

REPORT



European Network of Fibromyalgia Associations (ENFA) Annual Conference and General Assembly 2019

Saturday 18 May 2019

Heraklion, Crete, Greece

A holistic approach to the management of fibromyalgia across the life course

The European Network of Fibromyalgia Associations (ENFA) Conference 2019, with support from The Arthritis Foundation of Crete, took place on Saturday 18 May 2019 in Heraklion, Crete, Greece. 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.



The President of ENFA, Souzi Makri, welcome delegates to the ENFA Annual Conference 2019.

Striving for individualised, multifaceted care

The conference aimed to inform and empower representatives of Fibromyalgia associations throughout Europe, by providing them with the opportunity to meet international colleagues to discuss and reflect on the current fibromyalgia landscape, while developing and strengthening the European network. The conference also aimed to highlight the complexity of fibromyalgia and chronic pain, due to the diverse symptoms which usually delay diagnosis for several years. In addition, the conference demonstrated how the approach to managing fibromyalgia should be individualised and multifaceted, comprising of physical therapy, pharmacological therapy, psychological therapy and social support, made through shared decisions between the individual with fibromyalgia, their family and appropriate professionals. Through such a holistic approach, delegates discussed how management can be effective and thus how individuals with fibromyalgia can remain active, be independent and have a good quality of life. A life course focus was also highlighted, given that fibromyalgia can affect people of all ages - including young people.

Welcome from the Arthritis Foundation of Crete - καλως ηρθατε!

The conference was opened by **Roula Angelidaki Stara**, Vice President of **The Arthritis Foundation of Crete**. Roula introduced the Foundation, which was established in 2003 by a group of people with rheumatic and musculoskeletal diseases (RMDs). It is managed entirely by volunteers, and as of May 2019, had 934 members. The Foundation collaborate with a variety of organisations, and are founding members of **AGORA**, an umbrella platform representing patient organisations of people with RMDs in Southern Europe, and **Reumazein**, the Panhellenic Federation of Patients, Parents, Caregivers and Friends of Children with Rheumatic Diseases Association.



Social media engagement

Throughout the conference, delegates and external followers were able to engage in the conference through Facebook, Instagram and Twitter, using the hashtag **#ENFA2019**.

Although they are not a large organisation, they offer a lot of activities organised for members. A number of social and cultural events are arranged, giving people living with RMDs a platform for sharing experiences. One of the key objectives here is to motivate people to become and remain active, despite symptoms. Examples of activities the Foundation have undertaken to fulfil their mission include renovating the short stay hospital room where patients receive biological treatment, **an inspirational photo album** with photos of people who carry on with their life and interests despite health issues and the implementation of a self-management education programme for members. Another interesting initiative, that could increase effectiveness of care, include shared decision-making workshops between healthcare professionals and patients to encourage mutual understanding.

The Foundation recently held a campaign for early detection of RMDs across the island of Crete. Part of the campaign was screening for RMDs by a doctor free of charge, which resulted in a number of referrals. In addition, the Foundation has received the volunteer input from local healthcare professionals, in particular with their helpline, which is staffed by two psychologists to answer questions two days per week in the evening. Since launching in 2018, 225 people have made use of the helpline.

Recent activities of ENFA

Souzi Makri, President of ENFA, proceeded with an overview of activities carried out by ENFA since 2018, as well as some legacy activities which have shaped ENFA to date. At the time of the meeting, ENFA had 18 member organisations. One of the earliest achievements of ENFA was the petition to the European Parliament to recognise fibromyalgia as a disease in Europe.

This led to Members of the European Parliament adopting the written declaration 69/2008 on fibromyalgia. It was an important milestone that opened a path for ENFA's future endeavours. However, Souzi highlighted the challenges in obtaining funding within the area of fibromyalgia, given the current situation and a lack of targeted treatments approved for fibromyalgia management within Europe. During 2018, ENFA continued to advocate for the approval of three medicines that are currently licensed by the Food and Drug Administration (FDA) to treat fibromyalgia in the United States of America. These questions, alongside the question of exploring why functional magnetic resonance imaging (fMRI) is not accepted as a method for diagnosis, were submitted to the European Commission.

In 2018, international fibromyalgia awareness day coincided with the **ENFA Annual Conference and General Assembly in Malta**. The event, titled 'In every disability there is an ability', included a session in the Parliament of Malta, alongside an array of distinguished speakers which resulted in valuable media exposure.



Delegates representing ENFA at the The International Congress on Controversies in Fibromyalgia in Vienna, Austria.

