



European Network of Fibromyalgia Associations (ENFA) Annual Activity Report 2018

21st EULAR Annual European Conference of PARE

ENFA was represented by the Vice President of ENFA at the 21st EULAR Annual European Conference of PARE which was held in Brussels, Belgium from Friday 16th to Sunday 18th February 2018, and it was hosted by [ReumaNet](#). The 2018 theme, 'Don't Delay, Connect Today' was built on the theme of 2017 conference in Portugal, with the aim of working together towards prevention, early diagnosis and access to care of rheumatic and musculoskeletal diseases (RMDs). The president of ENFA was invited to participate as a facilitator.

EPF 2018 Annual General Meeting

On the 14th April 2018, ENFA was represented by its President at the European Patients' Forum (EPF) 2018 Annual General Meeting (AGM). On the 15th April 2018, the Leadership meeting took place with the following objectives:

- Raising awareness on the EP elections
- Design together the patients' community messages and to ensure that health is a key topic in the election.

ENFA Annual Conference and General Assembly 2018

The ENFA Annual Conference and General Assembly 2018 was held between 11th and 12th May 2018 in Malta, in cooperation with ME/CFS Alliance Malta. The event aimed at supporting people with fibromyalgia and coincided with the International Fibromyalgia Awareness Day. ENFA hosted two events on 11th and 12th May 2018: A Parliamentary session at Parliament building and a conference at San Anton Palace, Balzan.

The two-day event was placed under the distinguished patronage of H.E. President of Malta Marie Louise Coleiro Preca. The general title of the Conference was "In every disability there is an ability". A report was produced by Board Member, Simon Stones, and is available here:

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<https://www.enfa-europe.eu/wp-content/uploads/2018/07/ENFA-Report-2018.pdf>

Here is what the President said during the opening ceremony of the European Civic Prize on chronic pain and fibromyalgia:

“I believe that the issue of chronic pain must take on more importance within our healthcare systems and policies, both at the widest possible European level, to push for a proactive and effective change.”

The new board of ENFA which emerged from the GA consisted of:

- President: Souzi Makri
- Vice-President: Mateja Krzan
- Secretary: Gunilla Göran
- Treasurer: Simon Stones
- Member: Joana Vincente
- Member: Ricardo Fonseca

13th Patients' Rights Day

On the 23rd May 2018, the President of ENFA participated at an event for the 13th Patients' rights day at the European Parliament and gave a presentation on the topic “improving the therapeutic adherence, the patient perspective.”

Steering Committee Meeting of the SIP Platform

On the 25th October 2018, the President and the Secretary of ENFA participated in the Steering Committee of the SIP platform in Brussels. The aims of the Steering Committee were to allow for the different initiatives on the National level to present their work; and advance with the work of the joint statement. The Steering Committee served as platform for meeting with potential endorsees, the exchange of best practises amongst patients, experts and policy makers around future policy on chronic pain.

Plans for the future

In the beginning of 2018, the European Commission selected SIP as one of the three thematic networks within the Health Policy Platform, in which SIP will be working towards a joint statement on the Societal Impact of pain in the European Union.

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Questions to the European Commission

In July 2018, we sent the following questions to the European Commission:

Γιατί δεν έχουν λάβει έγκριση στην Ευρώπη από την Ευρωπαϊκή Επιτροπή Φαρμάκων (EMA) τα τρία σκευάσματα που εγκρίθηκαν στις ΗΠΑ για την Ινομυαλγία(4), από τον αντίστοιχο Οργανισμό FDA, για την ανακούφιση των συμπτωμάτων και κατ' επέκταση την Παραμονή στην εργασία;

Γιατί δεν εφαρμόζεται η χρήση του fMRI για την διάγνωση της Πάθησης ώστε να απόδεικνύεται η ύπαρξη κάποιας αναπηρίας;

Why have European Union Medicines Committee (EMA) not approved the three US approved Fibromyalgia preparations for symptom relief and hence stay at work in Europe? Why is fMRI not used to diagnose the condition to prove the existence of a disability?

As an answer, we were referred to the reasons why EMA has not granted a marketing authorization to these compounds. For the second question, the EC answered that diagnostic tools fall within the responsibility of the member states.

Patients as Partners Conference 2019

In January 2019, during the “Patients as partners” conference, the President of ENFA participated on a panel discussion with the topic “Patient advocacy: What impact is it having on clinical trials”.

DIA Conference 2019

In March 2019, the President of ENFA was offered a fellowship to participate at the DIA conference in Vienna and spoke on the topic ‘GDPR and clinical trials: The Patient Perspective’.

1st International Controversies of Fibromyalgia 2019

In March 2019, the President of ENFA presented the work of ENFA at the 1st “International Controversies of Fibromyalgia” conference. A report was produced by Eva Deurloo and it is available here: <https://www.enfa-europe.eu/fibromyalgia-2019/>

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Biosimilars Advocacy Meeting

In March 2019, the President and the Secretary of ENFA were invited to participate in an advocacy meeting and a subsequent conference in Amsterdam, on Biosimilars. The meeting was organized by Medicines in Europe.

22nd EULAR Annual European Conference of PARE

In April 2019, the President of ENFA and Eva Deurloo participated at the 22nd EULAR Annual European Conference of PARE conference in Prague, Czech Republic. The general topic was a continuation of the “Don’t delay connect Today-time2work”.

EPF 2019 Annual General Meeting

In April 2019, the President represented ENFA at the EPF AGM and Leadership meeting.