

REPORT



European Network of Fibromyalgia Associations (ENFA) Conference 2018

in partnership with ME, CFS & Fibromyalgia Alliance Malta - VO/818

Friday 11 May to Saturday 12 May 2018

Attard/Valletta, Malta

In every disability, there is an ability

The European Network of Fibromyalgia Associations (ENFA) Conference 2018, in partnership with ME, CFS & Fibromyalgia Alliance Malta - VO/818, took place from Friday 11 May 2018 until Saturday 12 May 2018 in Attard and Valetta, Malta. Titled 'In every disability, there is an ability', the conference was held under the distinguished patronage of Her Excellency Marie-Louise Coleiro Preca, President of Malta. Coinciding with International Fibromyalgia Awareness Day on Saturday 12 May, the conference provided a platform for a variety of different stakeholders to meet, learn and reflect.



The President of Malta, Her Excellency Marie-Louise Coleiro Preca, officially opened the conference.

Informing, educating and empowering

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 debate the current fibromyalgia landscape, while developing and strengthening the European network. The conference also aimed to inform and educate politicians about the challenges facing people with fibromyalgia, as well as the impact of fibromyalgia on society. This was achieved over a two day programme, commencing with a parliamentary session on the social inclusion of invisible disabilities at Parliament Ta' Malta in Valetta, followed by a formal conference session convened at San Anton, the Presidential Palace in Attard, Malta.



President of ENFA, Souzi Makri, addresses the parliamentary session audience about the burden of invisible, chronic illness.

Parliamentary session on Saturday 11 May

The parliamentary session was officially opened by the Speaker of the House of Representatives, the Honourable **Anġlu Farrugia MP**. The President of ME, CFS & Fibromyalgia Alliance Malta, **Ruth DeBono**, then delivered a motivating and powerful speech about the inclusion of people with disabilities, touching on discrimination at home, at work and in society. This was followed by a speech from the President of ENFA, **Souzi Makri**, who introduced ENFA and the state of fibromyalgia on a European level.

“Participants had the opportunity to meet international colleagues to discuss and debate the current landscape for fibromyalgia, as well the chance to develop and strengthen the European network.”



Speakers and facilitators of the conference held at San Anton Palace in Attard, Malta on Saturday 12 May 2018.

Honorary Professor, **Dr Stephen Bevan**, then delivered a lecture about better working conditions for people living with fibromyalgia, myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). Stephen emphasised that conventional thinking about working needs to change, urging society to place an emphasis on capacity, not incapacity. Unfortunately, despite legislation being in place, such as the Equality Act (2010) in the United Kingdom (UK), it is not necessarily enforced in all circumstances, leaving people with fibromyalgia and related conditions without the respect and equal opportunities they are entitled to as citizens.

A variety of different stakeholders then provided experiences and testimonies about how conditions like fibromyalgia, ME and CFS have dramatic effects on the quality of life of those living with the conditions, as well as family, friends and wider society. **Rebecca Camilleri** and **Josette Sacco**, two individuals with ME, discussed the need for enhanced ways of living and working, such as relaxing rigid employment rules and access to a wider range of long-term treatments. Nurse educator, **Maria Gauci**, discussed the need for research and action into alternative therapies such as medical cannabis, as well as fibromyalgia clinics focusing on patients' overall health and wellbeing, which was raised by fibromyalgia patient, **Maria Spiteri**, who emphasised that one size does not fit all. **Patricia Carbonaro** spoke from the parent perspective, expressing her concern as to who is going to be there to support her child and their health in the future.

Cristabel Cutjar, a young person and University student living with fibromyalgia, then provided her account about how the educational system could be improved so that it is inclusive of people with conditions like fibromyalgia. Cristabel emphasised the need for early intervention and planning prior to commencing study at a given educational institution, so that all of the necessary support is in place from the outset. **Felix Schembri** advocated on behalf of men with fibromyalgia, who are a seldom-heard group in society, where he discussed about access to social benefits such as the blue badge for people living with invisible disabilities like fibromyalgia. The impact of conditions like fibromyalgia was reaffirmed by **Antoinette Camilleri**, who shared her experience of when two members of the family are experiencing chronic ill health, and how this impacts individuals physically, psychosocially and economically. **Ruth DeBono** concluded this section by introducing the launch of a national awareness campaign in Malta.