In March 2019, ENFA attended The International Congress on Controversies in Fibromyalgia in Vienna, Austria. This was the first international congress gathering experts from across the world to discuss scientific advances in fibromyalgia. There was a wealth of discussion on both genetic and environmental risk factors, as well as medicinal cannabis. **A report can be viewed here.**

Souzi then went on to mention the 11th revision of the ICD (ICD-11), where fibromyalgia is classified under MG30.01 Chronic widespread pain. At this moment in time, it is difficult to predict the practical implications of this change. Souzi went on to highlight some interesting research published in January 2019 regarding proteins identified in spinal fluid that are potentially associated with chronic pain, including ten proteins potentially associated with chronic pain in fibromyalgia. **The article was published here.** Souzi concluded that the development of a reliable biomarker for fibromyalgia would be incredibly useful and only further research can help us to move closer to such target.

The clinician's perspective

Consultant Rheumatologist, **Nikolaos Kougkas**, then discussed the holistic approach to fibromyalgia treatment from the perspective of a clinician. Nikolaos admitted that people with fibromyalgia often complex health problems and there are few effective treatments to offer with sufficient evidence behind them. Importantly, he felt that people with fibromyalgia require a lot of patience and time to navigate from symptom-onset to appropriate management of their disease, which is often scarce in the doctor's office.

Nikolaos felt that after a prompt diagnosis, a structured programme of patient education should be offered at the earliest opportunity. Any treatment plan should be individualised according to the needs of the patient, with decision-making shared between the patient, their carer if appropriate, and healthcare professionals. Any treatment plan should be preceded by a comprehensive assessment followed by a multidisciplinary approach offering both non-pharmacological and pharmacological treatment. According to Nikolaos, the most important part of the treatment must always be patient education.

The suggested core components of the non-pharmacological part of the multidisciplinary rehabilitation programme included: Cognitive Behavioural Therapy (CBT), hot water therapy with or without exercise, relaxation and mindfulness techniques, physiotherapy and psychological support.

Pharmacological treatments that have been prescribed include analgesics and non-steroidal anti-inflammatory drugs, though there is limited evidence behind the effectiveness of these medicines. Certain antidepressant and anticonvulsant medicines are often offered in low doses to people with fibromyalgia, with the desired effect of the medicine relieving pain, improving sleep, and reducing fatigue.

Nikolaos emphasised that in order to find the optimal pharmacological treatment, one may have to try different combinations. The first choice should always be the non-pharmacological options, including exercise where possible, following the updated **European League Against Rheumatism (EULAR) recommendations for the management of fibromyalgia.**

“ Any treatment plan should be individualised according to the needs of the patient.”

A discussion about which medical discipline is the most appropriate to take care of fibromyalgia ensues. In Greece, the GPs tend not to have a lot of experience and therefore refer people with suspected fibromyalgia to rheumatologists. In Portugal, there is a dilemma as rheumatologists tend to say that fibromyalgia is a disease of the central nervous system, and want neurologists to take care of patients, whereas neurologists disagree, and patients often end up falling into a gap within the system. Delegates expressed different points of view concerning the most appropriate discipline to take care of fibromyalgia.

However, the clear message was that input from multiple healthcare professionals across a range of disciplines, in a timely and co-ordinated manner, is needed.



Nikolaos Kougkas sharing the rheumatologist's perspective.

Psychosocial factors in fibromyalgia

Health Psychologist, **Georgia Dimitraki**, then facilitated workshop looking at the role of psychosocial factors in fibromyalgia. Georgia began by presenting the most important techniques for pain management-based CBT, informed by chronic pain theories. Modern medicine's understanding of the process of chronic pain stems from the Gate Control Theory, which had a notable impact on the study of pain because it recognised that psychological factors can play an important role in the experience of pain.



Georgia Dimitraki facilitating a workshop exploring psychosocial factors in fibromyalgia.

According to the gate control theory, pain messages travel from the periphery of the body through nerve 'gates' in the spinal cord and up to the brain. The theory uses the metaphorical concept of 'gates' in the central nervous system to describe how some pain messages are allowed to get through and reach the brain, while others are blocked. Things which can 'open the gate' include muscle tension, anxiety, depression, too much or too little activity, poor diet, and a limited support network. On the other hand, things that can 'close the gate' include certain medicines, stability, relaxation, distraction, pacing and social support, among other things. A discussion then followed about the impact of negative thoughts on the level of pain and several practical examples were given. Georgia explained the vicious cycle of pain which affects people's work, relationships, social activities and self-esteem. This can result in avoiding activities, the person withdrawing and becoming less active, which leads to a decline in physical functioning. Pacing and cognitive restructuring were outlined as two steps in helping people to break the cycle.

