

Basic data of Patient Association: *Cyprus*



Name

FAP Association of Patients & Friends in Cyprus
211 Members (70 patients ,rest friends & mutation carriers)

Date of establishment

May 2015

Juridical status (Association or Foundation)

Association - Registered by The Ministry of Welfare

Official address

16A,Athinas Tarsouli,Kato Polemidia,4152-Limassol,Cyprus

Type(s) of Amyloidose covered

ATTR hereditary, mutation Val30Met (Portuguese type)

Estimated numbers of persons affected

60 Persons developed the disease and received a liver transplant since 1993

Around 150 others were found to be having the mutation, but did not develop yet.

3 patients enrolled for Alnylam's trial

2 patients are about to be on treatment with Tafamidis

Number of patients treated at the major expertise center (Cyprus Institute of Neurology and Genetics).

All of them.

Goal and Objectives of the organisation

Please see attached Plan of activities doc

Administration (Board/Secretariat, Advisory Councils)

The Board has 7 members which are elected every 3 years, the Board then elects the president

(Statutory) meeting and frequency

Board Council meet every 2 months.

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

Please see attached Plan of activities doc

Main centers of expertise in the country

The Cyprus Institute of Neurology and Genetics (www.cing.ac.cy)

Other centre, part of the network: Nicosia and Limassol General Hospitals

Financing (main sources of income)

Donations from members ,private persons, Ministry of Health (2017 onwards), Pharmaceutical Companies (2017 onwards)

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

Member of the Cyprus Federation of Patient Associations and Friends

Member of the Cyprus Alliance of Rare Disorders

Contact

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