

The European Fibromuscular Dysplasia Initiative

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The main aims of the European Fibromuscular Dysplasia Initiative (FMD), coordinated by A. Persu (UCL, Brussels, Belgium) in tight collaboration with M. Azizi, X. Jeunemaitre and P.-F. Plouin (HEGP, Paris, France) are (i) to standardize clinical practice/ update the European consensus on FMD (Persu et al., *J Hypertens* 2014 Jul;32:1367-78); (ii) establish a network of expert centers in Europe; (iii) establish a European patient association; (iv) establish a European FMD registry; (v) coordinate research on FMD in Europe; (vi) facilitate interactions with the ESC-ACCA SCAD Study Group (Chair: D. Adlam, Leicester, UK), the US FMD registry and other related initiatives all over the world.

The European FMD registry (Persu et al., *Hypertension*. 2016; 68:832-9), launched on the occasion of the first national FMD meeting in Brussels (12th December 2015) and subsequently endorsed by the European Society of Hypertension (<http://www.eshonline.org/esh-content/uploads/2016/10/Call-FMD-registry-2016.pdf>) is at the crossroads of these different objectives. It has been adapted from the French FMD registry (coord. P.-F. Plouin), created in 2010 to merge existing local FMD databases, and includes over 50 items covering demographic and clinical characteristics of FMD, family history, type, localization, associated complications and interventions. It is both prospective and retrospective, is linked with a DNA/RNA biobank and, since October 2017, a bank of images. A flexible, user-friendly online platform has been developed by the team of Laurent Toubiana (LIMICS/IRSAN, Paris, France), which allows adding an indefinite number of new events during follow up of individual patients (Toubiana et al., *Stud Health Technol Inform*. 2015; 210:887-91). Specific modules can be developed according to local interests.

Since its creation 3 years ago, the European FMD registry includes 687 patients (609 patients with “classical” FMD and 78 with SCAD) from 17 countries, including 3 extra-European countries: Argentina, Japan and Tunisia. The main characteristics of patients included in the registry and other preliminary analysis will be shown for the first time at the meeting.