Pacing is the skill that enables you to be more active without feeling pain. Time-based pacing is a process where activity breaks are based on time intervals, rather than how much of a task you have completed. You can start by identifying a task that you typically do every day which increases your pain. Then estimate the length of time you are able to carry out the task without causing pain and note it down. This becomes your 'active time'. Then calculate how long you will need to rest before being active again, which is called your 'rest' time. The aim is to look at your average time and try to increase 'active time' gradually, to a point that you feel works for you.

The goal of CBT was introduced, as a way of modifying maladaptive automatic thoughts and behaviours with the aim of improving levels of pain. This is also known as cognitive restructuring. It works by identifying automatic thoughts and consequences such as negative, automatic thoughts about pain. The so-called ABC model helps us identify the relationship between thoughts, actions and consequences. A stands for Antecedent (i.e. the situation that triggers the response), B stands for Beliefs (our thoughts/interpretation of the situation/event), and C stands for Consequences (the way we feel or behave). The process for cognitive restructuring, as shown by Georgia, is shown below.

Situation

Describe the event that led to unpleasant emotion.

Emotion

Describe the emotion you were having (e.g. sad) and rate from 0-100.

Thoughts

Write down your automatic thought(s) (e.g. I can't do this).

Evidence for

Write down if there is any evidence (facts) that these thoughts are true.

Evidence against

Write down if there is any evidence (facts) that these thoughts are false.

Coping thoughts

Write down what you can say to yourself instead of the automatic thought(s).

Emotion

Re-rate your original emotion from 0-100.

Georgia concluded her workshop by enabling delegates to practice some relaxation techniques which can help people gain control over many bodily functions. Research has demonstrated that relaxation can have many benefits, such as increased energy, decreased muscle tension and fatigue, improved sleep, lower blood pressure, and decreased pain. Three relaxation techniques were demonstrated: Diaphragmatic breathing, progressive muscle relaxation, and visual imagery. **An example of a progressive muscle relaxation training can be accessed here.**

“ **One of the main benefits of the programme is the group dynamic which evolves through meeting people going through similar experiences.**”

Self-management and fibromyalgia

Souzi Makri then shared highlights from a self-management programme organised by the **Cyprus League Against Rheumatism (CYPLAR)**, based on the self-management model published by AGORA. The self-management programme consists of five weekly meetings, each lasting 2.5 hours at the CYPLAR office. Delivered by patient trainers, psychologists and trained staff, the programme aims to educate and inform people living with fibromyalgia and other RMDs about techniques and tools to help them to manage their pain more effectively. Through the sharing of experiences alongside structured content, the programme helps to build confidence, positive thinking and better communication, with a view to enhancing the quality of life of those living with RMDs.

The programme structure begins with an introductory meeting, focusing on self-management principles and patients creating their own self-management plan with small and attainable goals. The subsequent meetings cover different topic areas to discuss all the challenges of having an RMD, as well as potential solutions. Home assignments are given during meetings to be completed before the next one.

One of the main benefits of the programme is the group dynamic which evolves through meeting people going through similar experiences. **Souzi** concluded that the programme has been well received by participants. Committed to developing the programme in a rigorous manner, CYPLAR are working with the University of Cyprus is to evaluate and validate the programme.

The emotional aspect of chronic pain

Lizy Zommer from **Roots for Generations** in Israel went on to describe her personal experience of fibromyalgia. She began by emphasising that pain is not only physical sensation, but one with biological, psychological and emotional factors too. Lizy describes herself as being in remission, after finding a management strategy which has worked for her, including a combination of frequent massages and CBT.

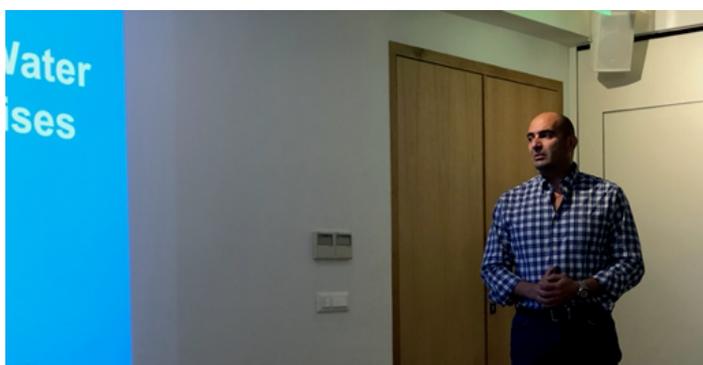
Lizy also discussed the value of emotional intelligence, which includes self-awareness, the ability to manage emotions, internal personal motivation, empathy and an ability to deal with relationships. She went on to explain how people define emotions in different ways, but how emotions control our thinking, behaviour and actions - including the intensity of pain felt by people. Using some of the techniques provided by Georgia can be useful in helping people to begin to learn to control certain emotions.



Lizy Zommer presenting about the emotional aspect of chronic pain and fibromyalgia.

