



# Annual Report 2021/2022

Gunilla Göran  
President of ENFA

The year 2021 was a hectic one for ENFA. ENFA have a growing workload which needed a lot of discussions. ENFA increased the membership activities, founded and continued the work with the scientists. The board had a lot of email traffic on several subjects and to provide information and invitation to our members on the various projects.

These activities and invitations from organisations require many ours from the board members even more than in previous years as we are becoming more recognised as an active and important stakeholder.

The 2021 General Assembly 14 th June was a virtual meeting on zoom.

At the beginning of 2021, we had 21 nacional members, from fifteen countries.

Since last GAM the Board continued to meet regularly.

### **ENFA Board meetings**

Between 12 June 2021 and Saturday 10 June 2022, seven virtual board meetings were held and minuted on the following dates:

- 29 June 2021
- 15 September 2021
- 4 November 2021
- 16 December 2021
- 25 January 2022
- 14 March 2022
- 30 May 2022

In addition, a variety of tasks were discussed and dealt with by e-mail and WhatsApp throughout the period.

## Current member organisations of ENFA

As of June 2022, ENFA's members include:

1. Belgium: FOCUS Fibromyalgie Belgique
2. Belgium: Vlaamse Liga voor Fibromyalgie-Patiënten (VFLP)
3. Bulgaria: Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD)
4. Croatia: Udruga za oboljele od mijalgičkog encefalomijelitisa, disautonomije i fibromialgij - The Association for patients with Myalgic Encephalomyelitis, Dysautonomia and Fibromyalgia
5. Cyprus: Αντιρευματικός Σύνδεσμος Κύπρου, Cyprus League Against Rheumatism (CYPLAR)
6. Denmark: Fibromyalgi- & Smerteforeningen
7. Greece (Crete): Σύλλογος Ρευματοπαθών Κρήτης, Arthritis foundation of Crete
8. Israel: Inbar – The Israeli Association for those with Rheumatic Diseases
9. Israel: Roots for Generations
10. Italy: AISF Onlus Associazione Italiana Sindrome Fibromialgica
11. Italy: Associazione Fibromialgici “Libellula Libera”
12. Netherlands: Fibromyalgie en Samenleving (FES)
13. Norway: Norges Fibromyalgi Forbund
14. Portugal: Associação Nacional Contra a Fibromialgia e Síndrome de Fadiga Crónica (MYOS)
15. Portugal: Associação Portuguesa de Fibromialgia (APJOF)
16. Serbia: Udruzenje Obolelih od Reumatskih Bolesti Srbije (ORS)
17. Slovenia: Društvo za fibromialgijo
18. Spain: Asociación Coruñesa de Fibromialgia y Síndrome de Fatiga Crónica (ACOFIFA)
19. Spain: Coalición Nacional de Fibromialgia y Síndrome de Fatiga Crónica
20. Sweden: Fibromyalgiförbundet
21. Sweden: Reumatikerförbundet
22. United Kingdom of Great Britain and Northern Ireland: Fibromyalgia Action UK

## **ENFA Scientific Advisory Committee meetings**

This team is made up of health professionals from different areas, residing in different European countries.

The objective will be to provide ENFA with scientific advice and consultancy for projects that we intend to develop as well as for issues related to Fibromyalgia, such as research, etc.

We hope that very important projects will emerge from here that can change the paradigm for FM patients.

- 22 February 2022

Focus of the meeting:

- Presentation of ENFA and the board and SAC Members
- Presentation Managing Fibromyalgia in Europe
- Discussion about changes made from ICD 10 to ICD 11 concerning FM followed by written question about the topic sent to all members then day after

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The meeting was attended by over thirty scientists from all over Europe, ENFA board was represented by the President and the treasurer. The meeting was chaired by Karin Oie Forseth and Stefano Coaccioli board members and SAC Liaison Officers.

As a background, interesting to know that this is the second version of SAC – already 12 years ago there was an idea to create a collaboration between researchers/clinicians and patients. ENFA's expectations are along this line with patients and researchers' hand in hand. Further to make to make joint statements and to arrange webinars.

Stefano Coaccioli informed about ENFA sending a request to the European Commissaire for Health and Food Safety to declare the goals of ENFA and attaching two articles relevant to this matter. Discussion followed of the very important change of classification of FM from ICD 10 to ICD 11 a new coding for FM MG 30.01 Chronic widespread pain

The new coding is controversial among many researchers in the FM field  
The president of ENFA raised question about what consequences SAC members believe this change will imply for patients and how will the new coding of FM impact our lives as patients when it comes to diagnosing, treatment and rehabilitation?

At the summing up Stefano Coaccioli underlined that SAC as very important factor to obtain the goals of ENFA. SAC-meeting is scheduled to be held twice a year.

- Fibromyalgia Position Paper

P Sarzi-Puttini, V Giorgi, F Atzeni, et al. Clinical Experimental 2021,39,3,Suppl.130 Pg. 0186-0193

- Diagnostic and therapeutic care pathway for fibromyalgia

2021,39,3,Suppl.130 P Sarzi-Puttini, V Giorgi, F Atzeni, et al. Clinical Experimental 2021,39,3,Suppl.130 Pg. 0120-0127

## **Virtual Round Table Meetings**

### 9 th June 2021

ENFA board decided to initiate a Virtual Round Table Meeting inviting national members.

