



European Network of Fibromyalgia Associations (ENFA)

Annual report 2019/20



Foreword from the President

I am delighted to be able to share with you some of the highlights of the work achieved by the European Network of Fibromyalgia Associations (ENFA) in 2019 and 2020. I hope you will agree that as well as increasing our visibility, we have also taken the necessary steps to reflect, learn and begin to implement progressive changes to the organisation to ensure its sustainability for the community into the future.

The COVID-19 pandemic has demonstrated that despite the best intelligence, sometimes we cannot plan for every eventuality. The same could be said for my tenure as President of ENFA. Unfortunately, since my appointment in May 2019, difficult personal events have mandated me to reflect on my voluntary commitments. So, it was with a heavy heart that I announced my resignation as President and Board Member of ENFA, as well as a Director of Fibromyalgia Action UK.

It has been a pleasure to lead ENFA with my fellow board members since May 2019, and to have been a Board Member since May 2018. It has been warming to see ENFA's membership grow, as more organisations across Europe share our vision for a brighter future for those living with fibromyalgia. I will always stand in solidarity with this community and thank each and every individual who gives their time and energy to our cause.



Simon

Simon R. Stones BSc (Hons) MMRS
President



Governance

ENFA Board meetings

Between Saturday 18 May 2019 and Saturday 05 September 2020, seven virtual board meetings were held and minuted on the following dates:

- Thursday 20 June 2019 18:00 – 19:45 CEST
- Friday 12 July 2019 18:00 – 18:45 CEST
- Monday 07 October 2019 16:00 – 17:00 CEST
- Wednesday 02 December 2019 19:00 – 20:00 CET
- Monday 03 February 2020 20:00 – 21:00 CET
- Monday 22 June 2020 20:00 – 21:30 CEST
- Tuesday 04 August 2020 19:00 – 20:00 CEST

In addition, a variety of tasks were discussed and dealt with by email throughout the period.

New member organisations of ENFA

ENFA welcomed three new member organisations:

- Bulgaria: Bulgarian Organization of the Patients with Rheumatic Diseases;
- Israel: Inbar – The Israeli Association for those with Rheumatic Diseases
- Italy: Associazione Fibromialgici “Libellula Libera” – A.P.S.

Current member organisations of ENFA

As of August 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: Dansk Fibromyalgi-Forening
- 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 Jovens com 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

After the 2019 General Assembly, as part of the membership survey, members were asked to update their general email



address, nominated liaison person, and liaison person's email address. Furthermore, a mapping process also commenced to identify organisations from other European countries who may be interested in joining ENFA.

Legal advice and support

Through the intervention of ENFA's President, Simon Stones, Vice-President, Gunilla Göran, and Treasurer, Ricardo Fonseca, ENFA have now sought the professional advice and support of Lauryssen.law – Mr Koen Lauryssen, who will act as a power of attorney for ENFA forthwith to ensure ENFA is fully compliant with the necessary legal requirements for international non-profit associations registered in Belgium. Some of these necessary steps have been unintentionally overlooked but are now in hand. Furthermore, this process will also enable full control of ENFA's finances by the elected Board. All of the necessary steps are in place, ready to be implemented upon the election of the new Board during the General Assembly on Saturday 05 September 2020. Finally, ENFA's current registered address in Belgium is hosted by Belgian member organisation, Vlaamse Liga voor Fibromyalgie-Patiënten (VFLP). Discussions are currently ongoing between ENFA and VFLP to ensure appropriate arrangements are in place and documented for transparency purposes.

Financial management

Expenditure in previous financial years has been unsatisfactory. In 2019, ENFA suffered a financial loss of € 3,532,13. When the current Board were elected, it was agreed from the outset that a more disciplined, and cautionary approach was required. ENFA's



primary sources of income are from membership fees (€ 100 per organisation per annum), and if secured, unrestricted educational grants from industry sponsors. In 2019, € 3,500.00 was secured and gratefully appreciated from Grünenthal. However, in 2019, the Annual Conference and General Assembly alone cost € 8,055.77. This was significantly more than the organisation's income. Therefore, the Board had provisionally agreed to either host a virtual Annual Conference and General Assembly 2020 or attempt to secure funding to host a members' meeting on the back of a formally organised conference (e.g. the International Controversies of Fibromyalgia). However, this was discussed prior to the COVID-19 pandemic, which ultimately forced ENFA to organise a virtual General Assembly for 2020. 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 ENFA.

