



Annual Report 2020/2021

Gunilla Göran
President of ENFA

ENFA Board meetings

Between Saturday 5 September 2020 and Saturday 12 June 2021, six virtual board meetings were held and minuted on the following dates:

- 7 October 2020 18:00 – 19:30 CEST
- 5 November 2020 18:00 – 19:30 CEST
- 16 December 2020 18:00 – 19:30 CEST
- 4 February 2021 18:00 – 19:30 CEST
- 17 March 2021 19:00 – 20:00 CET
- 28 April 2021 18:00 – 19:30 CET
- 9 June 2021 18:00 – 19:30 CEST

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

Board Members elected 5th September 2020, for a period of 3 Years.



Meet the new board members

  President Gunilla Göran Reumatikerförbundet (SRA)	  Vice President Ricardo Fonseca Myos - Associação Nacional Contra a Fibromialgia e Fadiga Crónica	  Treasurer Egidio Riva AISF Onlus Associazione Italiana Sindrome Fibromialgica	  Secretary Boryana Boteva Bulgarian Organization of the Patients with Rheumatic Diseases (BOPRD)	
  Board Member Stefano Coaccioli Associazione Fibromialgici "Libellula Libera" - A.P.S.	  Board Member Eva Deurlao Fibromyalgiförbundet	  Board Member Karin Øien Forseth Norges Fibromyalgi Forbund (SRA)	  Board Member Judi Olsen Dansk Fibromyalgi-Forening	  Board Member Joana Vicente APJOF - Associação Portuguesa de Fibromialgia

Current member organisations of ENFA

As of September 2020, ENFA's members include:

- Belgium: FOCUS Fibromyalgie Belgique
- Belgium: Vlaamse Liga voor Fibromyalgie-Patiënten (VFLP)
- Bulgaria: Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD)
- Cyprus: Αντιρευματικός Σύνδεσμος Κύπρου, Cyprus League Against Rheumatism (CYPLAR)
- Denmark: Fibromyalgi- & Smerteforening
- Greece (Crete): Σύλλογος Ρευματοπαθών Κρήτης, Arthritis foundation of Crete
- Israel: Inbar – The Israeli Association for those with Rheumatic Diseases
- Israel: Roots for Generations
- Italy: AISF Onlus Associazione Italiana Sindrome Fibromialgica
- Italy: Associazione Fibromialgici “Libellula Libera”
- Netherlands: Fibromyalgie en Samenleving (FES)
- Norway: Norges Fibromyalgi Forbund
- Portugal: Associação Nacional Contra a Fibromialgia e Síndrome de Fadiga Crónica (MYOS)
- Portugal: Associação Portuguesa de Fibromialgia (APJOF)
- Serbia: Udruzenje Obolelih od Reumatskih Bolesti Srbije (ORS)
- Slovenia: Društvo za fibromialgijo
- Spain: Asociación Coruñesa de Fibromialgia y Síndrome de Fatiga Crónica (ACOFIFA)
- Spain: Coalición Nacional de Fibromialgia y Síndrome de Fatiga Crónica
- Sweden: Fibromyalgiförbundet
- Sweden: Reumatikerförbundet
- United Kingdom of Great Britain and Northern Ireland: Fibromyalgia Action UK

Legal advice and support

As Meeting Minutes from ENFA GAM 5th September stated the following was agreed: A power of attorney is granted to Laurysse. Law - Mr. Koen Laurysse, lawyer, with registered office at 1570 Galmaarden, Werfstraat 89 and VAT number 0816.665.863 to all administrative formalities to be undertaken to register the decisions at the competent Court of Commerce and to publish all relevant information in the Belgian Official Gazette. Unfortunately, the Covid-19 affected us all and despite many calls and emails to Mr. K. Laurysse who works pro bono ENFA board has not had the opportunity to complete the collaboration with Mr. K. Laurysse. Discussions are ongoing between ENFA and VFLP to ensure appropriate arrangements are in place and documented for transparency purpose.

Financial Management 2020

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. Very soon after ENFA GAM 2020 we lost contact with our webhost and after great stress and searches we found out that our host had sold his business without notifying us. We lost contact with our members and our site was down for over two months.