Already the first meeting was held on 9th June directly after ENFA GAM 2021. The purpose of RT meeting is that national members and ENFA board can be seen each other (even if it is in small squares!)

ENFA board wants to open up for a more direct contact, dialogue and inclusion from all members in our common issues. We want to create space to get to know each other, share experiences and strategies for future actions and events. To feel united in the network.

### 30 th March 2022

The second RT meeting was held with invited guests. Prof. Winfried Häuser and Prof Winfried Rief to give lectures about the new implemented International Classification of Diseases ICD-11. World Health Organisation and WHO and the International Associations of the Study of Pain IASP has worked together for 7 years to revise the ICD-10. This is the 11th change since 1948. Chronic pain has its own code MG.30.00. Fibromyalgia is coded MG.30.01 A new category of pain is Nociplastic pain.

Prof W. Rief worked in the task force of revising the ICD-10 he explained the lengthy process of revising the classification on the diseases. Prof W. Häuser explain his concern that FM has lost the link to musculoskeletal disorders.

Round Table meeting with invited national members continued the discussions after the lecturers. We discussed the Classification of Functionality, Disability and Health ICF.

## **Legal advice and support**

As mentioned in last year's Annual Report we lost contact to pro bono lawyer Mr. Koen Lauryssen. To continue the legal advice to all administrative formalities to be undertaken to register the decision at the competent Court of Commerce and to publish all relevant information in the Belgian Official Gazette we contacted the pro bono non-profit organisation "The Good Lobby" who advised and contacted the pro bono organisation Maarten Vanderhaeghe at Pierstone, an alliance of lawyers registered by the Brussels Bar Association.

Mr. M. Vanderhaeghe advised me and Mr. Joop van Griensven on which documents and forms we have to fill in.

## **Financial Management 2021**

ENFAS primary sources of income are from membership fees. Moving forward, attention needs to be paid to securing further funding to enable more activities to take place. The current board feel a project-based funding approach may be most useful and that any meetings should have clear objectives and demonstrable outcomes of benefit to both members and the organisation. The financial report was prepared by Mr. Joop van Griensven, former Treasurer of ENFA. Joop van Griensven has been managing payments, given he was the previous treasurer with access to the bank accounts.

## **Organisational transparency**

All decisions related to ENFA are fully agreed upon by the Board. It has been appropriate for smaller group of the board on particular tasks to work via mailings and call by WhatsApp but for decisions the entire board always Involved. Finally, ENFA regular updates the European Commission Transparency Register to ensure public Information about ENFA Is accurate. ENFA have a good collaboration with our new web host and have been able to use ENFA web site without any problems and ENFA can reach out with social media.

The board decided to revise ENFA statutes, it is an ongoing work.

## Events and appointments

The President and board members have participated in meetings arranged by organizations of which ENFA is a co-opt member therefore no voting-right.

- European Patients Forum EPF
- EPF – European Medicine Agency, EMA
- EPF – EU
- Pain Alliance Europe PAE
- Societal Impact of Pain (SIP) SIP Stakeholder Forum
- EULAR Standing Committee of PARE Meeting
- EULAR YOUNG PARE Meeting
- European Health Forum Gastein
- EuLAP
- SASP

EULAR PARE Conference - Best practice Fair: Presentation of the poster of the project E-Book "Management of Fibromyalgia in Europe", by Gunilla Göran.

### 3<sup>o</sup> International Virtual Congress on Controversies of Fibromyalgia

ENFA participated in the session "What's Behind Fibromyalgia: The role of patients' associations"

Gunilla Goran - "The Institutional Role of ENFA"

Karin Forseth - "The mission of the Scientific Committee of ENFA"

### 4<sup>o</sup> International Virtual Congress on Controversies in Fibromyalgia:

ENFA participated in Session 10 - The Patients Associations: Do we need them? With the participation of:

Gunilla Goran - "Introducing the European Network of Associations"

Joana Vicente - "Management of Fibromyalgia in Europe"

Egidio Riva - "ENFA project for an Acknowledgement's Resolution by EU Commission"

The International Fibromyalgia Awareness Day 2022 - Posts on social media

"Meet our members" activity - As you know, ENFA is formed by national associations, and each one does a wonderful job in their respective countries, and so we want to know our members better and share with our followers.

This project consists of a presentation where you expose the history of your association, objectives, projects, etc.

This presentation is made through Zoom, recorded, edited and later posted on our website and social media.

Videos: <https://youtube.com/playlist?list=PLyDgN7nyZoBk9MIUZFrCL4-1LHGq1PUuL>

Translation of the "Survey on Chronic Pain - Diagnostics and treatment" for Pain Alliance Europe.

SASP Virtual Meeting: The Many Ways of Pain

### **Research**

- FRIDA
- IMI-Patient Consortium
- FOREUM <https://www.foreum.org/>

### **Conclusion**

The intention of the board is to achieve as much as possible for the benefit of people with Fibromyalgia. With support of our network the national members and the determination of the board we will have a good chance to make this a success.

Sincerely  
ENFA Board





June 2021