



General Assembly Minutes June 10th 2017 Hotel Excelsior, Valetta, Malta

Following participants signed the attendance:

NAME	ORGANISATION	E-MAIL ADDRESSES
(Roula) Argyuri Stara Jasmina Simic	Arthritis Crete ORS, Udruzenje obolelih od reumatskih bolesti Srbije	roulange@windtools.gr jasminaana@gmail.com
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ENFA President, Mrs Souzi Makri, opened the meeting and greeted all the participants. She thanked Grunenthal for their support, enabling ENFA presence at the SIP conference and this event.

Short “tour de table” was held, then Souzi introduced FM awareness video, Monique Fibromyalgie, that was launched the month before at the round table meeting held in EU Parliament. The video was made thanks to the Grunenthal support, and was translated in all ENFA languages.

Minutes from the last General Assembly were approved.

Souzi went on about activities that had been carried out the year before. It was a good year for ENFA, thanks to Grunenthal its members participated in many activities and raised awareness about FM. She again emphasized the importance of FM documentary and invited everyone to use it in raising awareness. (Detailed annual activities report is provided in the attachment.)

Souzi thanked to the board members for a wonderful year, especially to Mrs. Lizy Zommer and Mr. Joop van Griensven who, unfortunately, would leave the board as their term had ended. Three new board members were elected: Ms. Gunilla Goran, Mr. Nick Steenkamp and Ms. Jasmina Simic.

Mr. Joop van Griensven presented annual financial report (detailed report is provided in the attachment).

Souzi Makri introduced activity plan for the next year. She invited everyone to think about prospects for grants. A grant from Grunenthal will be asked for again. Novartis is developing a new drug for neuropathic pain, Souzi is establishing collaboration with them and expecting funds from their side as well. As for the next general assembly, the date and collaboration with SIP - it is currently unknown in which way SIP would develop. Joop suggested we wait for another two months during which the future direction of SIP would be decided, and then we would see if we can have another GA together with SIP event.

The draft of new web-site was shown. We would wait for the new photos from SIP event to be published online. Joop invited members to send news and information from their countries and make it available online through ENFA web-site. It should be more interactive than the old one. Jasmina asked for suggestions for the web-site as the web-developers need more inputs in order to complete it, the web-site can be re-shaped many times and all the ideas are welcome - we need to make the web-site user-friendly for all the patients.

Joop informed everyone that Dr. Daniel Claw is the name they should be looking for when it comes to research on FM.

ENFA will attend the EULAR Pare Conference in Brussels in 2018. A poster would need to be made, also a new ENFA logo, as the existing one is very small in resolution and it cannot be used for posters, web-sites, presentations, etc. The poster design is also important because each year there is a poster competition and that is the opportunity for ENFA to attract attention, raise awareness and potential new members. Souzi invited everyone to think of an idea that could be promoted via the poster. Joop suggested that the poster portrays history of ENFA, the round table at EU, the video, and similar.

Souzi said that she had had a lengthy discussion with Cypriot MP about writing declaration aimed at promoting FM in EU Parliament. Arranging a meeting with a commissioner of DG SANTE and discussing problems FM people face can help. She asked the present to share ideas about FM topics for discussion - e.g. FM and work, how to help people keep their work and still remain productive, reintegration of people with FM at work, etc. We need to keep the track of their agenda on EU website. Mateja had spoken to MPs from Slovenia and they are willing to support us. She invited everyone to go to their MPs and ask them to stand for our rights. The questions about FM should be raised in the Parliament from different countries. We should speak with our MPs simultaneously. Joop pointed out that with lobbying we would be addressing three committees at the same time: Human Rights Committee, as are asking for

equal rights at work, Social Committee, as we are asking about employment, and Health Committee as we want to address issues related to FM. Having started with the FM video we should continue with one strong topic, whether it be rehabilitation and reintegration of the workforce, or else, and focus only on that. We should not change the message during the period. Before we start developing the questions for MPs, we should know the full plan in advance of what we want to achieve. Souzi suggested we make an action plan for that. Joop suggested we continue following the SIP initiative and use all the things that they are doing, as they had already opened the door for us. We should make the use of all the resources we have. Souzi had spoken with Neil Betteridge from EULAR office and he would advise us on how to proceed. Souzi asked Mateja to write a proposal of the final goal and final questions we can focus on.

Roula raised the question of getting disability for FM. Elisabeth Bovy said that they take part in many TV and radio shows and speak about FM, raising awareness about invisible disabilities. They are worried about overdiagnosing and misdiagnosing - e.g. a patient was diagnosed with FM while he had thyroid cancer.

Joop suggested we use the speech of Maltese President when we address MPs, and then ask them what is it that they can do in their countries. Joop will write a letter to the Commissioner asking for a meeting at about the FM awareness day. The meeting with Commissioner would be our start of the journey of lobbying for FM workforce. Souzi suggested that at the day of the meeting we also organize a small conference with a presentation, or a workshop that would cover our goal. Joop said that the meeting shouldn't be on the 12 May as people would organize events in their countries, and there are many other organizations that would raise awareness on that day. Maltese President could also be our guest at the event. Ruth will check if the President would be available around the 12 May.

Joop suggested that during that event one presentation should cover the difficulties of diagnosing FM (given by a doctor), as that is an issue in Malta. Another presentation could be done by a patient who would say what it's like living with FM (by giving facts and numbers, not inviting for the tears), and an expert should cover the topic of difficulties at work.

Ruth asked about inviting doctors at the event, as they could learn about the process of diagnosis. Joop agreed that inviting doctors is a good idea, but they should not be involved in discussions as that would lead the event into a completely different direction. Souzi said that we need an action plan for getting a grant for the event.

At the end of the meeting Lizy and everyone else thanked Joop for all the years and the work he had done for ENFA.

Joop said that it had been a pleasure working for and with ENFA, he had in mind that he had been working for the future of the children hoping they would have a better future. He pointed out that along the way he had met fantastic people which gave him satisfaction and motivation to continue.

Souzi closed the meeting saying the we had done a lot, but there is plenty to be done yet, and she asked for the contribution from everyone.