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
- Annual European Congress of Rheumatology EULAR 2021
- The 2nd International Virtual Congress on Controversies in Fibromyalgia
- The International Fibromyalgia Awareness Day 2021
- The president on behalf of ENFA have sent video-recorded greetings to national member.

EPF - 2021-2026 Strategic Plan – Second Membership Consultation

2 September 2020 on work in progress, goals and the roadmap towards 2026. ENFA President Gunilla Görán attended the virtual meeting.

EPF 2020-2021 Extraordinary General Meeting (EGM) 3rd of October.

EPF current Constitution does not allow EPF to hold online General Meetings without the prior written approval of all its voting members. EPF online AGM in April 2020 was legally possible thanks to a temporary Royal Decree by the Belgian government that allowed online General Meetings even if not stated in the Constitution of the association. Unfortunately, such Decree has not been extended. The Belgian law allow us to organise an online general meeting and online voting if all full members of EPF agree. ENFA President Gunilla Görán attended the virtual meeting.

EPF Knowledge Transfer Programme 10 November 2020.

Boryana Boteva leader of the programme and ENFA Secretary introduced the programme for the ENFA Board. Health Technology Assessments (HTAs) assess whether a new pharmaceutical innovation works better, equally well, or worse than existing alternatives, while also considering its cost implications for the patient and impact on healthcare systems. Providing national policy makers with evidence-based information, HTAs help shape health policies that are safe, effective, patient-focused and cost-effective and guide informed reimbursement decisions. However, the type and level of patient involvement in HTA processes across Europe is varied, reflecting the different rationale, motivation and approach applied in each country. The debate on including patients in HTA was highlighted as legislation for an EU-wide HTA was being developed, as multiple patient organizations called on EU policymakers to guarantee an adequate involvement of patients in all HTA activities. Failing to incorporate patients is a missed opportunity as this group can offer important perspectives on how a new technology can affect the daily routine, treatment, capacity to work and overall health of someone living with a health condition. Involvement of patients in HTA activities, including joint consultations, early dialogues, scoping and assessments can ensure meaningful involvement that leads to improvements in patient outcomes.

EPF HTA Patient Advocacy Summit | October 13, 20 and 27, 2020,

EPF Telemedicine & E-Health Webinar – what are we really talking about?” Speakers: Dr. Nick Guldemon, who is currently Associate Professor Integrated Care and Technology at Erasmus School of Health Policy & Management. He is advisor for the Dutch House of Representatives and board member of the Innovative Medical Device Initiative IMDI.nl and a member of the commission on the national eHealth implementation agenda. Jessie Cunnett Associate Director, Head of Health and Social at Traverse, a consultancy focusing on people development. Traverse partnered up with EPF UK member National Voices to design a research on telemedicine and remote consultation. Dr. Marcin Rodzinka, Mental Health Europe Advocacy and Policy Officer, who will present the view of his community on e-health and telemedicine. The three-series was attending by ordinary member Karin Øien Forseth and President Gunilla Göran on 23 October.

EPF Data Saves Lives (DSL) Under the Magnifying Glass: Workshop 9 December 2020 Shaping our DSL toolkit to support practical implementation of health data sharing initiatives In order to support patient groups to put health data sharing initiatives in place and raise awareness of the value of responsible health data sharing among their communities, we are developing a DSL toolkit in 2021. The content will be shaped by you – our multidisciplinary stakeholders! We'd like you to think about what guidance you'd like to see in the toolkit, what kind of templates would be helpful and what information on the topic of health data should be included. Call for topics to raise awareness of in 2021. Our activities in 2020 have raised awareness of a variety of different topics relating to health data, from the importance of using real-time data during the COVID pandemic, to bridging differences in access to health data between West and Central/East Europe. We'd like you to think about topics you'd like to see explored in 2021.

EPF – European Medicine Agency, EMA Virtual public meeting on COVID-19 vaccines 11 December 2020 In October, EPF and EURORDIS wrote jointly to Guido Rasi, then Executive Director of the EMA, requesting a public meeting on COVID-19 vaccines during the COVID-19 pandemic, EPF has been keeping a close eye on the pandemic response not only of the European Commission but also the EMA. We are included as patient representative in the EMA's COVID-19 Task Force (ETF) and follow developments closely in the Patient and Consumer Working Party (PCWP). President Gunilla Göran and Board Member Karin Øien Forseth attended the virtual public meeting.