Organisational transparency

As part of ENFA's commitment to improving its transparency, ENFA's President, Simon Stones, has firstly ensured that all decisions related to ENFA are fully agreed upon by the Board. Where it has been appropriate for a smaller group of the Board to work on particular tasks, it has been made clear that regular email and/or video conference updates are required to ensure equity of knowledge and transparency in decision making across the leadership team. Similarly, the Board are committed to increasing transparency with its members, particularly through the annual report and financial report, as well as



through discussions during the General Assembly. The current President, Simon Stones, as part of his transition process to the incoming President and Board, has also listed some recommendations to ensure good governance for ENFA in the future. The Board have also taken the decision to ensure that vacancies to join the Board are advertised to all ENFA members. These are then scored against a matrix by the Board to help to minimise any selection bias. Finally, ENFA regular updates the European Commission Transparency Register to ensure public information about ENFA is accurate.

Strategic vision

Upon appointment of the new Board, the President initiated the development of a new, five-year 2025/2026 strategy for ENFA, focussed around seven areas of development. These were sent for consultation with ENFA member organisations, with feedback reported later on in this report. This strategy now needs to be finalised and approved by the Board for implementation.

File management

Historically, ENFA had no formal or transparent file management system, accessible by all Board members. This was problematic and caused inefficiencies in ENFA's operations. The President, Simon Stones, established a shared file management system to enable all ENFA-related files to be digitally stored. This enables tracking to take place on activities over previous years, as well as increasing transparency for Board members, present and future.



Communication with members

ENFA now use Mailchimp to primarily communicate with ENFA members by email, with ad-hoc emails making members aware of ENFA- and related-activities coming from either the President or Secretary.

Furthermore, to aid sharing of information, a closed Facebook group for members was established:

<https://www.facebook.com/groups/enfamembers>, as well as WhatsApp chat group for members: <https://chat.whatsapp.com/GnfVpEnfl2plvuoktNoVmO>.

Communication with the public

ENFA are active across a variety of social media platforms, including Facebook, Instagram, LinkedIn, and Twitter with the username @ENFA2008. The hashtag #ENFA is used with generic posts, followed by the year for specific conferences and general assemblies, e.g. #ENFA2019 and #ENFA2020. ENFA also maintains its website at www.enfa-europe.eu, as well two email accounts: president@enfa-europe.eu which is access by the President, and contact@enfa-europe.eu which is accessed by the Vice-President, Treasurer and Secretary.

Marketing and design

Following the 2019 General Assembly, ENFA's visual style was updated, including the introduction of a modernised logo, associated branded materials, and colour scheme. This has been applied across print and digital media.



Projects

Understanding the needs and expectations of ENFA members

Between September and November 2019, a survey was disseminated to ENFA member organisations to better understand their relationship with ENFA, in order to improve ENFA's capacity to work collaboratively on a national and European level. Sixteen organisations responded.

The top three reasons for joining ENFA were: i) To network with other associations; ii) To keep up with the latest news from Europe; and iii) To be part of a united patient and carer movement. Around three quarters (79%) followed the work of ENFA, with 90% saying that they definitely received communication from ENFA. Almost all (95%) organisations had communicated with ENFA in the past year, and almost all (95%) had participated in ENFA-organised events, typically the Annual Conference and/or General Assembly.

The key priorities identified included: i) Creating a regular electronic newsletter; ii) Creating a virtual platform for members; iii) Hosting webinars/other online activities; iv) More frequent personalised contact; and v) Creating a closed Facebook group for members.

The top three potential barriers for member organisations working with ENFA were: i) Lack of resource and/or time within the organisation; ii) Challenges in language/communication; and iii) Lack of clear direction from ENFA.



ENFA's current strengths in ascending order were ranked as: i) Networking with other European organisations; ii) A new leadership team with new and young individuals; and iii) Pooled experience/expertise from member organisations.

ENFA's top three current weaknesses were identified as: i) Limited funding opportunities; ii) limited presence on social media; and iii) Lack of paid secretariat/staff.

