

# FIRST INTERNATIONAL CONSENSUS ON THE DIAGNOSIS AND MANAGEMENT OF FIBROMUSCULAR DYSPLASIA

Short title: International Consensus on Fibromuscular Dysplasia

## Online Supplemental Material

### **Impact of FMD on quality of life and the role of patient associations**

#### *Quality of life considerations*

Surveys have demonstrated the psychological and emotional impact of a diagnosis of FMD. A recent qualitative study by Bumpus, et al. demonstrated five common themes expressed among FMD patients: symptom burden, worries and concerns, loss and change, health care experience, and resilience (1). Fear of the unknown, a sense of isolation, and delay in diagnosis may lead to anxiety, as does the lack of access to health care providers who are knowledgeable about FMD. Common concerns among patients with FMD are risk of death or stroke, financial burden, and worries that their children/family members would be affected (1). These findings were similar to informal surveys done by the patient organizations in the US and Europe. Patients may have concerns regarding risk of pregnancy and childbirth after diagnosis of FMD, particularly as there is little data available regarding pregnancy outcomes in this patient population.

Quality of life of patients with FMD depends on several factors including severity of disease, the nature and severity of symptoms (e.g., migraine headaches, pulsatile tinnitus), and whether the

patient has been diagnosed with an aneurysm or had a major vascular event such as an arterial dissection or stroke. For those patients with more severe disease, symptom burden may require some to stop work, or reduce working hours, bringing with it extra anxiety and financial worries (1).

Guidance given to patients for restriction of activities varies widely and is often based on the FMD experience of the treating physician. In the Bumpus study, patients with FMD who had been advised to give up or limit certain athletic activities report that this led to a sense of loss of their routine and of their identity (1). For all patients with FMD, symptomatic or not, there is often a sense of “what if!” that may contribute to anxiety and impair quality of life.

#### *International FMD patient associations*

The Fibromuscular Dysplasia Society of America (FMDSA) was founded in 2003 after a group of patients identified many unmet needs and a general lack of awareness and education about the disease ([www.fmdsa.org](http://www.fmdsa.org)) (2). FMDSA has experienced significant success and is recognized internationally as a leading resource for patients and physicians and in the funding of FMD research.

One of the challenges recognized by leadership of the FMDSA early on was the lack of resources for the population of international patients with FMD. International volunteers were identified to help with patient requests and to build resources within their countries with the assistance of the FMDSA. In 2012, The Fibromuscular Dysplasia Association of Australia

([www.fmdaa.org.au](http://www.fmdaa.org.au)) became the first international non-profit patient organization focused on this disease (3). The need for patients to share experiences and offer support, to provide access to the latest medical information, and to help stimulate research in languages other than English prompted the creation of Dutch and Belgian FMD patient associations. In 2014, the FMDGroepNL group ([www.fmdgroep.nl](http://www.fmdgroep.nl)) was established in the Netherlands, and the organization received non-profit status in 2017 (4). In 2016 the FMD-Be association ([www.fmd-be.be](http://www.fmd-be.be)) was established to address the needs of Belgian patients (5). Both organizations are supported by the scientific community. In addition to providing patient support and raising awareness of FMD, they have a common goal of working with researchers and scientific societies throughout Europe and ultimately creating a unified European network for patients with FMD.

Through the combined efforts of these groups, educational materials on FMD for patients and health care providers are now available in several languages, and they continue to work together to identify ongoing unmet needs and share resources to advance FMD awareness and provide support to patients with this disease. In addition to these international non-profit associations with focus on awareness, patient support, and research collaboration, social media platforms such as Facebook and Inspire have allowed for the development of smaller patient-led support and discussion groups, which also provide valuable support for patients with FMD.

## References

1. Bumpus SM, Kuck C, Heidt ST, Bluhm M. Diagnosed and living with fibromuscular dysplasia: A qualitative inquiry. *Vasc Med* 2016;21:539-546.
2. Fibromuscular Dysplasia Society of America (FMDSA). Website available at: <http://www.fmdsa.org/> . Accessed November 28, 2018.

3. Fibromuscular Dysplasia Association of Australia, Inc. (FMDAA). Website available at: <http://www.fmdaa.org.au/> . Accessed November 28, 2018.
4. FMD Groep Nederland. Website available at <https://www.fmdgroep.nl/> . Accessed November 28, 2018.
5. FMD Groep Belgie. Website available at <http://www.fmd-be.be/> . Accessed November 28, 2018.