EPF Extraordinary General Meeting 23 January 2021

EPF – EU "Evaluating the Cross-Border Healthcare Directive 23 March 2021: have patients' rights improved a decade on? "

EPF 2021 Virtual Annual General Meeting (AGM) on Saturday 17 April 2021. ENFA represented by President, Gunilla Göran

EPF - European Commission Webinar “Shaping a European Health Data Space for patients and with patients” 21 May 2021. jointly organised with the European Commission – DG Sante. The European Commission kindly shared the presentation they intend to use to introduce the EHDS and the main consultation elements. In the presentation, following general information on the EHDS, you will find slides dedicated to each pillar of the EHDS/Consultation with questions and open issues on which the EC is looking forward to hear your thoughts and reflections. This joint EPF and European Commission webinar aims to inform and engage EPF members and the broader patients’ community on the consultation process for the European Health Data Space (EHDS). During the webinar, following an introduction on the recent EPF work on the topic, DG SANTE representatives will share the overall plan for the EHDS, and discuss how the upcoming consultation will seek inputs on its core pillars. Following the presentations, the participants will be able to engage with questions and by sharing their views on the EHDS elements from the patients’ perspective.

Pain Alliance Europe PAE Survey 2021 Diagnostics and Treatment available in fifteen languages. Several of ENFA boardmembers have been translating PAE surveys to their own national languages. This survey is a second version of the survey conducted in 2017 . It will compare the responses from 4 years ago with the situation now, to see if there have been improvements over the past four years.

PAE will use the survey results as a snapshot of the lives of people with chronic pain across Europe - the picture may vary from country to country. However, the results will support our efforts to raise awareness among decision makers and policy makers.

Societal Impact of Pain (SIP) SIP Stakeholder Forum was held a virtual meeting 28 October 2020. President Gunilla Göran has been involved in SIP meetings in the last four years, SIP has now changed its organization and invite a smaller group of stakeholders to National Platform Call - Meetings.

SIP National Call - Meeting virtual 2020-2021 on 26 November, 8 February, and 6 May. ENFA represented by the President.

The International Fibromyalgia Awareness Day 2021 On Wednesday 12 May 2021, ENFA invited the National Members to send their 12th of May celebrations to ENFA website for publishing. President Gunilla Göran send a message “We are continuing to build strong association for Fibromyalgia”

EULAR Standing Committee of PARE Meeting virtual on 25 November 2020. ENFA was represented by President Gunilla Göran, Treasurer Egidio Riva, ordinary member Joana Vicente and Karin Oie Forseth.

EULAR Standing Committee of PARE Meeting virtual. EULAR Liaison Network This year 30 November election takes place to the United Nations' Committee on the Rights of Persons with Disabilities (CRPD). Nine members is to be elected for the Committee. The Liaison Network nominated the Danish candidate Sif Host to (CRPD). ENFA President Gunilla Göran attended the meeting.

EULAR PARE Webinar 12 November "Covid-19 and vaccination in RMD patients: what we know so far". The webinar was attended by the President Gunilla Göran.

EULAR YOUNG PARE first virtual online seminar 28 January 2021 "How Covid-19 affects the mental health of young people with RMDs". The webinar was attended by ENFA President Gunilla Göran and ordinary board member Joana Vicente also a member of the Young Pare Working group. Joana Vicente testified by a video about how to live during the lockdown.

EULAR PARE Webinar 23 February on the topic "COVID-19: Update on EULAR registries and vaccination". ENFA was represented by the President Gunilla Göran.

EULAR PARE ASSEMBLY Meeting, virtual, 29 March 2021. EULAR is becoming the European Alliance of Associations for Rheumatology so there for the EULAR Statutes have changed and there are also new By-Laws – and for the first-time official By-Laws for the PARE Committee. President Gunilla Göran was attending the meeting.

European Health Forum Gastein 11 March 2021 Webinar - Towards a European Health Union: "Have we failed to protect Europe's people?"

EULAT PARE Assembly, 2 June 2021 - President Gunilla Göran was attending the meeting.

ENFA was named as one of the organizations with special status in EULAR.



June 2021