

Basic data of Patient Association: *Sweden*



Name

FAMY-Norrbottn

Date of establishment

We started our own association in May 2002. Earlier we were a subgroup of the FAMY association in Skelleftea.

Juridical status (Association or Foundation)

Association. Registered by fiscal authorities as non-profit organization

Official address

Prästgårdsgatan 3, 941 31 Piteå, Sweden

Type(s) of Amyloidose covered

TTR Amyloidosis (ATTR)

Estimated numbers of persons affected

- ◆ 54 with ATTR (53 V30M and 1 V54M)
- ◆ 12 carriers

Totally we have 471 members. The members come from 13 different counties in Sweden.

Goal and Objectives of the organisation

We have 3 goals for our work:

- ◆ **Member support.** Set up for those affected by the disease and their families.
- ◆ **Information** about the disease.
- ◆ **Raising money** to support research

Member support:

- Meetings, summer excursion, christmas party
- Visiting members who are unable to attend our meetings

Information:

- Website and facebook
- TV, Radio and written press
- Brochures
- Our own newspaper that we send to the members, health care centers and hospitals (4 times/year).
- Once a year we invite Swedish researchers to a seminar where the results of the latest research is summerised.

Raise money:

- Various activities where we sell coffee and homemade cakes (donated by the members).
- Lotteries
- Companies that advertise in our newspaper.
- Telegrams (to memory of a person)
- Cooperation with a glass blower. We sell selected products with good commission
- Cooperation with a glasses shop. We receive a commission for each glasses sold.
- We organize concerts.
- Lions clubs sell calendars and donate the access to FAP-research.

Administration (Board/Secretariat, Advisory Councils)

The Board has totally 9 members (including substitutes)

(Statutory) meeting and frequency

Board of directors have meetings 4 times/year.

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

See text under **Raise money**

Main centers of expertise in the country

FAP-team in Umea (prof. Ole Suhr had worked there). National Responsible for the disease.

FAP-team in Pitea (4 doctors and 2 nurses)

FAP-team in Skelleftea (1 doctor and 2 nurses)

When you have a referral, from a doctor at the health care center, you will visit the FAP-team.

Research is conducted primarily at the university hospitals in Umea, Uppsala, Stockholm (Huddinge) and Gothenburg (Sahlgrenska).

We encourage our members to participate in different research projects.

Financing (main sources of income)

Donations from private persons, activities, Lions Club, Sponsors
Contributions from the state for personnel costs

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

Member of The National Association for Rare Diseases

Contact

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