

# From small networks to associations

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## Introduction

In 2012, Rare Diseases Denmark took over a Network for people living with Ultra Rare Diseases (NURD) from the Danish National Board of Social Services. NURD is funded with grants from the Ministry of Social Affairs for operations and with funds from private foundations for activities. The purpose is to:

- Offer PLWURDs the possibility of joining diagnosis specific network groups
- Guide members to existing associations, RareConnect, Facebook groups etc.
- Support the bigger network groups in the process of forming their own associations

In addition, the network equips Rare Diseases Denmark with:

- Broader knowledge about how to manage life with an ultra-rare disease
- Recruitment of volunteer Counselors to our Helpline with experience-based knowledge about living with an ultra-rare disease



## Peer-to-peer network

NURD is for patients and relatives for whom there is no relevant patient association in Denmark, because patients are so few in number. NURD is a community platform where members with the same ultra-rare diagnosis are connected with each other. Once connected, they have the opportunity to exchange experiences concerning every aspect there is about living with a rare disease. Some diagnosis specific network groups establish groups on social media platforms, others gather once a year in private quarters or alike.

Particularly beneficial for those who are alone with their disease, Rare Diseases Denmark facilitates a secret group on Facebook for all NURD-members. This gives them the opportunity to connect across groups. Also, we facilitate a yearly one-day Workshop for all NURD-members focusing on adapting to and living the everyday life with rare diseases.

## From network to association

NURD has close to 700 members registered representing approximately 200 different ultra-rare diseases. In nearly 90 of the diagnosis-specific network groups there is only one member. About 10 network groups have more than 12 members. When a diagnosis specific network-group reach more than 12 – 15 members, Rare Diseases Denmark make them aware of the possibility of forming a patients' association. We offer them funding and support in the process of setting up a board of directors and formulating the drafted statutes. Recently, network-groups of Bardet-Biedl, Fibrous Dysplasia and Calvé-Perthes were supported to transform from diagnosis specific network groups to patients' associations.



## Facts

A recent study shows that members of NURD are more challenged than PLWRD who are members of one of Rare Diseases Denmark's 53 patients associations. Members of NURD:

- Experience more need for psychological help at the time they or their child are diagnosed
- Feel less informed about civil rights
- Who receive support, have to corporate with many more professionals

The members' information is processed confidentially and in accordance with the Personal Data Act. NURD is supported by three employees part time at Rare Diseases Denmark.

## Rare Diseases Denmark

- Rare Diseases Denmark is a national alliance for 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.
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