



European Network of Fibromyalgia Associations (ENFA) General Assembly 2019 Minutes

Saturday 18 May 2019

Heraklion, Greece

Present

Elisabeth Bovy	FOCUS Fibromyalgie Belgique	Belgium
Marija Bucic	Udruzenje Obolelih od Reumatskih Bolesti Srbije	Serbia
Eva Deurloo	Fibromalgiförbundet	Sweden
Ricardo Fonseca*	Myos	Portugal
Karin Øien Forseth	Norges Fibromyalgi Forbund	Norway
Gunilla Göran*	Reumatikerförbundet	Sweden
Mateja Kržan*	Drustvo za Fibromialgijo	Slovenia
Souzi Makri*	Cyprus League Against Rheumatism	Cyprus
Judi Olsen	Dansk Fibromyalgi-Forening	Denmark
Egidio Riva	Associazione Italiana Sindrome Fibromialgica	Italy
Lizy Zommer Schupack	Roots For Generation	Israel
Roula Angelidaki Stara	The Arthritis Foundation of Crete	Greece
Simon Stones*	Fibromyalgia Action UK	United Kingdom

* indicates 2018-2019 Board members

Apologies

Joana Vicente*	Associação Portuguesa de Jovens com Fibromialgia	Portugal
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1. Opening and welcome

Souzi Makri, the president of ENFA, opened the General Assembly with a warm welcome for everyone.

2. Tour de table

All members were asked to introduce themselves and the organisation they represent. Thirteen members were present, with one apology from Joana Vincente. Five out of six Board members were present.

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3. Minutes General Assembly, 12 May 2018

Souzi Makri circulated the minutes of the last General Assembly by email prior to the 2019 General Assembly.

All members present approved the minutes without any modifications.

4. Annual activity report 2018

Souzi Makri circulated the annual activity report for 2018 by email prior to the 2019 General Assembly. She then read a summary of the report to members. Souzi Makri completed the report from 2018 to April 2019 to aid the incoming President. Activities ENFA have been involved in include:

- 21st EULAR Annual European Conference of PARE 2018
- European Patients' Forum (EPF) 2018 Annual General Meeting
- ENFA Annual Conference and General Assembly 2018
- 13th Patients' Rights Day 2018
- Steering Committee Meeting of the SIP Platform 2018
- Questions to the European Commission 2018
- Patients as Partners Conference 2019
- DIA Conference 2019
- 1st International Controversies of Fibromyalgia 2019
- Biosimilars Advocacy Meeting 2019
- 22nd EULAR Annual European Conference of PARE 2019
- EPF 2019 Annual General Meeting.

Gunilla Göran and Souzi Makri stated it was important that ENFA attend EPF meetings to ensure the voice of ENFA is represented within the broader patient organisation community.

ACTION: 2018 activity report to be published on the ENFA website and disseminated on social media.

Representation within EPF working groups

Mateja Kržan also remarked that she is a member of the 'Access to Healthcare' working group at EPF. Souzi Makri also remarked that she is on a Task Force at EPF on developing a roadmap on people to be involved in lay summaries. Ricardo Fonseca also remarked that he is a member of a Task Force at EPF developing a 'Guide to vaccination for people with chronic diseases'.

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EPF and EULAR Standing Committee of PARE membership

Souzi Makri confirmed that ENFA are a co-opted member of EPF since ENFA does not have enough members. Souzi Makri also confirmed that ENFA are co-opted members of the EULAR Standing Committee of PARE.

Website and social media

Simon Stones remarked that since 2018, ENFA had re-launched on Facebook, Instagram, LinkedIn and Twitter, and acknowledged Joana Vincente for her sterling work in helping to establish the platforms, create content and improve communications over the year.

5. Financial report

Souzi Makri declared that an educational grant was provided by Grünenthal for €3,500 to enable the Annual Conference to take place.

ACTION: Report of the ENFA 2019 Annual Conference and general Assembly to be shared with Grünenthal once prepared and finalised.

Souzi Makri provided an overview of the current financial situation for ENFA. The elected treasurer up to 2018 resigned due to ill health, and so Joop van Grievensen has been managing payments, given he was the previous treasurer with access to the bank accounts.

