

ENFA General Assembly 2021 Minutes

Saturday 12 June 2021, 11:00 – 14:15 CEST

Virtual – Zoom

Present

Elisabeth Bovy	Belgium	FOCUS Fibromyalgie Belgique
Boryana Boteva*	Bulgaria	Bulgarian Organization of the Patients with Rheumatic Diseases
Tea Pavkovic	Croatia	Association for patients with Myalgic Encephalomyelitis, Dysautonomia and Fibromyalgia in Croatia
Marina Ioannidou	Cyprus	Cyprus League Against Rheumatism
Judi Olsen*	Denmark	Dansk Fibromyalgi-Forening
Lizzy Sommer	Israel	Roots for Generations
Egidio Riva*	Italy	Associazione Italiana Sindrome Fibromialgica
Stefano Coaccioli*	Italy	
Ann Kristin Opstad	Norway	Norges Fibromyalgi Forbund
Karin Øien Forseth*	Norway	Norges Fibromyalgi Forbund
Joana Vicente*	Portugal	Associação Portuguesa de Jovens com Fibromialgia
Ricardo Fonseca*	Portugal	Associação Nacional Contra a Fibromialgia e Síndrome de Fadiga Crónica (Myos)
Jelka Smrekar	Slovenia	Društvo za fibromialgijo
Andrea Aída Franco	Spain	CONFESQ (Spanish coalitions of FM, ME/SFC, MCS, EHS)
Gunilla Göran*	Sweden	Reumatikerförbundet
Birgitta Gustafsson	Sweden	Fibromyalgiförbundet
Des Quinn	United Kingdom	Fibromyalgia Action UK

*indicates 2020–2021 ENFA Board members.

Apologies

Maria Bucic	Serbia	Udruzenije obolelih of Reumatskim Bolesti Srbje (ORS)
Eva Deurloo*	Sweden	Fibromyalgiförbundet

Apologies not received / unconfirmed attendance

Belgium	Vlaamse Liga voor Fibromyalgie-Patiënten
Greece (Crete)	Arthritis Foundation of Crete
Israel	Inbar – The Israeli Association for those with Rheumatic Diseases
Netherlands	Fibromyalgie en Samenleving
Spain	CONFESQ (Spanish coalitions of FM, ME/SFC, MCS, EHS)

1. Opening and welcome and approval of the Agenda of the GAM

Gunilla Göran, the president of ENFA, opened the General Assembly with a warm welcome for everyone and thanked to the ENFA Board for the great work during last several months.

All delegates present approved the Agenda.

2. Approval of the ENFA General Assembly 2020 minutes

All delegates present approved the minutes without any modifications, and these were subsequently taken as final. The minutes were sent by e-mail prior to the ENFA General Assembly 2021.

All delegates present approved the ENFA GA Assembly Minutes 2020.

3. Balance/financial report 2020 for approval

All delegates present approved the balance/financial report for 2020. The report was sent by e-mail prior to the ENFA GAM 2021

All delegates present approved the financial report for 2020.

4. New member of ENFA to be approved

Mr Egidio Riva, treasurer of ENFA presented the new candidate member association Association for patients with Myalgic Encephalomyelitis, Dysautonomia and Fibromyalgia in Croatia and asked the Tea Pavkovic – Vice – president to say some words about the Association. The organization is established in January 2020 and aims to support patients and their families. The organization is a member of Rare diseases Croatia and The European Myalgic Encephalomyelitis Alliance (EMEA).

All delegates present approved the new member of ENFA.

Actions: to add the Association for patients with Myalgic Encephalomyelitis, Dysautonomia and Fibromyalgia in Croatia to the list of member organizations

5. Annual report 2020 for approval

The Annual report was sent by e-mail prior to the ENFA GAM 2021

The president explains that the Board still struggles with the legal support, but that the question will be solved.

Gunilla Göran mentioned that the financial status of ENFA is not particularly good. Egidio Riva, ENFA treasurer will explain later.

Gunilla Göran described how the ENFA Board works: meetings, email, WhatsApp and how often the Board meetings take place.

Gunilla encouraged member organizations to send e-mails to the ENFA Board with any kind of question and proposals.