Members of Parliament (MP) from the incumbent government and parliamentary opposition were provided with opportunities to answer questions provided to them by the ME, CFS & Fibromyalgia Alliance Malta. MPs responded to various efforts that could be implemented within the Maltese healthcare system for these individuals, and were able to absorb the issues raised during the session. The Speaker of the House of Representatives, the Honourable **Anġlu Farrugia MP**, concluded the session in summary, and thanked everyone for their contributions.

Social media engagement

Throughout the conference, participants and external followers were able to engage in the conference through Facebook, Instagram and Twitter, using the hashtag **#ENFA2018**.

Conference session on Saturday 12 May

The conference session, held at San Anton Palace in Attard, was formally opened by Her Excellency, **Marie-Louise Coleiro Preca**, President of Malta. President Coleiro Preca delivered a thought-provoking speech, with commitment for the people of Malta living with fibromyalgia, ME and CFS.

Ruth de Bono then discussed some of the difficulties encountered in Malta, from the ongoing perspective of the ME, CFS & Fibromyalgia Alliance Malta. Ruth provided some recommendations, which included: i) A working fibromyalgia and ME clinic or a one stop shop where a protocol for proper diagnoses was established; ii) Weekly home help for those with restricted mobility; iii) Long-term therapy available without bureaucracy acting as a barrier for treatment access; iv) A scheme where employers are encouraged to employ people who can work from home; and v) Exploration and research of other therapies being investigated or used elsewhere.

Souzi Makri then delivered a speech, discussing the history of ENFA and the network's commitment to supporting national organisations and advocating on an international level. Souzi reminded participants that fibromyalgia has been recognised by the World Health Organisation (WHO) as a disease since 1992, as mentioned in the list ICD-10, M-79-7, even though it is still questioned by a number of health professionals and authorities in 2018.

“It's not health conditions that disable people... it's society which doesn't recognise people's right to genuine equality.”

Prior to presentations from the invited speakers, Souzi Makri presented President Coleiro Preca with a gift in recognition of her warm welcome and invitation for ENFA to celebrate International Fibromyalgia Awareness Day 2018 in Malta.



Professor of Medicine and Rheumatology, **Professor José Antonio Pereira da Silva**, then delivered a motivating and powerful lecture. José said that fibromyalgia-associated pain is just the 'tip of the iceberg', stating that there is a large amount of underlying activity ongoing which contributes to the pain experienced. He discussed at length the physical and psychological dimensions of fibromyalgia, including contextual factors such as personality and how this can influence people's response to the condition, and indeed questioning whether there is a link between personality traits and conditions like fibromyalgia. José supplemented his thoughts with some research findings, such as a functional Magnetic Resonance Imaging (MRI) study which demonstrated that people with fibromyalgia experience a greater intensity of pain at smaller stimulus intensity, compared to 'healthy' people. He called for the community to steer away from damaging statements, such as it's 'all in people's heads' - recognising that people with fibromyalgia aren't lying, and that basic and clinical research is urgently needed to fully understand the underlying processes ongoing in people with fibromyalgia.

This was followed by Honorary Professor, **Dr Stephen Bevan**, who is also Head of Human Resources Research Development at the Institute for Employment Studies. In his talk, Stephen shared some alarming figures, including evidence which suggests that around 100 million citizens within the European Union (EU) are living with chronic musculoskeletal pain - a high proportion of whom are of working age. Unfortunately, these individuals are still being left behind in the labour market. He touched on how conditions like fibromyalgia are often poorly understood, in part due to the fluctuating nature of the condition, which makes it difficult for those living with the condition to predict how they will feel. Stephen provided evidence to suggest that the indirect cost of fibromyalgia, ME and CFS, such as from the loss of work, is often four times as high as the direct costs associated with the conditions, for example, through treatment, hospital admissions, and diagnostic examinations. Stephen concluded with examples of good practice, including prompting the medical community to recognise good work as a clinical outcome of care, reflecting on the positive therapeutic benefits that work can have when the workplace is supportive, flexible and adapted to each individual.



