

Name

Famy-Skellefteå

Date of establishment

We started our association in 1983

Juridical status (Association or Foundation)

Association registered by fiscal authorities as non-profit organization

Official address

Storgatan 50 , 931 85 Skellefteå

Type(s) of Amyloidose covered

TTR- Amyloidosis (ATTR)

Estimated numbers of persons affected

70 with ATTR

Totally we have 300 members and 70 with the disease.

Most of them from Västerbotten (part of Sweden)

Goal and Objectives of the organization

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, concerts



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 summed.

Raise money:

-Lotteries

-Companies that advertise in our newspaper

-Telegrams (to memory of a person)

-Sales of our FAMY-candles

-Sales of FAMY-T-shirts

-Organize concerts.

-Contributions from the municipality

-Contributions from Lions

Administration (Board/Secretary, Advisory Councils

The Board has totally 7 members (including substitutes)

1 person at the office

(Statutory) meeting and frequency

Board of directors have meetings 8 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 Umeå (prof.Ole Suhr had worked there) National responsible for this disease. Doctors and nurses.

Fap-team in Piteå(4 doctors and 2 nurses)

FAP-team in Skellefteå (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 Umeå, Uppsala, Stockholm (Karolinska) and Gothenburg (Sahlgrenska)

We encourage our members to participate in different research projects.

Financing (main sources of income)

Donations from private persons, sponsors, activities, Lions Club, membership fees and municipal contributions

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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