

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



Name

Asociación Española de la Enfermedad de Andrade – Amiloidosis hTTR

Date of establishment

13-11-2016

Juridical status (Association or Foundation)

Non profit organization

Official address

Sor Clara Andreu, 15 bjs. 07010 Palma de Mallorca. Spain

Type(s) of Amyloidose covered

hTTR

Estimated numbers of persons affected

3 000 in Spain

Goal and Objectives of the organisation

AEEA-AhTTR

-Fines. The aims or objectives of this Association are to contribute to the study, treatment and prevention knowledge of Andrade's Disease or Hereditary Transthyretin Amyloidosis (AhTTR). Consequently, the following are considered fundamental purposes:

- a) To promote the improvement of the quality of life of the patients of Andrade's Disease.
- b) To maintain relations and collaborate with other Associations and other organisms of fight against the Disease of Andrade, in Spain as well as abroad, to know the advances that occur in all aspects of this disease
- c) Participate in the discussion and solution of the problems posed by Andrade's disease in the epidemiological, clinical, diagnostic, therapeutic, preventive and socio-economic aspects.
- d) Information to relatives in blood on the hereditary mechanism of the disease with the consequent genetic counseling and to make it included in the portfolio of Public Health services throughout the Spanish territory. Dissemination of knowledge and advances on the study of the disease and its treatments and to promote the development of activities for the training of specialized technical personnel and teachers, addressed to interested parties Article 60.

Administration (Board/Secretariat, Advisory Councils)

Sonia Gutierrez Nadal President, Jose Cuesto Feria Vicepresident Carmen Nadal Massanet Vicepresident 2, Pedro Clar Tomas Secretary and Treasurer.

(Statutory) meeting and frequency

Once a month.

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

Forms of Action.

The specific forms of action of the Association will be the following: training of specialized physicians

- A) Collaborate in diagnosis, treatment and prevention of Andrade's disease.
- B) Promotion and financing of participation in scientific meetings and national and international congresses of medical staff and social partners that the Association considers indicated.
- C) Organization of a library and creation (where possible) of a periodical publication newsletter intended for affected families to keep them abreast of the progress that is being made and give them the appropriate advice for the treatment of patients of the disease
- D) Creation of scholarships for the training of doctors, physiotherapists or health assistants specialized in Andrade's disease. To obtain the sponsorship of the Local Administrations, Autonomous State or of the European Economic Community, that can contribute to the maintenance of the needs of this Association f. Counseling and assistance to the sick and their families in relation to the psychological and socioeconomic problems caused by the disease.

Main centers of expertise in the country

Son Llatzer Hospital. Palma de Mallorca

Financing (main sources of income)

Donation from private persons, donation from pharmaceutical companies, State administration.

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

FEDER (Federacion española enfermedades raras), ASVEA (Asociacion Valverdeña enfermedad de Andrade). ABEA (Asociacion Balear enfermedad de Andrade).

Contact

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