Members ranked ENFA's top three opportunities for the future as: i) Research interest in fibromyalgia; ii) Interdisciplinary partnerships with other communities (e.g. the chronic pain community) and iii) Popularity of awareness-raising for fibromyalgia.

It was felt that in the next five years, ENFA's top three projects to promote should be: i) Research into the pathophysiology of fibromyalgia; ii) Research into treatments for fibromyalgia; and iii) Awareness-raising about fibromyalgia. Most members (90%) said that they would like to work more closely with ENFA on specific projects by email and at pre-organised meetings such as the General Assembly. Around one third (63%) said they would join a specific advisory board, and around one fifth (21%) expressed interest in co-funding specific projects.

ENFA's provisional 2025 strategy was then presented to members for voting and suggestions. Members were presented with seven strategy statements and were asked to prioritise on a scale of 1-7, with one being most important, and 7 being least



important. Scores were calculated for those ranked 1-4, into descending order of importance:

- 90% favoured ‘We want everyone to understand fibromyalgia’;
- 90% favoured ‘We want to build strong, interdisciplinary partnerships with research institutions and other bodies’;
- 84% favoured ‘We want to stimulate and support world-class research’;
- 84% favoured ‘We want to focus on the specific needs of children, young people, young adults and families’;
- 79% favoured ‘We want to support and empower people living with fibromyalgia’;
- 79% favoured ‘We want to unite local and national patient organisations’;
- 63% favoured ‘We want to support and power families, friends and carers’.

From this ranking process, around two-thirds of members generally favoured the contents of ENFA’s 2025 strategy, highlighting specific areas of focus more important to them (e.g. public understanding and research focus), versus less important areas of focus (e.g. supporting families, friends and carers).

Finally, free-text suggestions included:

- Assigning a Board member to prepare ENFA reports;
- Assigning a Board member to be the liaison person with member organisations;
- Greater empowerment of national organisations by ENFA.



Fibromyalgia position paper/consensus document

ENFA Ordinary Board Member, Egidio Riva, has been leading and representing ENFA as part of a voluntary, European initiative to develop a position paper/consensus document on fibromyalgia. In summary, the position paper is being coordinated by Professor Sarzi Puttini (Italy), alongside an international team of professionals and endorsement from ENFA. It is anticipated that the paper will be presented and hopefully endorsed by scientific societies in Europe, before being presented to the European Parliament in order to have a common diagnostic and therapeutic programme for people with fibromyalgia. There are plans to include a session at the upcoming International Congress on Controversies in Fibromyalgia to enable ENFA, its members and other relevant delegates to be able to contribute further to this paper.



Events and appointments

ENFA Annual Conference and General Assembly 2019

The ENFA Annual Conference and General Assembly 2019 was held on Saturday 18th May 2019 in Heraklion (Crete), Greece, with support from the Σύλλογος Ρευματοπαθών Κρήτης, the Arthritis Foundation of Crete. Titled 'A holistic approach to the management of fibromyalgia across the life course', the conference enabled delegates from across Europe to discuss strategies for individualising the management of fibromyalgia by focusing on the physical, psychological and social wellbeing of people living with fibromyalgia.

Speakers at the 2019 annual conference include former President of ENFA, Souzi Makri, Consultant Rheumatologist, Nikolaos Kougkas, Health Psychologist, Georgia Dimitraki, Roots for Generation member, Lizy Zommer, and Cyprus League Against Rheumatism member, Andreas Iacovou.

Following the annual conference part of the programme, the formal General Assembly was held. Twelve European countries were represented, including: Belgium, Cyprus, Denmark, Greece, Israel, Italy, Norway, Portugal, Serbia, Slovenia, Sweden and the United Kingdom. During the General Assembly, Souzi Makri stepped down as President, and a Board Member. Souzi was thanked for her outstanding contributions to ENFA, and the wider fibromyalgia community. Mateja Kržan also stepped down as Vice-President but wished to remain an ordinary board Member for a further year before her term of office formally ended. Prior to the General Assembly, Joana Vicente also stepped down from



the Board due to competing commitments. Joana was thanked for her contributions over the past year.

