

Basic data of Patient Association: *France*



Name

Association Française contre l’Amylose

Date of establishment

August 1994

Juridical status (Association or Foundation)

Association. Registered as a Charitable Association in 2014

Official address

ASSOCIATION FRANCAISE CONTRE L’AMYLOSE

66 Rue Saint Jacques

13006 MARSEILLE

Type(s) of Amyloidose covered

All types of Amyloidosis

Estimated numbers of persons affected

4000 (3500 = AL Amyloidosis 1000 = TTR or senile heart amyloidosis 500 = AA Amyloidosis)

Goal and Objectives of the organisation

- Promote medical research to fight against Amyloidosis
- Improve the knowledge of the disease among the public concerned (doctors, patients, various organizations) and communicate widely
- Develop synergies with existing organizations dealing with genetic diseases
- Contribute to the “well being of patients” in “breaking” their loneliness while facing the disease (communication between patients, information on the progress of research, guidance, networking)

Information

Website and Facebook - Flyers - Brochures

Our own newspaper that we send to the members, health care centers and hospitals (1 or 2 times/year)

A ***Scientific Council*** of 16 members which includes the coordinators and partners of the Reference Centers, the medical experts of the disease. We invite them to annual **seminar** where the result of the latest research is summarised.

Raise money

Subscriptions - Donations from private persons - Activities - Sponsors contributions

Administration (Board/Secretariat, Advisory Councils)

The board has totally 6 members

(Statutory) meeting and frequency

Board of directors have meetings 2-3 times/year.

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

- Phone calls and Patient Support Group
- Active participation in innovating actions : Patient Therapeutic Education...
- 2 annual Awards : one for research, one for an action for patients' wellness
- Studies funding for a better understanding of the different forms of the disease
- PhD fundings
- Assistance in recruiting patients to participate in treatment tests, participation in surveys for pharmaceutical firms
- Annual meeting with the Scientific Council
- Support for assessment audits and renewal of Reference Centers
- Attendance to annual events organized by doctors
- Financing specific actions (patient card, self-rehabilitation booklet and movie, ...)

Main centers of expertise in the country

Established in 2005 by the Ministry of Health (Rare Diseases Plan), they are responsible for defining the care and treatment protocols and for driving a regional network of competence centers to offer the same quality of service to the whole territory.

- **AA AMYLOIDOSIS** *Tenon Hospital in Paris* - Reference Center for inflammatory origin amyloidosis and Familial Mediterranean Fever (FMF)
- **AL AMYLOIDOSIS (2 sites)** *University Hospital in Poitiers and Limoges* - Reference Center on primitive amyloidosis and other immunoglobulin deposition diseases
- **HEREDITARY AMYLOIDOSIS (multisite)** *University Hospital in Kremlin Bicetre* - Reference Center for Familial Amyloid Polyneuropathy
- **AMYLOIDOSIS (all forms)** *Henri Mondor University Hospital in Créteil* - Expert Center

Financing (main sources of income)

See text under **Raise money**

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

Member of The National Association for Rare Diseases, Eurordis, Alliance Maladies Rares, Orphanet

Contact

AFCA ASSOCIATION FRANCAISE CONTRE L'AMYLOSE

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FRANCE

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