Simon Stones then presented the 2018 financial report, prepared by Acting Treasurer Joop van Grievensen. Simon Stones explained that since his election as Treasurer in 2018, he has only been in the role of an administrator, since he has not been able to access the bank accounts or process transactions. Simon Stones and Souzi Makri confirmed that they had been pursuing this handover since May 2018. The total loss reported for 2018 was €6,228.82.

Simon Stones discussed a number of items related to finances moving forward. He emphasised the importance of having two signatories on the bank account, which can be completed electronically. For example, the

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Treasurer initiates the payment via the online bank system, and then another Board member, such as the President, authorises said payment.

Simon Stones stated that this is essential for transparency and accountability purposes and is obligatory for non-for-profit organisations in many countries. Simon Stones also made clear that the President and Treasurer must both be able to access the online bank account, as should any other Board member. To facilitate the process, Souzi Makri had contacted Marco Greco as President of EPF, on behalf of ENFA, given their extensive knowledge and since they are also based in Belgium. A response is due from Marco.

ACTION: To circulate Marco Greco's response to the Board, and action the resolution of the current financial situation as a matter of priority.

Simon Stones remarked that 2018 was a bad financial year for ENFA, and that current spending would result in bankruptcy within three years. Therefore, Simon Stones suggested the new Board would need to consider the most appropriate steps forward. Souzi Makri suggested the 2020 general assembly could be done virtually if required, as it has been done that way in the past.

ACTION: To formulate an action plan for ENFA's 2020 and 2021 conferences and General Assembly.

Simon Stones also asked members whether they felt an annual membership fee of € 100 was sufficient, or should it be increased. If not, then would a virtual meeting be acceptable. Souzi Makri remarked that it should be no more than € 100, since this is comparable to EPF and Pain Alliance Europe (PAE). The annual fee will therefore continue to be € 100.

Elisabeth Bovy asked if her organisation had paid. Simon Stones confirmed that all members have now paid for 2018 (or are in the process of issuing payment). 2019 invoices for payment will be issued after the 2019 General Assembly.



ACTION: To create and send invoices to member organisations for ENFA 2019 Membership Fees.

6. Activity plans 2019–2020

Assessment of member organisation needs and expectations of ENFA

Ricardo Fonseca suggested ENFA need to understand why organisations are choosing not to become members of ENFA. Gunilla Göran agreed.

Ricardo Fonseca remarked that €100 may be too expensive for some of the smaller organisations. Simon Stones said that ENFA need to demonstrate what member organisations get out of membership. Souzi Makri suggested that a member of the Board needs to be assigned the role of following up with new and existing organisations. Gunilla Göran suggested one incentive of membership of ENFA could be the concept of ENFA being a member of larger organisations such as EPF, EULAR PARE and PAE.

Ricardo Fonseca suggested ENFA devise a survey to ask what new and existing organisations would expect from ENFA membership, what they would like from membership, their goals and ambitions and so on.

ACTION: To formulate a project plan for the assessment of member organisation needs and expectations of ENFA.

Communication with ENFA member organisations

Souzi Makri suggested a regular newsletter to members to keep people informed. Simon Stones remarked that ENFA can easily do this through Mailchimp, which ENFA has already set up to ensure they were GDPR compliant. This platform had been used prior to the 2019 General Assembly to communicate documents to members.

ACTION: To formulate a project plan for an ENFA member organisation newsletter.



Collaboration with external organisations

Lizy remarked that collaborations with other organisations can be beneficial, potentially locally.

Ricardo Fonseca suggested contacting Pain Alliance Europe (PAE) for linking with the Societal Impact of Pain (SIP). Mateja Kržan remarked this requires both partners to be involved, and the way conferences historically used to be run are now different. Souzi Makri suggested asking whether ENFA could have a platform within SIP but this would require a national partner.

ACTION: To maintain and strengthen partnership with PAE and SIP.

Aspiring for shared learning and collaborative members

Judi Olsen remarked that she feels ENFA need to be more proactive in facilitating the sharing of best practices and collaborative working, involved external partners. Judi Olsen suggested establishing a strategy assessing competencies, involving the exchange of vision, strategy etc. for the sharing of national organisations and ENFA.

