

Basic data of Patient Association: *Brazil*



Name

Associação Brasileira de Paramiloidose

Date of establishment

November, 1989

Juridical status (Association or Foundation)

Association. Registered by fiscal authorities as non-profit organization

Official address

Rua Alves Guimarães, 1217 ap 43 - São Paulo/SP 05410-002

Type(s) of Amyloidose covered

TTR Amyloidosis (hereditary and wild type)

Estimated numbers of persons affected

TTR hereditary 2,000

Number of patients treated at the major expertise centre

Goal and Objectives of the organisation

- a) Promote screening for all patients with Familial Amyloidotic Polyneuropathy of Portuguese type and other mutations of ATTR in Brazil
- b) provide to national health system information about FAP and its needs
- c) To work with the relevant authorities, towards the establishment of a program to assist patients with FAP, including creation of regional centers of care and treatment by specialist staff
- d) Cooperate with Central or Local Government as well as with other organizations in pursuit of these purposes
- e) Promote the development of appropriate legislation to the interests of patients with FAP
- f) inform and enlighten all FAP patients and their families on disease characteristics, diagnose and treatment;

g) support, by all means in their power, all the research programs of the FAP

h) Promote the integration of ABPAR to national and / or international organizations, related to research and the awareness of the disease , especially by the Portuguese Association of FAP, and also other FAP associations using the maximum exchange of information and knowledge about same, in order to facilitate their development, with the goal of getting treatment and eradication of this disease

i) Edit and publish educational and didactic-scientific material

j) To promote courses, seminars, conferences, congresses and other related activities on the FAP in its varied presentations or types, with a view to optimizing their goals

k) Maintain exchange and / or agreements with related or similar companies, both national and international

l) work with the Ministry of Health, Brazilian Medicine Agency, Customs, Agency of Supplemental Health, and other national agencies and authorities of the Union, States and Municipalities, pharmaceutical companies and medical community, with a view to optimizing their goals

Administration (Board/Secretariat, Advisory Councils)

The Board of directors has 6 members. Fiscal Council 2 members. All elected every 3 years. Chairmanship rotates.

(Statutory) meeting and frequency

Board of directors meet every month. General Assembly once a year at least.

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

Main centers of expertise in the country

Federal University of Rio de Janeiro - University Hospital - CEPARM (Centro de Estudo em Paramiloidose Antônio Rodrigues de Melo - National Reference Center on hATTR.

Other centers:

University of São Paulo - Hospital das Clínicas de Ribeirão Preto

University of São Paulo - Hospital das Clínicas de São Paulo

Federal University of São Paulo - Escola Paulista de Medicina - Centro de Doenças Neuromusculares

Financing (main sources of income)

Subsidies; donations from private persons, donations from pharmaceutical companies for specific patient-oriented activities.

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

Member of Eurordis (Rare Diseases Europe)

Member of Brazilian Alliance of Genetics

Member of ALIBER (Iberoamerican Alliance for Rare Diseases)

Contact

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