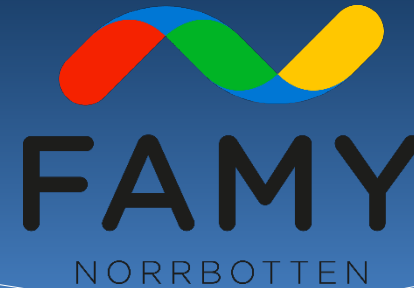



Susanne Berglund



- * Worked in the association since Dec-1997, then as a subdivision to FAMY Västerbotten (1984).

2002 we started FAMY Norrbotten.

- * I don't have the disease myself but my father in law was diagnosed in 2015
- * My family= my husband, three children, and four grandchildren
- * My other family= the association 

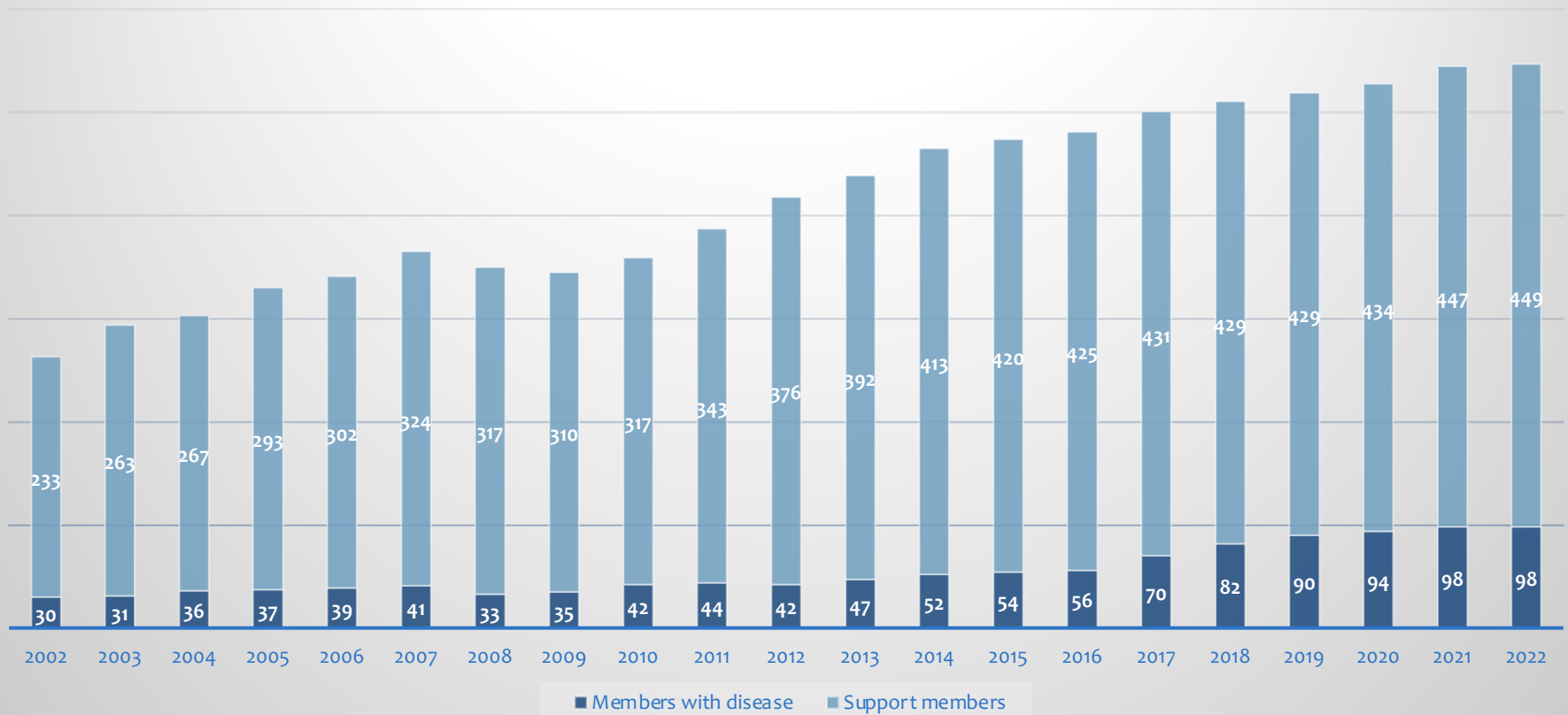


We get a government grant to be able to have me as an employee

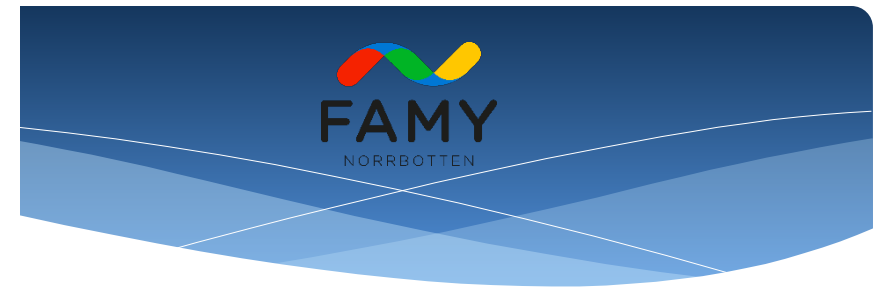
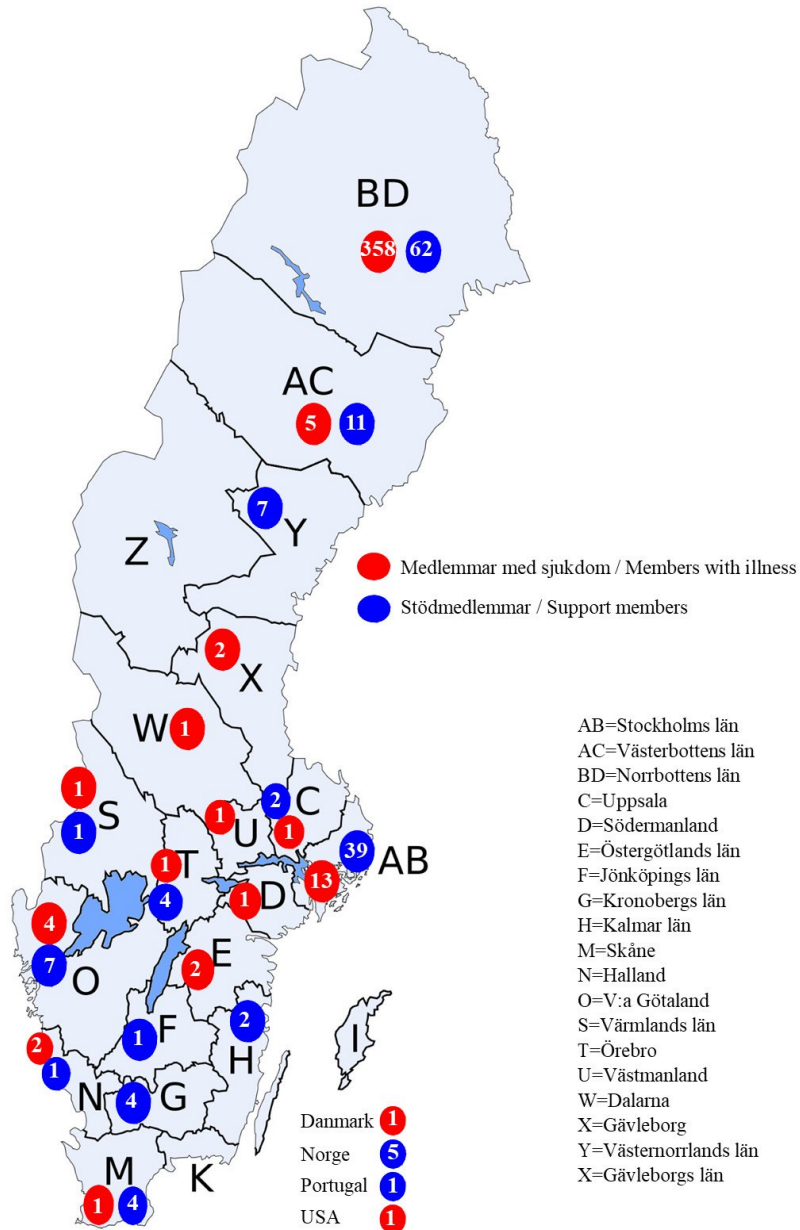
We have a cheap rental of our office

We are several associations in this house

Members 2002-2022 (April)



Members in Sweden



- We have totally 98 members with illness and 449 support members
- Association FAMY Västerbotten have 79 members with illness and 200 support members

About 8000 person in Sweden are affected but not diagnosed or treated.

About 5% of them have the disease

**ATTRv=Familial Amyloidosis with Polyneuropathy – FAP
and also ATTRwt-CM=cardiac amyloidosis**

Our association is working towards three objectives:

***To be here for our members and their relatives, MEMBERSHIP CARE**

- Meetings 3-4 times/year when we get together and discuss things. We invite different lecturers, eat lunch and sometimes entertainment.
- We offer digital presence for those members who can not come to our meetings in person (that's new and very appreciated)
- Digital / personal coffee meetings once a month
- Contact by phone, facebook, e-mail and sometimes members come to our office

*To **INFORM** about the disease for healthcare professionals and the general public



Newspaper 4 nr/year

Social media

Research Seminar

Team at hospital
(doctors and nurses that
patients can call every day)

Brouchers

Project Health Center
(We visit them and inform about early
symptoms and "red flags" that may
lead to further investigation.