Souzi Makri and Egidio Riva remarked that it would be beneficial for national organisations to report activities to ENFA for publication. This could facilitate shared learning, and could be reported in the newsletter, and for example, as a series of short presentations at the Annual Conference.

ACTION: To formulate a project plan for shared learning and collaboration opportunities for ENFA members.

Website visibility

Eva Deurloo also suggested about improving Search Engine Optimisation (SEO) of ENFA, since she had experienced difficulties in finding the website via a search engine. Other members in the room found ENFA high in the search ratings, but others did not. This evidently needs to be investigated.

ACTION: To improve SEO of the ENFA website using the most appropriate meta tags.



Fundraising

Lizy Zommer Schupack also suggested crowdfunding for a conference as a way of fundraising money.

Mateja Kržan asked Lizy as to whether such approaches have worked for her organisations, given similar experiences in the past for ENFA have not worked. Lizy Zommer Schupack remarked that one organisation in Israel had received sufficient funding through this, though admittedly the organisation was supporting children with disabilities. Ricardo Fonseca, who has used crowdfunding for local activities, remarked that people have to know the organisation crowdfunding, the condition etc. Ricardo Fonseca stated that crowdfunding approaches could work if ENFA organises an awareness activity which local/national level organisations can adopt but did not believe it would be useful for funding for ENFA itself. Souzi Makri stated this was a similar case in Cyprus. Egidio Riva remarked that national organisations need to share experiences/knowledge, and how to engage national organisations about ENFA which could bring funding opportunities with it.

ACTION: To formulate an action plan for identifying and securing appropriate funding opportunities.

Dissemination of educational materials

Egidio Riva remarked that Italy were translating the *fm fibromialgia* textbook from Italian to English (covered by AISF), and ENFA could facilitate in distribution (at no cost to ENFA). Egidio Riva suggested inclusion of the ENFA logo on the back of the book. Simon Stones, Eva Deurloo, Mateja Kržan and Eva Deurloo remarked that first, the book would need to be reviewed by the Board (and likely all members) before this could be considered. Simon Stones also remarked that the involvement of the original authors and publisher would need to be sought, though he remained cautious about inclusion of the ENFA logo on materials ENFA were not initially involved in conceptualising. Simon Stones suggested that ENFA could more easily disseminate digital copies as a resource but had queries over the inclusion of the ENFA logo. Simon Stones suggested this be kept on the agenda for future board meetings.

ACTION: To follow up with the translation of *fm fibromialgia* by AISF.

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Five-year strategic plan, 2020–2025

Souzi Makri suggested the development of a new strategic plan for ENFA, suggesting three years. Simon Stones suggested five years, with an in-built stratification of short- (e.g. 2020), medium- (2021–2023), and long-term (e.g. 2024–2025 and beyond) goals. All members were asked to share any of their ideas or ‘dreams’ for ENFA over the next five years. Some were replicates of items discussed in the 2019–2020 activity plan. Ricardo Fonseca remarked that members should not focus now on specific details, since these can be discussed at a later date. Ideas suggested included:

- Survey of existing associations.
- Recruiting new members to ENFA.
 - Video of Board members explaining why to join ENFA and what ENFA does.
- Newsletter.
- Sharing of best practices among members.
 - Forum for sharing e.g. slots at annual conference, spotlights in the newsletter.
- Enhancing education and competency.
 - Shared training and learning opportunities.
 - Sharing good ways of working.
- Establishing strategic alliances.
- Dissemination of information and educational materials.
 - For example, the Italian textbook.
- Raising awareness in Europe.
- Engagement with policy makers.
 - Event in Parliament.
 - Engaging MEPs to invite a group of people to Parliament.
- More involvement for younger people with fibromyalgia.
- Building a network of professionals within the fibromyalgia community.
 - Medical and scientific advisory board.
 - Medical liaison network.
 - ENFA representing pillars of patients/carers, healthcare professionals and scientific communities.
 - Give them access to patients/carers, but also for ENFA to reach out to them.



- Exchange of research that is ongoing in individual countries.
- Increasing ENFA partnerships with academic institutions/universities.
 - For example, the European Registry project which Simon Stones is involved in.

