia Global Impact Survey, Advancing Understanding, Aiding Diagnosis.

When this was finished negotiations began for the text of the written declaration. Finally there was an understanding between five members of the European Parliament. For tactical reasons the written declaration was presented to the European Parliament in September. So by the end of the year it would be clear whether this declaration was accepted or not. Because the written declaration received enough support, there was a continuation and in early 2009 it received more than ½ +1 signatures, so it was accepted by the European Parliament.

Meanwhile there was basic work done and the ENFA website went online August 2008.

Also in that same period the first contacts were made in order to get ENFA officially registered according to Belgium law. This took a long period and resulted in the president and treasurer going to Brussels to formally pass the Statutes by the notary. This was in October 2008. After that all the necessary paper work was presented to the minister of justice from Belgium in order to get the official approval to be registered as an international non profit association (IVZW). Because of the political problems in Belgium during that period this administrative issue took much longer than expected. Finally on March 27<sup>th</sup> 2009 everything was in order and we became an official registered association who could be a potential sponsor partner.



In October the e-petition was placed on the website and it gave the website a lot of visitors. After some starting difficulties the e-petition was signed by a lot of people which resulted in a first presentation of 10,000 signatures to the European commissioner responsible for health affairs, Mrs. Vassiliou. These signatures were presented by Dr. Adomou one of the initiators of the written declaration. This happened on April 22<sup>nd</sup> 2009. At this moment the e-petition has been signed by almost 32,000 people.

In October 2008 the first contacts with EFIC were made regarding their announcement to call a European year against fibromyalgia. This resulted in a press conference in the European Parliament with the members who took the initiative for the written declaration and representatives of ENFA and EFIC.

The last thing in 2008 was a committee meeting early in December 2008. This opportunity was also used to go to the European Parliament to ask for signatures for the written declaration by visiting the diverse national members of European parliament. The committee took this opportunity also to express their thanks to the members who took the initiative for the written declaration and also to present to them a small token of our appreciation. The next day we discussed the future of ENFA and made up some initiatives for which different members of the committee had responsibility.

## Disappointments 2008

Although we had a lot of success in 2008 there were also disappointments. First of all the rejection by the EMEA of Cymbalta as a medicine with a European trading license. As ENFA we supported Lilly with their attempt to get Cymbalta approved. Some individual members of the committee also supported Lilly.

The second disappointment was the problem of finding sponsors for ENFA. Although we tried hard, we faced the difficulties of the financial crisis which resulted in cutting expenses by the industry. The second reason was that there was no medicine approved which made it difficult for the industry to sponsor our association.

## 2009

The year 2009 showed two faces regarding the development of ENFA.

In the early days of 2009 we received the news that the written declaration was accepted by the European parliament.

As we had written a letter to the EMEA as a protest against the refusal of Cymbalta as a medicine with a European trading license, ENFA was invited to a meeting with representatives of the EMEA. Due to weather circumstances the first meeting was postponed to March 16<sup>th</sup> 2009. As a committee we agreed that we would aim on the negative effect on research and development of medicines due the two rejections, that would be our first purpose. Although we were welcome, the result was disappointing because we felt that we were not heard. The only positive result was that we were invited to be part of the Patients



Consultancy Board of the EMEA. We did fill in the necessary forms but we never did receive a first official invitation. However we have been placed on their mailing list.

A positive result was the European activity on March 7<sup>th</sup> by raising awareness in the diverse European city of the members' states. Despite the short notice the national associations were able to put together a beautiful result.

After this event we were informed that the sponsoring by Pfizer had stopped so there was no financial possibility to continue to get the support by EACON financed. Now this is the moment to speak of our appreciation for EACON and especially for Laura Jakovljevic, for their support at the start of ENFA, the written declaration, the round table discussion, the e-petition and the awareness day of March 2009. But also to fulfil a key position within the communication of ENFA. Although Laura offered her services on a voluntary basis, because of her busy workload this could not be at the same level as we were used to.

In that same period we were confronted with some other disappointing news. This involved the committee members. The secretary was forced to have a lower input because of personal circumstances. The committee member with first responsibility for new members was forced to have a lower input because of poor health circumstances. The member responsible for PR laid down her function and finally the member for research was confronted with health problems.

The other committee members were occupied with their national associations.

These reasons meant that the development of ENFA was forced to a lower gear than was expected in May 2008.

In the meantime Lyrica from Pfizer was also rejected a European trading license which created even more problems for ENFA as well.

