

ENFA General Assembly 2020

Minutes

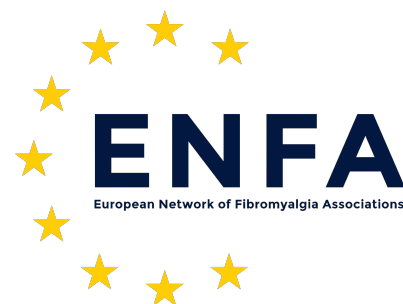
Saturday 05 September 2020, 12:00 – 14:15 CEST

Virtual – Zoom

Present

Elisabeth Bovy	Belgium	FOCUS Fibromyalgie Belgique
Boryana Boteva	Bulgaria	Bulgarian Organization of the Patients with Rheumatic Diseases
Souzi Makri	Cyprus	Cyprus League Against Rheumatism
Marina Ioannidou	Cyprus	Cyprus League Against Rheumatism
Judi Olsen*	Denmark	Dansk Fibromyalgi-Forening
Jens Arenbach Nielsen	Denmark	Dansk Fibromyalgi-Forening
Lizzy Sommer	Israel	Roots for Generations
Egidio Riva*	Italy	Associazione Italiana Sindrome Fibromialgica
Francesco Piccerillo	Italy	Associazione Fibromialgici “Libellula Libera” – A.P.S.
Stefano Coaccioli	Italy	Associazione Fibromialgici “Libellula Libera” – A.P.S.
Joana Vicente	Portugal	Associação Portuguesa de Jovens com Fibromialgia
Maria Bucic	Serbia	Udruzenje Obolelih od Reumatskih Bolesti Srbije
Mateja Kržan*	Slovenia	Društvo za fibromialgijo
Eva Deurloo*	Sweden	Fibromyalgiförbundet
Gunilla Göran*	Sweden	Reumatikerförbundet
Simon Stones*	United Kingdom	President; <i>Formerly</i> Fibromyalgia Action UK

*indicates 2019–2020 ENFA Board members.



Present for temporary period

Koen Laurysen	Belgium	Laurysen.law
Kirstine Amris	Denmark	The Parker Institute, Copenhagen University Hospital

Apologies

Ricardo Fonseca*	Portugal	Associação Nacional Contra a Fibromialgia e Síndrome de Fadiga Crónica (Myos)
Karin Øien Forseth	Norway	Norges Fibromyalgi Forbund

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
Norway	Norges Fibromyalgi Forbund
Spain	Asociación Coruñesa de Fibromialgia y Síndrome de Fatiga Crónica
Spain	Coalición Nacional de Entidades de FM, SFC/EM, SQM y EHS
United Kingdom	Fibromyalgia Action UK

1. **Joining and e-networking**

Delegates were asked to join from 11:00 CEST to ensure that any technical difficulties could be resolved. Jens Arenbach Nielsen hosted the meeting on Zoom and was present from the start to ensure delegates had no technical difficulties.

2. **Opening and welcome**

Simon Stones, the president of ENFA, opened the General Assembly with a warm welcome for everyone promptly at 12:00 CEST.

3. **Delegate introductions**

All delegates were asked to introduce themselves, the organisation they represent, their role within their organisation, and one activity which they had been doing during the COVID-19 pandemic. Sixteen delegates were present, with two joining slightly later into the meeting. Two apologies from Ricardo Fonseca and Karin Øien Forseth were received. Six out of seven Board members were present. Eight national organisations did not send apologies and were unconfirmed as attending.

4. **Approval of the ENFA General Assembly 2019 minutes**

Simon Stones circulated the minutes of the ENFA General Assembly 2019 by email prior to the ENFA General Assembly 2020. All delegates present approved the minutes without any modifications, and these were subsequently taken as final.

ACTION: ENFA General Assembly 2019 minutes to be published on the ENFA website and shared with Laurysen.law – Mr. Koen Laurysen.