ACTION: To prepare an ENFA 2019–2020 activity plan plus an ENFA 2020–2025 five year strategy.

ACTION: To prepare project plans to facilitate the conceptualisation of new initiatives.

7. Elections

Egidio Riva and Eva Deurloo had applied to join the Board prior to the 2019 General Assembly. Judi Olsen during the 2019 General Assembly also stated that she would like to join the Board. New Board members were asked to give a brief introduction, their experience, and why they wished to join the Board.

Egidio Riva explained his reason for joining the ENFA Board, as a carer and volunteer. He also emphasised the importance of including the importance of continuing to campaign at the European Parliament, and then in national countries. He explained he has great knowledge of organisational management and working with politicians and policy makers.

Eva Deurloo is a Physiotherapist and has worked with people with fibromyalgia in the pain unit. She explained how she realised how patients have to manage their own health and wellbeing. She is also a coach for patients and has been involved in a project for her organisation and has enabled her to make a difference on an individual level, but also a public health level.



Judi Olsen works full time with people with fibromyalgia, and has a background in French and Economics, and Cross Media Communication, plus over 20 years in psychological training. She has experience of working in governmental institutions and has involved in the broader Danish patient organisations.

Souzi Makri confirmed the constitution for ENFA states the Board can consist of up to 10 members.

Souzi Makri confirmed that she was stepping down as President and leaving the Board. Souzi Makri confirmed that she would continue as Member representing Cyprus League Against Rheumatism.

Mateja Kržan also confirmed she was stepping down as Vice President, but would remain on the Board. Mateja Kržan suggested Gunilla Göran as the Vice President. Simon Stones was suggested by Souzi Makri as President, with agreement from other members.

Therefore, the new elections of the ENFA Board took place as follows:

President	Simon Stones
Vice President	Gunilla Göran
Treasurer	Ricardo Fonseca
Secretary	Eva Deurloo
Member	Mateja Kržan
Member	Judi Olsen
Member	Egidio Riva

ACTION: Souzi Makri to provide Simon Stones with relevant information and documents as President.

8. Any other business (AOB)

No additional business was raised.



9. Closing remarks

Souzi Makri thanked everyone for their positive attitude and contribution in the 2019 Annual Conference and General Assembly.

Simon Stones thanked Souzi Makri for her work as President and Board Member of ENFA over the years, acknowledging her efforts and determination. Mateja Kržan presented Souzi Makri with a small gift of appreciation.

Simon Stones also thanked Joana Vincente in her absence for her work on the Board in the last year, particularly with regards to social media. Unfortunately, Joana had to step down from the Board in May 2019 due to competing priorities.

ACTION: To prepare formal recognition to outgoing members of the Board.

The minutes were prepared by Simon Stones.

10. Actions arising from the General Assembly 2019

- 2018 activity report to be published on the ENFA website and disseminated on social media. – **ACTIONED BY SS**
- Report of the ENFA 2019 Annual Conference and general Assembly to be shared with Grünenthal once prepared and finalised.
- To circulate Marco Greco's response to the Board, and action the resolution of the current financial situation as a matter of priority.
- To formulate an action plan for ENFA's 2020 and 2021 conferences and General Assembly.
- To create and send invoices to member organisations for ENFA 2019 Membership Fees.
- To formulate a project plan for an ENFA member organisation newsletter.
- To maintain and strengthen partnership with PAE and SIP.
- To formulate a project plan for shared learning and collaboration opportunities for ENFA members.
- To improve SEO of the ENFA website using the most appropriate meta tags.

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- To formulate an action plan for identifying and securing appropriate funding opportunities.
- To follow up with the translation of *fm fibromialgia* by AISF.
- To prepare an ENFA 2019–2020 activity plan plus an ENFA 2020–2025 five–year strategy.
- To prepare project plans to facilitate the conceptualisation of new initiatives.
- Souzi Makri to provide Simon Stones with relevant information and documents as President.
- To prepare formal recognition to outgoing members of the Board.

The minutes were approved by:

Outgoing President	Souzi Makri
President	Simon Stones
Vice President	Gunilla Göran
Treasurer	Ricardo Fonseca
Secretary	Eva Deurloo
Member	Mateja Kržan
Member	Judi Olsen
Member	Egidio Riva