Participants at the ENFA Conference 2018, which took place at San Anton Palace in Attard, Malta.

Patient leader and researcher, **Simon Stones** then shared his personal experience of fibromyalgia, as well as some of the activities undertaken by Fibromyalgia Action UK. Simon reflected on some of the myths about fibromyalgia, sharing his frustrations when

people tell him that he's far too young to have fibromyalgia. He touched on the variability of the condition, labelling it as 'waking up to the unknown every day'. As someone with multiple conditions, Simon voiced the challenges patients face when navigating specialised healthcare systems which don't necessarily focus on the individual health and wellbeing of people, and the interactions and complexity between multiple conditions and symptoms. Simon also discussed how self-management was an essential skill that he had acquired to help him manage fibromyalgia to the best of his abilities, before highlighting how becoming involved in research as a patient research partner empowered him to take control.

“ **A fibromyalgia diagnosis often feels like the last resort diagnosis... when nobody seems to really know what is wrong.**”

Mark Shrimpton shared his experience of working with chronic pain, emphasising that people with disabilities want careers just like anyone else - not just the first job that comes along.

Then, the Commissioner for the Rights of Persons with Disability, **Oliver Scicluna**, discussed the importance of the social model for people with invisible disabilities, prompting a shift away from the medical model. He mentioned how people with disabilities are expected to conform to societal norms, and how collectively, these norms need to be challenged.

The President of the Malta Federation of Persons with Disability (MFOPD), **Marthese Mugliett**, then talked about employment for people with invisible disabilities in Malta. This was followed by some closing remarks, given by the President of ME, CFS & Fibromyalgia Alliance Malta, **Ruth DeBono**. The ENFA General Assembly followed shortly after the conference.

ENFA General Assembly

ENFA were kindly offered the invitation to hold the General Assembly at San Anton Palace, which took place shortly after the formal conference session on Saturday 12 May. Nine European countries were represented at the General Assembly, including: Belgium, Cyprus, Denmark, Israel, Portugal, Slovenia, Spain, Sweden and the United Kingdom.

With agreement from the existing board, three new members were elected. These were:

- **Simon Stones (UK)**
representing Fibromyalgia Action UK
- **Joana Vincente (Portugal)**
representing Associação Portuguesa de Jovens com Fibromialgia (APJOF)
- **Ricardo Fonseca (Portugal)**
representing Myos - Associação Nacional Contra a Fibromialgia e Síndrome de Fadiga Crónica

Existing ENFA Board members were re-elected, including: **Souzi Makri** as President, **Mateja Kržan** as Vice-President, and **Gunilla Göran** as Secretary. Newly-elected member **Simon Stones** was also elected as Treasurer.

During the General Assembly, **Souzi Makri**, on behalf of ENFA, signed a memorandum with **Mariano Votta** on behalf of Active Citizenship Network (ACN). This memorandum help ENFA to emphasise the importance of collaboration between ACN and ENFA, presenting new opportunities for both associations moving forward.

Activities for the 2018/2019 year were discussed, with an emphasis placed on enhancing ENFA's presence on social media. It was agreed that this would be co-ordinated by **Joana Vincente** and **Simon Stones**. A review of European member countries would also be undertaken.

Acknowledgments

ENFA kindly thank Grünenthal for funding the ENFA Conference 2018.



ENFA Members at the General Assembly held on Saturday 12 May 2018 at San Anton Palace in Attard, Malta.

ME, CFS & Fibromyalgia Alliance Malta

The ME, CFS & Fibromyalgia Alliance Malta is a non-governmental organisation and network supporting individuals with fibromyalgia, ME, and CFS and their respective carers and support groups. Together, they advocate on behalf of the ME, CFS and Fibromyalgia community to improve public awareness of these conditions, while striving to improve the quality of life for these individuals.

For more information about the Alliance, please email:
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ENFA wish to express their sincere gratitude to the ME, CFS & Fibromyalgia Alliance Malta, for the pleasure of co-operating with them in the preparation and delivery of the ENFA Conference 2018.