The importance of water exercise

Andreas Iacovou, an experienced physical education trainer from Cyprus, explained the benefits of warm water exercise and stretching for people with fibromyalgia. He started by explaining the technical differences between physical activity, exercise and professional sport. Physical activity is flexible and any bodily movement produced by skeletal muscles that results in energy expenditure above resting level; whereas exercise is structured, planned, targeted, guided and repetitive. Andreas went on to discuss a list of therapeutic benefits from warm water exercise.



Andreas Iacovou introducing the concepts of water exercise, and the difference between static and dynamic stretching.

These include increased blood return to the heart, decreased blood pressure, reduced muscle spasms, increased respiratory rate and a reduction of lower limb oedema (fluid build-up). Andreas told delegates how the density of water (specifically buoyancy and hydrostatic pressure) makes it easier to do exercises, without adding unnecessarily loads onto joints. The warmth also helps to dilate blood vessels and reduce pain, by reducing the sensitivity of sensory nerve endings, which is why it is often recommended as a useful therapy for people with fibromyalgia and other RMDs.

The goal of exercise should be to improve general physical conditioning leading to better activities of daily living. Since water exercise increases flexibility, endurance and strength, it is suitable. The optimal training frequency is three times per week at a low-to-intermediate intensity.

You can change the intensity by using different techniques that change the resistance and velocity. It's like a toolbox to individualise the training to the individual. During the last part of his talk, Andreas emphasised how stretching is vital for maintaining flexibility. He reminded delegates that most people will stretch to some extent at the start of each day. He stated that there are essentially two types of muscle stretching - static and dynamic, which are used for different purposes.

Static stretching means a stretch is held in a challenging but comfortable position for a period of time, usually somewhere between 10 to 30 seconds. Static stretching is the most common form of stretching found in general fitness and is considered safe and effective for improving overall flexibility. Dynamic stretching means a stretch is performed by moving through a challenging but comfortable range of motion repeatedly. Although dynamic stretching requires more thoughtful coordination than static stretching (because of the movement involved), it is gaining favour because of its apparent benefits in improving functional range of motion.

Andreas specifically focused on static muscle stretching, recommending three sets holding at 30 seconds, several times a day, using a maximum range of motion at a very slow and steady speed to have the desired effect. Such stretching can be done practically anywhere - whether in the office, stood in the kitchen, or in bed. Learning to embed such stretching exercises as part of your daily routine could be beneficial.



ENFA Members at the General Assembly held on Saturday 18 May 2019 in Heraklion, Greece.

ENFA General Assembly

The ENFA General Assembly took place shortly after the formal conference session on Saturday 18 May 2019. Twelve European countries were represented at the General Assembly, 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 a Board Member. Prior to the General Assembly, Joana Vicente stepped down from the Board due to existing commitments. Joana was thanked for her contributions over the past year.

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:

- **Eva Deurloo** (Sweden), elected Secretary representing Fibromalgiförbundet
- **Judi Olsen** (Denmark) representing Dansk Fibromyalgi-Forening
- **Egidio Riva** (Italy) representing Associazione Italiana Sindrome Fibromialgica

Activities which ENFA had been involved with since the 2018 General Assembly included: 13th Patients' Rights Day 2018, Steering Committee Meeting of the SIP Platform 2018, Patients as Partners Conference 2019, DIA Conference 2019, 1st International Controversies of Fibromyalgia 2019, Biosimilars Advocacy Meeting 2019, 22nd EULAR Annual European Conference of PARE 2019, and the EPF 2019 Annual General Meeting.



The newly elected ENFA Board.

From left to right: Gunilla Göran (Vice President), Simon Stones (President), Mateja Kržan, Egidio Riva, Judi Olsen, Ricardo Fonseca (Treasurer) and Eva Deurloo (Secretary).

Since 2018, ENFA had re-launched on Facebook, Instagram, LinkedIn and Twitter, and acknowledged Joana Vincente for her sterling work in helping to establish the platforms, create content and improve communications over the year.

Activities for the 2019/2020 year were discussed at length among all members, and will include:

- ▶ Formulating a refreshed, and ambitious strategy for ENFA.
- ▶ Exploring the needs and expectations of ENFA member organisations.
- ▶ Enhancing communication with ENFA member organisations.
- ▶ Facilitating greater shared learning and collaboration among member organisations.
- ▶ Supporting researchers and institutions in delivering world class research.
- ▶ Strengthening collaboration with external organisations and partners in the fields of fibromyalgia, chronic pain, rheumatology, and patient education/care.
- ▶ Increasing ENFA's visibility through the website, social media platforms and participation in external events.

The General Assembly concluded with optimism and excitement for the year ahead!

Acknowledgments

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