

Rare Diseases Denmark HELPLINE

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Introduction

Rare Diseases Denmark currently conducts a Helpline project (2016-2021) partly granted by the Danish Health Authorities and partly by private funding. The core activity of Helpline is to contribute to better empowerment for all people living with a rare disease (PLWRD) - patients and relatives. Helpline is a member of European Rare Diseases Helplines (ENRDHL) and RådgivningsDanmark, the Danish association for social, free counseling services.

Empowerment

Helpline works on the principle of help to self-help and is based on the professional approach of empowerment which includes following five proxies of empowerment on an individual level:

- Theoretical knowledge
- Practical knowledge
- Self-experienced knowledge
- Role modelling
- Networking

Through three core services Helpline strengthens the empowerment of PLWRD by providing:

- Information
- Coping support
- Individual counseling

Helpline is staffed partly by volunteers with experience-based knowledge about life with a rare disease and partly by professionals.

Helplines significant results

Initially Helpline was dimensioned to handle 200 – 400 enquiries per year. This criteria was more than met the first year and the number of enquiries has increased with more than 50 pct. from 407 the first year to 627 the third year (2018/2019). Once a year Helpline runs a satisfaction survey and effect measurement among the PLWRD contacting Helpline. The results show that Helpline meets the success criteria for the project since at least 75%:

- **Immediately:** declare to be satisfied or very satisfied with the response of their enquiry
- **After 2-3 months:** experience one or more of the proxies for empowerment.

In 2019 Helpline received quality accreditation from RådgivningsDanmark.

“I contacted Helpline to get in touch with others with the same diagnosis, I got that and we have super good mail correspondence.” Comment from a respondent on the satisfaction survey.

Evaluation

The unique combination of professionals and volunteers is the core strength of Helpline. The knowledge that the voluntary counselors contributes with can only be gained through experience.

To ensure a high quality Helpline draw on different tools such as the satisfaction survey, annual reports and annual self-evaluations. The annual report focus on registration practices, caller profile analysis and discovers important challenges that can be used in Rare Diseases Denmark's political work to improve life for PLWRD. Besides the support from small patient associations, Helpline is the only service of targeted counseling to PLWRD and their relatives in Denmark.

The ambition is that as the year of 2022, Helpline will be fully implemented and operating under Rare Diseases Denmark. We consider that opportunities are good.

Valuable tools

In addition to providing counseling, Helpline draws on following three tools:

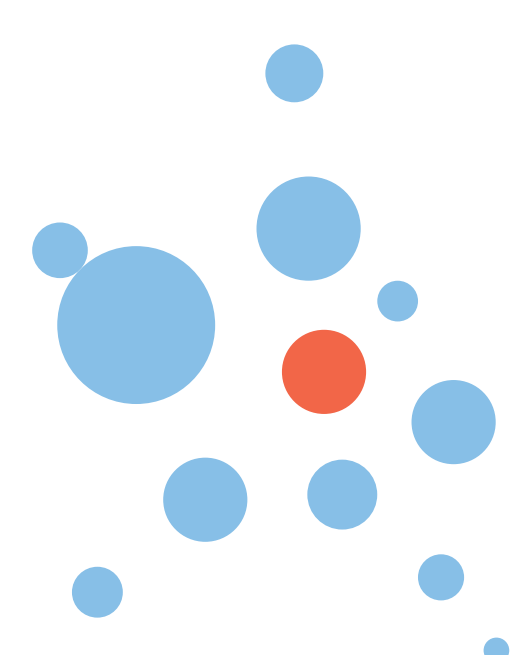
- Network for Ultra Rare Diseases
Offer PLWRD the possibility of joining diagnosis specific networking groups
- A corps of Layrepresentatives
Volunteer Layrepresentatives supports PLWRD at meetings with case officers, doctors and other professionals
- A corps of Navigators
Volunteer Navigators supports PLWRD over a period of time up to 6 months at meetings, in everyday life and more.

“Counselor took me seriously, responded immediately, and provided me with a layrepresentative for my meeting with the municipality. It is the best and fastest help I have received during my entire illness.” Comment from a respondent on the satisfaction survey.

Rare Diseases Denmark

Rare Diseases Denmark is the national alliance for rare patient associations. The associations are mainly run through voluntary work by patients and their relatives. The work of Rare Diseases Denmark is based on volunteers and a small professional secretariat. Rare Diseases Denmark has an ambition to work for all PLWRDs also those without a relevant patient association.

For more information: sjældnediagnoser.dk/helpline | mail@sjældnediagnoser.dk | + 45 33 14 00 10



Sjældne Diagnoser



Help Lines
for Rare
Diseases