We raise money to **SUPPORT RESEARCH**

”Channelswim” every year April 30th
(We sell coffee bread, coffee and fish pond for the children)



Lions Club

Telegram Gifts

Companies that advertise
in our newspaper

Activities with companies

Glass products that we sell →



Telegram

Din e-postadress:

Ange din e-postadress



Ditt namn

Vad avser telegrammet

- ☒ Begravning
☐ Högtidsdag

Vem gäller telegrammet

Datum för begravning / högtidsdag

Var ska telegrammet skickas

Vers / En sista hälsning / Varmt deltagande/ Vem är telegrammet från

Välj telegram

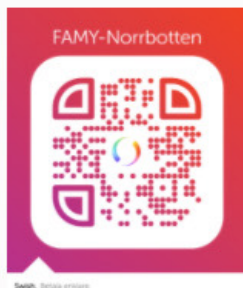
Bild 1

Betalningsalternativ

- ☒ Jag betalar direkt till Bankgiro 5085-2730
☐ Jag betalar direkt via Swish 123 061 92 60 (går bra att skanna QR-koden nedan)
☐ Vänligen skicka inbetalningskort

Skicka

Tack för Ditt/Ert stöd!



Telegramverser

Skriv nr på versen, som du väljer, i meddelanderutan



Bild 1



Bild 2



Bild 3



Bild 4



Bild 5



Bild 6 Högtidsdag