5. **Annual report 2019/2020**

Simon Stones circulated the ENFA annual report for 2019/2020 by email prior to the ENFA General Assembly 2020. He then read a summary of the report to delegates. Simon Stones completed the report from May 2019 to September 2020 to aid the incoming President and the newly elected Board. This was supplemented with a series of recommendations to the newly elected Board from Simon Stones. The report began with a foreword from the President, followed by three sections: Governance, Projects and Activities. Simon Stones highlighted these briefly during the General Assembly.



a) Governance of ENFA:

- Seven Board meetings were held between May 2019 and September 2020.
- Three new member organisations joined ENFA: Bulgarian Organization of the Patients with Rheumatic Diseases (Bulgaria); Inbar – The Israeli Association for those with Rheumatic Diseases (Israel) and Associazione Fibromialgici “Libellula Libera” – A.P.S. (Italy).
- ENFA now had a total of 21 member organisations.
- A database update was undertaken in June 2019.
- Legal advice and support had been sought from Laurysen.law – Koen Laurysen, which would be discussed later on.
- Discussions were underway with Vlaamse Liga voor Fibromyalgie-Patienten to have a formal agreement in place regarding ENFA’s registered address in Belgium.
- Financial management was highlighted, including an unsatisfactory expenditure loss in 2019, which would be outlined further during the financial report.
- Organisational transparency has been improved upon, including full Board agreement on all decisions and greater transparency in annual reporting.
- A new strategic vision for 2025/2026, which was formulated in 2019/20, sent for consultation with members, and will now be implemented.
- A new file management system to enable the Board to access current and legacy documents for the organisation.
- Communication with members now through Mailchimp, supplemented by ad-hoc email notices from either the President, Vice President, Treasurer or Secretary.
- A closed Facebook group and WhatsApp chat group for members was established.
- A closed WhatsApp chat group for the Board was established.
- Communication with the public has been a focus through social media, with ENFA active on Facebook, Instagram, LinkedIn and Twitter.
- Two dedicated email addresses for ENFA in full use, one by the President, the other by the Vice President, Treasurer and Secretary.
- A refreshed logo, branding materials and colour scheme implemented across print and digital media.

b) Projects ENFA has been involved in include:

- Understanding the needs and expectations of ENFA members, co-ordinated by Ricardo Fonseca, Treasurer of ENFA. Simon outlined some key findings, including member priorities for joining ENFA, key priorities for the future, potential barriers for international collaboration; strengths of the network, current weaknesses, and components for the future strategy.
- Fibromyalgia position paper/consensus document, co-ordinated by Egidio Riva, Ordinary Board Member of ENFA. This is being co-ordinated centrally by Professor Sarzi Puttini (Italy), alongside an international team. It is anticipated that the paper will be presented to scientific societies in Europe, before going to the European Commission.

c) Activities ENFA have been involved in over the 2019/20 period include:

- ENFA Annual Conference and General Assembly 2019;
- European Patients' Forum (EPF) Capacity Building Module on Empowering Leadership and Positive Governance
- International Congress on Controversies in Chronic Pain in Systemic Rheumatic Diseases
- Fibromyalgia Registry Meeting
- EPF – Medicines for Europe Dialogue
- Societal Impact of Pain (SIP) Platform Symposium
- 1st EPF Congress 2019
- EPF 2020 Annual General Meeting
- EPF Ethics Committee
- EPF Working Group on Access to Healthcare Systems
- International Fibromyalgia Awareness Day 2020
- European League Against Rheumatism (EULAR) Standing Committee of PARE Meeting 2020
- EULAR 21st Annual European Congress of Rheumatology 2020
- Pain Alliance Europe (PAE) 2020 Annual General Meeting.

ACTION: ENFA annual report 2019/2020 to be published on the ENFA website and disseminated on social media.



6. Governance and legal support

Koen Laurysen of Laurysen.law joined the General Assembly. Simon Stones introduced Koen and asked him to provide a summary of the activities he is undertaking on behalf of ENFA.

Koen Laurysen reflected that ENFA currently appoints the Board for a term of one year, and the bylaws allow the appointment of a Board for a term of three years (and each Board Member can be re-elected for another two other terms). Once the new Board has been appointed later in the General Assembly, the newly elected President will be responsible for collecting a copy of the Board Members' ID-card / passport / driving license (1 out of the 3) and their full private addresses, place of birth and date of birth. These will be sent to Koen Laurysen.

Koen Laurysen also remarked that the General Assembly meeting minutes will be in English, since this is the working language of ENFA. However, since Dutch is the official legal language of ENFA, Koen Laurysen will translate an extract of the relevant information into Dutch, and recommended ENFA gave Koen Laurysen a power of attorney to register all relevant information to the Brussels Court of Commerce (as well as to sign the legal documents for publication in the Belgian Official Gazette). This is documented below.

