

Basic data of
Patient Association:
.....**ITALY**.....



Name

FAMY Associazione Italiana Amoloidosi Familiare

Date of establishment

The 25th January 2013

Juridical status (Association or Foundation)

Association. Registered as non-profit organization by fiscal authority.

Official address

Via Altura, 3 - 40139 Bologna

Type(s) of Amyloidose covered

ATTR hereditary

Estimated numbers of persons affected

Around 400 patients

Goal and Objectives of the organisation

The main aim is to protect the rights of people suffering from amyloidosis and become a point of reference for the patients and their relatives. In addition, we are working to provide appropriate information concerning the symptoms of the disease in order to get people diagnosed and treated as soon as possible.

Administration (Board/Secretariat, Advisory Councils)

The board has 5 members and lasts for 3 years. The President is appointed by Member's Assembly.

(Statutory) meeting and frequency

Board's members meet every 3-4 months.

Activities accomplished, undertaken or planned (in relation to each of the objectives)

- Maintenance and updating of the Association's website
- Project organizing some yearly meetings whereas doctors involved with the ATTR disease make patients and their families aware about recent developments in drugs and clinical tests for new medications
- Plan drafting a pamphlet (available also via web) focusing on first symptoms of the disease, thus it could be detected as soon as possible

Moreover FAMY joins international medical conferences and meetings on Amyloidosis.

Main centers of expertise in the country

Popedale Sant'Orsola in Bologna (St. Orsola Hospital in Bologna), Ospedale San Matteo in Pavia (St. Matteo Hospital in Pavia) and Università di Messina (University of Messina).

Financing (main sources of income)

Donations from private persons and companies.

Cooperation with other organizations or membership of federal bodies (national or international)

None

Contact

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