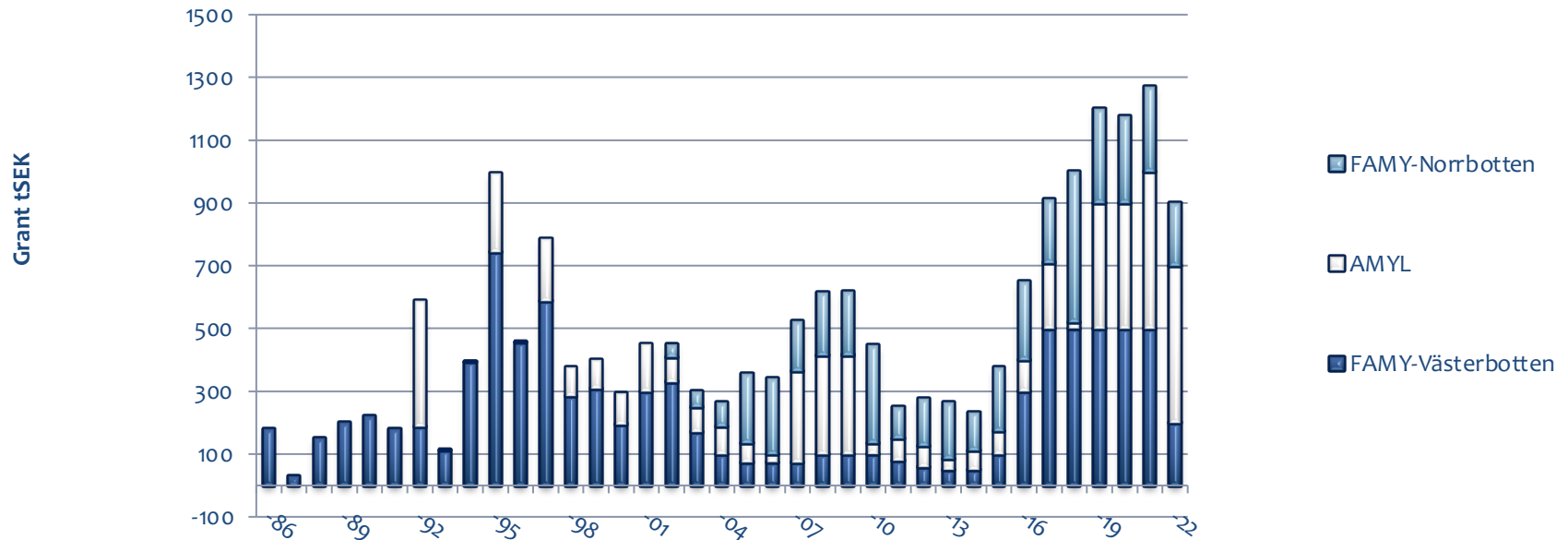
FAMY
NORRBOTTEN

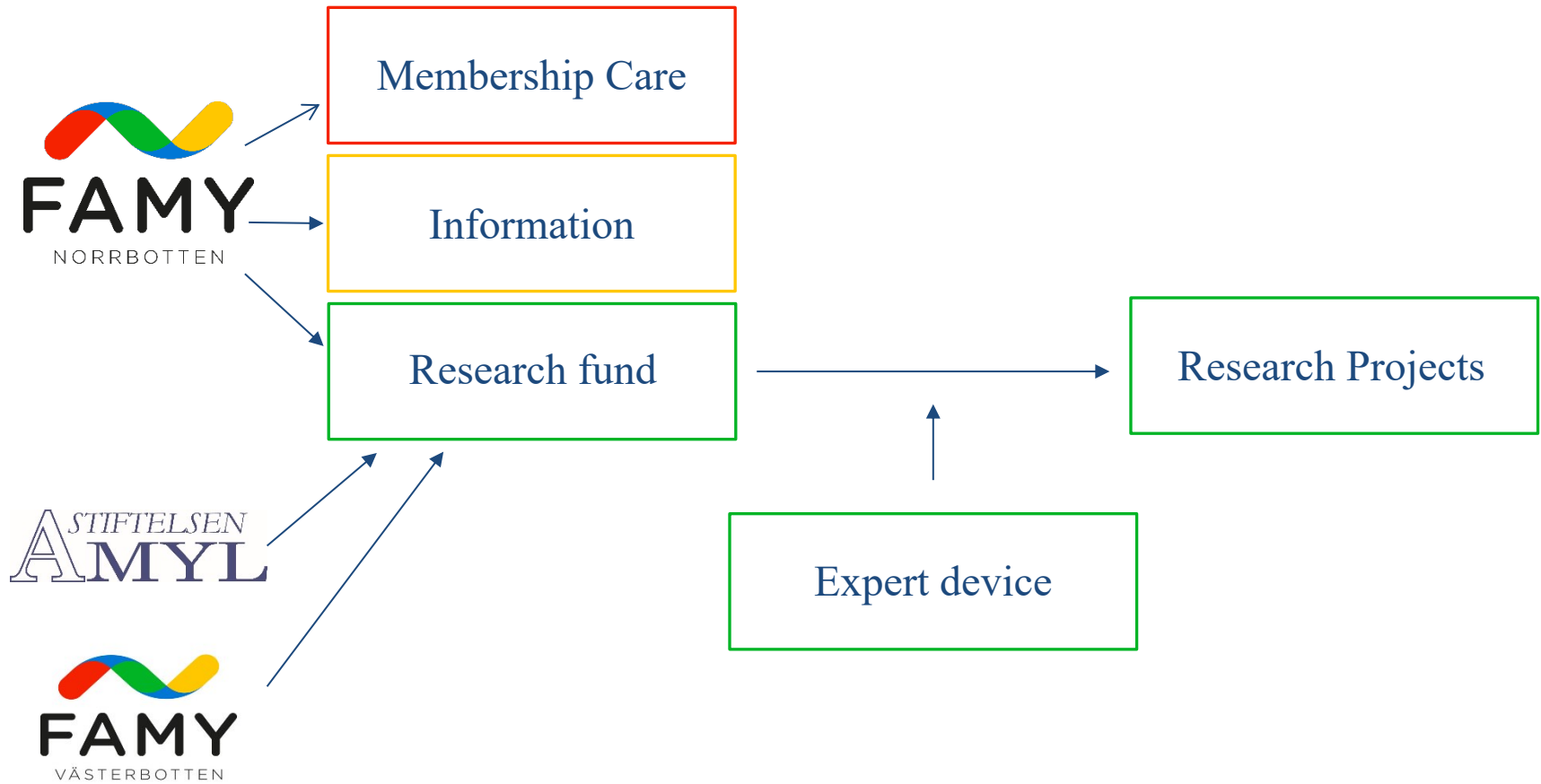


We accept telegram gifts
(funerals and holidays)

Grant of money to FAP-research Totally 18,3 MSEK 1986-2022

about €1 748 782





Research Seminar once a year FAMY Norrbotten / FAMY Västerbotten

The researchers report their work they have done with the help of grants from us

2019



Kenneth Lång

Malin Olsson

Intissar Anan

Rayomand Press

Elisabeth Ihse

Per Westermarck

ISA (International Society of Amyloidosis) Uppsala 2016 First time we met!



Holland, France, Brazil, Spain, Japan, Germany
Italy and Sweden

1st European ATTR Amyloidosis meeting Paris 2-3 november 2017



ISA (International Society of Amyloidosis) Kumamoto 2018

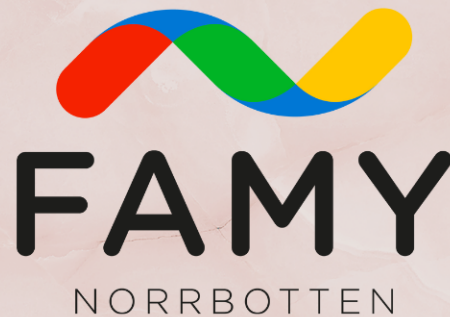
Susanne was invited to talk about how we work in our association



*Membership care

*Information

*Support research



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