Together with the minutes and forthcoming forms to register, Koen Laurysen will also have to register ENFA's recent annual accounts (accounting year ending on 31 December 2019. Koen Laurysen stated that such formality has not been undertaken in the past. Therefore, he would reprint ENFA's annual accounts of the past years together with the past minutes showing their approval, so that the file can be updated at the court. Koen Laurysen will also facilitate the rendering of a year tax declaration since this is a requirement for non-profit associations registered in Belgium. The Belgian Crossroads Bank for Enterprises / Belgian UBO register will also be updated.

Once all of the above corporate work has been completed at the court, Koen Laurysen will contact ENFA's local ING agency, sending them ENFA's



documents to arrange the ENFA Board to have access to the association's accounts. Koen Lauryssen anticipated that all of this will be completed before December 2020.

Finally, the following was agreed: A power of attorney is granted to Lauryssen.law - Mr. Koen Lauryssen, lawyer, with registered office at 1570 Galmaarden, Werfstraat 89 and VAT number 0816.665.863 to all administrative formalities to be undertaken in order to register the decisions hereabove at the competent Court of Commerce and to publish all relevant information in the Belgian Official Gazette.

Simon Stones thanked Koen Lauryssen for his support in aiding ENFA to move forward with these processes which have hindered ENFA for the past few years. Koen Lauryssen left the General Assembly.

ACTION: The newly elected ENFA Board to provide the necessary personal details to Koen Lauryssen after the General Assembly.

7. Financial report 2019

Including the approval of the annual accounts ending on 31 December 2019 and the granting of discharge of the current Board for the accounting year ending on 31 December 2019.

Simon Stones circulated the ENFA financial report for 2019 by email prior to the ENFA General Assembly 2020. On behalf of Ricardo Fonseca, Simon Stones provided an overview of the current financial situation for ENFA. The report was prepared by Joop van Grievensen, former Treasurer of ENFA. Joop van Grievensen has been managing payments, given he was the previous treasurer with access to the bank accounts. This has continued since 2018 because of legal challenges, which will soon be resolved with Koen Lauryssen's support.

Simon Stones declared that an unrestricted educational grant was provided by Grünenthal for €3,500 to partly enable the ENFA Annual Conference 2019 to take place.

The total assets as of 31st December 2019 were €10,964.17, compared to €14,791.76 on 31st December 2018. The total income for 2019 was €5,600.00. Income consisted of annual membership fees (including late payments) and an unrestricted educational grant. The total expenditure for 2019 was €8,988.55. Expenditure consisted of Annual Conference 2019 fees (including accommodation, food, beverages and travel), additional travel costs, website annual fees, EPF membership fee, and EPF Congress costs. Financial benefits/costs came to -€143.58. In summary, the total loss reported for 2019 was €3,532.13. This was less than a loss of €6,228.82 in 2018.

Simon Stones remarked that 2019 was another bad financial year for ENFA, and that current spending would result in bankruptcy within three to four years. Simon remarked that the Board had already agreed to take a more disciplinary approach to spending in 2020, which has been aided by hosting a virtual General Assembly.

All delegates present approved the financial report 2019 without any modifications, and this were subsequently taken as final. They also granted the discharge of the current Board for the accounting year ending 31st December 2019.

Simon Stones also asked delegates whether they felt an annual membership fee of €100 was sufficient moving forward, since it is agreed each year at the General Assembly. There were no comments from delegates, so it was agreed that the annual fee will continue to be €100.

ACTION: ENFA financial report 2019 to be published on the ENFA website and shared with Laurysse.law – Mr. Koen Laurysse.

8. Financial forecast 2021

On behalf of Ricardo Fonseca, Simon Stones provided an overview of the current 2021 financial forecast for ENFA. The anticipated income is €6,809.62, the anticipated expenditure is €2,053.20, and the anticipated gross profit is €4,756.42. Income consists of financial benefits, unrestricted grants (anticipated at €3,500 in response to a project application



submitted to an industry sponsor), membership fees and a transfer of €1,000 from ENFA's savings account reserves. Expenditure includes administration, financial/legal consultancy, conference attendance, General Assembly/Annual Conference, professional membership to other organisations, taxes, and the website annual fee.

Souzi Makri remarked that the Board would need to submit a project application to secure industry sponsor funding. Simon Stones replied to say that the Board understood this and would be waiting to prepare something for 2021.

