

FMD-Be



Association belge de patients
atteints de dysplasie fibromusculaire
FMD Groep België


FMD patient associations: Belgian experience and European perspectives

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**Second National Meeting on Fibromuscular Dysplasia
Saturday 10th December 2016**

The origin of FMD-Be

- A small group of 3 patients followed at UCL/
University Hospital St Luc
- An informal meeting (21/04/2016) to exchange ideas on
the creation of a Belgian patients association

 What are our objectives?

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dysplasie fibromusculaire / **FMD Groep België**

Objectives

- **To better understand FMD :**
 - to improve the access to information for FMD patients
(by providing information and support)
- **To develop a help and support network**
- **To help stimulate research**

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To promote a better understanding of FMD

- To make available to patients :

- Validated scientific information

- (in a format appropriate for the general public)

- Validated answers to questions posed by patients – FAQs

Requirements :

- A scientific committee to oversee the information given

- Information in the language spoken by the patient

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How do we plan to achieve this?

- **Creation of a logo (to give the group better visibility)**
- **A website**
- **A facebook group**

- **Making contact with other patients who show an interest in a patient association(an extra role for the doctor!)**
- **National and International contacts (other associations)**

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Information and support network

- FMD-Be : A Belgian network, within a European and a Worldwide network
- Patients amongst themselves
- The FMD Associations in relation to each other

TOGETHER TO SHARE KNOWLEDGE AND EXPERIENCE

Progress report

- We are a small group of FMD patients, with at least one representative speaking French, Dutch and English
- Creation of a logo
- Contacts have been made with other groups and FMDSA contacts in Europe, America and Australia
- Creation of a Facebook group  **FMD.Be.Patients**
- A web site has been created www.fmd-be.be
- Our attendance here today to increase the visibility of FMD-Be and circulate our contact details

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Difficulties encountered

- **Identifying and connecting with Belgian FMD patients**
The doctors role here is important (to date patient contacts have come via Prof. Persu and Prof. Van der Niepen)
- **Enlargement of the Scientific Committee**
- **Finding fellow patients with an interest in joining and actively contributing to the group**
- **Funding – for website creation and hosting**

LA DYSPLASIE FIBROMUSCULAIRE/ FIBROMUSCULAIRE DYSPLASIE

Un site d'information à l'intention des patients/ een Website voor patiënten



What is fibromuscular dysplasia (FMD)?

Fibromuscular dysplasia (FMD) is a disease of the artery wall, without a link to atherosclerosis (cholesterol deposits) or inflammation. Sometimes this can lead to an arterial stenosis (narrowing), a dilation (aneurysm) or a dissection (tear) of the affected artery. A stenosis or a dissection can be responsible for a reduction in arterial blood flow. The effect of this reduced blood flow depends on the location of the arteries involved. A ruptured aneurysm could be a cause of internal bleeding and would require urgent medical attention.

Many patients affected by FMD have no symptoms or detectable signs of the disease during medical examination. Often the disease is picked up during medical imaging (CT scan or IRM) carried out for another reason.

This site aims to provide scientifically valid and up to date information.

It has been realised by the patient association in conjunction with a scientific (medical) committee.

This information is not intended to replace that given to you by your doctor!

LANGUAGES



- [What is fibromuscular dysplasia \(FMD\)?](#)
- [Medical aspects](#)
 - [Symptoms](#)
 - [Diagnosis](#)
 - [Treatment](#)
- [FAQ's](#)
- [Current research](#)
- [About us](#)
- [Other patient associations](#)
- [Scientific literature](#)
- [Useful information](#)

RECENT POSTS

- [Saturday 10 December 2016 : Second National Meeting on Fibromuscular Dysplasia](#)
- [Participate in a clinical study \(BEL-FMD\)](#)

MANY THANKS

We are extremely grateful for all the assistance and support we have received from the FMD patient support groups and contacts :

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Evelyn Boot and Madelon Bouwmeester FMD-Groep Nederlands

Nina Verstraete – Swiss FMDSA contact

Angeline Young – UK FMDSA contact

Bronte Sterk – FMDAA (Australia)

We would like to thank you for attending this meeting today, for your interest in FMD and helping us generate better awareness and understanding of our disease

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Association belge de patients atteints de
dysplasie fibromusculaire / FMD Groep België

Contact us

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