Gunilla explained that there were some problems with the website and e-mail accounts, but the problem is solved now.

Gunilla introduced Joana Vicente, Board member, and thanked her for her particularly excellent job with social media.



Gunilla mentioned all International virtual meetings that she and other members of the Board has attended.

All the events are listed in the Activity report that has been sent to the members. Gunilla stated that by attending and collaborate such events we are having a stronger voice for fibromyalgia/chronic pain in Europe.

During the PARE GA, in May 2021 ENFA was announced as an organization with a special status. ENFA is a supporting member of EULAR according to the new statutes of EULAR.

All delegates present approved the Annual report 2020.

6. Activity plan 2021 for approval

The president explained that the ENFA **Scientific Advisory Committee (SAC)** is already established and ENFA board will continue to work on that matter. Gunilla thanked Karin Øien Forseth, Norway and Stefano Coaccioli, Italy, ENFA Board members for their challenging work on establishing the SAC.

The president of ENFA, mentioned the work on **Position paper (PP) and Diagnostic and therapeutic care pathway for fibromyalgia (DTCP).**

The PP is already published online May 13th in Scientific Experimental and Clinical Rheumatology.

Managing fibromyalgia survey was launched among ENFA member organizations. The survey will show how European countries manage caring for patients with chronic pain, fibromyalgia.

Joana Vicente reported that we have received answers from 9 organizations so far. ENFA has 21 member organizations, and it is important that ENFA receive answers from all countries that are its members.

The Faces of Fibromyalgia project - online awareness project in social media in to make fibromyalgia visible. Joana Vicente reported that there are more than two hundred people that participated in the project so far. ENFA board will continue working on this campaign.

All delegates present approved the activity plan 2021.

7. Budget for 2021 for approval

The Budget for 2021 was sent by e-mail prior to the ENFA GAM 2021 Egidio Riva, ENFA treasurer, reported that the financial situation of ENFA is not particularly good as there is not a pharmaceutical company that produces drugs for fibromyalgia, which means that there are not any sponsors that ENFA can have.

The liability now is around 12 000 EURO.

All delegates present approved the budget for 2021.

The president explained that one of her aims is to find financial support from different companies that produce assistive devices.



Lizzy Sommer, Israel, suggested that we might try to get some funds with Crowd funding through internet.

A) Membership fee for approval

Egidio Riva, ENFA treasurer, suggested to keep the annual membership fee to one hundred Euro as it was last year.

All delegates present approved the membership fee for 2021.

8. AOB

Andrea Aída Franco from Asociación Coruñesa de Fibromialgia y Síndrome de Fatiga Crónica is asking how to be more engaged with the Board and help. The president explained that members can e-mail the Board any time they want to ask a question or share thoughts, especially before Board meetings, which are taking place on Wednesday in period of six weeks.

Egidio Riva, ENFA treasurer, proposes to set a meeting before 21 st of September with all ENFA member organization, before submitting the PP and DTCP and the results from the Managing fibromyalgia survey to European commission.

All delegates present approved Egidio's proposal.

Discussions will continue at the Round the table discussion later.

9. Closing remarks

The president of ENFA, announced that Mr Joop van Griensven is awarded as honorary member of ENFA for his excellent work for fibromyalgia for over 20 years and for his work at ENFA.

The president on behalf of ENFA board appreciated ENFA national member organization for attending ENFA General Assembly 2021.

-"we know it is an uphill and challenging work to make awareness for fibromyalgia in all European countries. We appreciate your work, and we want as much as we can to support you in this work, we want to work transparent and have an open dialogue with you. There is still a long journey for a patient with fibromyalgia to be recognized and be well taken care of. We want to thank you for your loyal support and together we can get stronger, Thank you!"

The minutes were prepared by Boryana Boteva and Gunilla Göran



The minutes were provisionally approved by:

President	Gunilla Göran
Vice President	Ricardo Fonseca
Treasurer	Egidio Riva
Secretary	Boryana Boteva
Ordinary Member	Eva Deurloo
Ordinary Member	Stefano Coaccioli
Ordinary Member	Karin Øien Forseth
Ordinary Member	Judi Olsen
Ordinary Member	Joana Vicente

The minutes will be formally approved at the ENFA General Assembly 2022.