9. Appointment of the new Board

Simon Stones confirmed that he was stepping down as President, leaving the Board and had already stepped down as a representative of Fibromyalgia Action UK. It was also confirmed that Mateja Kržan was leaving the Board after the completion of her term plus re-elections, but Mateja Kržan would remain a representative of Društvo za fibromialgijo.

There were vacancies for two Ordinary Board members to replace Simon Stones and Mateja Kržan. However, given ENFA's constitution recognising that the Board can consist of up to ten members, it was agreed by the Board prior to the General Assembly to elect four new Board members to bring the Board size to 9, which would also aid quorum. Following a series of self-nominations, Simon Stones confirmed that four individuals had been selected:

Boryana Boteva (Bulgaria)
Stefano Coaccioli (Italy)
Karin Øien Forseth (Norway)
Joana Vicente (Portugal).

All delegates agreed to elect Boryana Boteva, Stefano Coaccioli, Karin Øien Forseth and Joana Vicente to the Board.

Gunilla Görän self-nominated for the role of President. All delegates agreed. Ricardo Fonseca self-nominated for the role of Vice President. All delegates agreed. Egidio Riva self-nominated for the role of Treasurer. All delegates agreed. Gunilla Görän proposed Boryana Boteva for the role of Secretary, which Boryana Boteva agreed to. All delegates agreed. Simon Stones



confirmed that Eva Deurloo and Judi Olsen would continue as Ordinary Board Members. All delegates agreed. Stefano Coaccioli, Karin Øien Forseth and Joana Vicente would be elected as Ordinary Board Members.

Therefore, the newly appointed ENFA Board consists of the following individuals:

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

Simon thanked everyone for their time and support in this appointment, congratulated the new Board, and passed on his good wishes for the future. Simon Stones also thanked the previous Board for their time, energy and commitment to ENFA, and that it had been a pleasure to lead the organisation since May 2019.

ACTION: Update the ENFA website with the newly elected ENFA Board members.

10. Break

Delegates were provided with a short 10-minute break, prior to re-joining at 13:25 CEST for the second part of the ENFA General Assembly 2020.

11. Keynote presentation and discussion

Kirstine Amris joined the General Assembly to deliver her keynote presentation, titled 'Diagnosing and treating fibromyalgia patients based upon a scientific, research-based approach behind all interventions'. A short question and answer session then followed. Kirstine Amris confirmed



that her slides would be available to delegates after the meeting, and that they were welcomed to email her with any further questions. Simon Stones thanked Kirstine Amris for joining the General Assembly.

ACTION: Circulate Kirstine Amris' presentation and email address to delegates.

12. Any other business (AOB)

No additional business was raised.

13. Closing remarks and e-photograph

Simon Stones thanked everyone for their time, positive attitude and contribution in the ENFA 2020 General Assembly and remarked that it had been a privilege to be a Board Member since May 2018, and President since May 2019. He wished everyone well for the future.

Gunilla Göran, as the newly elected President, then provided the closing remarks for the General Assembly. Gunilla Göran thanked Mateja Kržan for her work as Vice President and Board Member of ENFA over many years, acknowledging her efforts and determination. Gunilla Göran also thanked Simon Stones for his leadership as President, and for his work with ENFA over the last two years. Gunilla Göran wished everyone well and thanked all delegates for joining.

Finally, a group e-photograph was taken via the Zoom platform. All delegates then left the virtual meeting room, and the General Assembly formally ended at 14:15 CEST, 10 minutes later than scheduled.

ACTIONS ARISING FROM THE ENFA GENERAL ASSEMBLY 2020

1. ENFA General Assembly 2019 minutes to be published on the ENFA website and shared with Lauryssen.law – Mr. Koen Lauryssen.
2. ENFA 2019/2020 annual report to be published on the ENFA website and disseminated on social media.
3. The newly elected ENFA Board to provide the necessary personal details to Koen Lauryssen after the General Assembly.
4. ENFA financial report 2019 to be published on the ENFA website and shared with Lauryssen.law – Mr. Koen Lauryssen.
5. Update the ENFA website with the newly elected ENFA Board members.
6. Circulate Kirstine Amris' presentation and email address to delegates.

The minutes were prepared by Simon Stones.

The minutes were provisionally approved by:

Past-President	Simon Stones
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 2021.