In December 2008 we agreed that the website of ENFA should be upgraded. For that some action was taken and the committee received a proposal on which they had to react and give input. For the reasons mentioned above the input came from only a few people which caused a delay in the further development of the website. Despite several mails and verbal questions, we found out that no changes were made to the original proposal so there was no new website developed. At that point the committee felt they had to do something. By then it was already October before everything was clear so actions could be taken.

The few committee members who were active tried to organise a committee meeting several times. During this period some proposals for new members to join ENFA were made. A proposal was made for the committee members to decide how ENFA could continue when we had insufficient sponsoring. Those proposals were sent to all the committee members by the president with the question to react on them.

The committee received the question of whether the medical advisory board could be installed. Some people were invited before there was a decision from the committee. From the committee there were a few points which they felt strongly about and should be cleared first before installing the medical advisory board. First of all the medical advisory board should be without any conflict of interest. That means that members of the medical advisory board could not be influential board members of national associations. Second there was a feeling that before installing the medical advisory board we should agree as a committee and as the medical advisory board what the purpose and role should be of that medical advisory board. We did not have an understanding on that point. Thirdly there have been no talks between the president of the committee and the suggested president of the medical advisory board about ideas, working strategy, etc. For that reason the installation was cancelled which was known to all the committee members.

In June the president and the treasurer went to the EULAR conference in Copenhagen where they had meetings with different people. One of them was with the proposed member of the medical advisory board which could lead to the question of independence. In our conversation we fully agreed on that point that this was not desirable. Because this item also was brought forward in the national association he resigned from his function and only worked as a medical advisor for the national association. We were also able to speak to Dr. Ernest Choy about the medical advisory board and what his ideas were of what the medical advisory board should do and how it would work. When we were back from the conference we informed the committee members and told them that the installation could be done because the most important item was solved.

During the EULAR conference we also had contact with the Danish association and the candidate member from Sweden. With both we had very pleasant talks in which we were able to explain our difficulties and chances.

We also spoke to some professionals who were attending the conference and who had a good reputation in the fibromyalgia world. It then was pleasant to experience that we as ENFA had already built up a good name for ourselves.

During this conference we were also able to make contact with the past and present president of PARE which is the patient part of EULAR. We could speak informally about the possibility of PARE sponsoring ENFA and ways of how to work together.

On that sponsor field we were also able to make a first contact with UCB which is a company which is developing a medicine for fibromyalgia as well. We attended the meetings in which the researchers told about their work and how far forward they were.

When we were back in the Netherlands we followed up on the contact with UCB and managed to see them. They told us how far they were in their research and we told them about our difficulties and our possibilities. As a result of that meeting we sent them a letter in which we asked for sponsoring especially to create a greater democratic representation of ENFA. We asked them for money to sponsor general meetings and committee meetings so everybody should be able to participate. We sent the letter in early August and got an answer back in mid October in which they stated that there was no money left to sponsor this year. However they

would like to invite us to ask for sponsoring again in 2010. They also would like that it would be asked through the same channels as it was done in 2009. As a follow up on that, we have spoken again to the representative of UCB and she told us that it was indeed just because there was no budget left for 2009 and not because they were unwilling to sponsor. She advised us to send the same letter again early January 2010 and she also would try through her channels to get something for us.

During the period from end of March to June 2009 we changed our bank account so now it is on ENFA's name and not longer in the treasurer's personal name. This is important for any sponsoring contract.

As we are speaking of sponsoring we received some information from Pfizer that they would sponsor ENFA for an amount of €25,000 for the years 2009 and 2010. This after the vice president was frequently asking for information concerning their verbal announcement to ENFA. Although we have had that message in July and we gave them all the necessary documents and details, we just received a message from Pfizer that the dossier was sent to an other department of Pfizer which should provide us with the money. As we are writing this we still have not received anything.

Moneywise we also tried to get in contact with the former treasurer of ENFA in order to get the money back which she had promised to send to ENFA when she stepped down as treasurer. However on all our mails we have not received any answer. We also tried it through the Norwegian association but we did not get any answer back. We will keep trying, but we have to presume that this will be very difficult to get.

After the EULAR conference the president sent out a message to all the members dated August 7<sup>th</sup> 2009 in which he informed you all about what was happening within ENFA. He also sent out a note to all the committee members about the structure and future of ENFA with the request for a committee meeting and a general meeting. This was October 14<sup>th</sup>. After the mentioned deadline in this note he started with the preparations for a general meeting. The sending of the invitation and agenda crossed with the request for a general meeting by the Focus Belgium on behalf of other associations.