

Basic data of Patient Association: *Germany (Münster)*



Name

Patientenverband FAP e.V. Familiäre Amyloid Polyneuropathie

Date of establishment

We started our patient advocacy group at June 2016 in Münster

Juridical status (Association or Foundation)

patient advocacy group as non-profit organization

Official address

Albert-Schweitzer-Campus 1, A1, Raum 248.05., 48149 Münster

Andrea Albers, office (Andrea.Albers@ukmuenster.de)

Board of Directors: Herr Roland Straube (nickyroland@aol.com) and Herr Gerhard Quitschau (gerhard.quitschau@ergo.de)

Type(s) of Amyloidose covered

TTR Amyloidosis (ATTR)

Estimated numbers of persons affected

7 persons, 5 persons with TTR-Amyloidosis

Goal and Objectives of the organization

1. We want to support patients and their families (their needs, communication between patients, doctors and research)
2. Organizing national and international meetings with other patient groups and pharmaceutical companies
3. Care of patients in clinical trials
4. Promote medical research to fight against the disease

Administration (Board/Secretariat, Advisory Councils) The patient group has 7 members, 1 person at the office

(Statutory) meeting and frequency

We started with one meeting last year.

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