From the then current board, ENFA members unanimously agreed to elect Simon Stones as President, Gunilla Göran as Vice-President, and Ricardo Fonseca as Treasurer. Three new members were also elected to the board. Eva Deurloo was elected Secretary representing Fibromalgiförbundet (Sweden), Judi Olsen was elected an ordinary board member representing Dansk Fibromyalgi-Forening (Denmark), and Egidio Riva was elected an ordinary board member representing Associazione Italiana Sindrome Fibromialgica (Italy).

In summary, the new board of ENFA which emerged from the general assembly consisted of:

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

A summary and full report of the 2019 annual conference and general assembly was produced, and is available at the following link: <https://www.enfa-europe.eu/annual-reports/>.



European Patients' Forum (EPF) Capacity Building Module on Empowering Leadership and Positive Governance

In September 2019, Treasurer Ricardo Fonseca completed the EPF Capacity Building Module on Empowering Leadership and Positive Governance. You can read Ricardo's reflections here:

<https://www.enfa-europe.eu/epf-capacity-building-module-on-empowering-leadership-and-positive-governance/>.

International Congress on Controversies in Chronic Pain in Systemic Rheumatic Diseases

On Wednesday 25 September and Thursday 26 September 2019, ENFA was represented at the International Congress on Controversies in Chronic Pain in Systemic Rheumatic Diseases by its Ordinary Board Member, Egidio Riva. The event was held in Amsterdam, The Netherlands.

Fibromyalgia Registry Meeting

A meeting of an international team of healthcare professionals and researchers with an interest in fibromyalgia took place on Monday 30 September 2019 in Dublin, Ireland. ENFA was going to be represented by its President, Simon Stones, but unfortunately, he was unable to attend, and another representative could not be sought from the Board. Therefore, input was provided by email.

European Patients' Forum (EPF) – Medicines for Europe Dialogue

On Friday 25 October 2019, ENFA was represented at the EPF Medicines for Europe Dialogue by its Vice-President, Gunilla Göran. The event was held in Brussels, Belgium.



Societal Impact of Pain (SIP) Platform Symposium

On Thursday 07 November 2019, ENFA was represented at the SIP Platform Symposium by its Vice-President, Gunilla Göran. The event was held in Brussels, Belgium.

1st European Patients' Forum (EPF) Congress 2019

Between Tuesday 12 November and Thursday 14 November 2019, ENFA was represented by its Vice-President, Gunilla Göran, at the 1st EPF Congress 2019, which focussed on advancing meaningful patient involvement. The event was held in Brussels, Belgium.

European Patients' Forum (EPF) 2020 Annual General Meeting

On Saturday 25 April 2020, ENFA was represented by its President, Simon Stones, at the EPF 2020 Annual General Meeting (AGM), which was held virtually.

European Patients' Forum (EPF) Ethics Committee and Working Group on Access to Healthcare Systems

On Saturday 25 April 2020, ENFA Ordinary Board Member, Mateja Kržan, was elected to the newly formed EPF Ethics Committee for a tenure up until 2023: <https://www.enfa-europe.eu/mateja-krzan-elected-to-the-epf-ethics-committee/>. In addition, Mateja is also a member of the EPF Working Group on Access to Healthcare Systems.



International Fibromyalgia Awareness Day 2020

On Tuesday 12 May 2020, ENFA launched its 'Are you with us?' social media campaign, coinciding with International Fibromyalgia Awareness Day, to help raise awareness and push for more people to speak up against fibromyalgia: <https://www.enfa-europe.eu/international-fibromyalgia-awareness-day-2020/>.

European League Against Rheumatism (EULAR) Standing Committee of PARE Meeting 2020

On Wednesday 03 June 2020, ENFA was represented by its President, Simon Stones, at the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) meeting, which was held virtually. ENFA are co-opted members of the EULAR Standing Committee of PARE, and so have non-voting rights.

21st Annual European Congress of Rheumatology 2020

Between Wednesday 03 June 2020 and Saturday 06 June 2020, ENFA was visible at the 21st Annual European Congress of Rheumatology 2020, which took place virtually. ENFA was represented by several board members, including the President, Simon Stones.

Pain Alliance Europe (PAE) 2020 Annual General Meeting

On Wednesday 24 June 2020, ENFA was represented by its President, Simon Stones, at the PAE Annual General Meeting (AGM), which was held virtually.