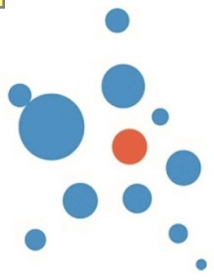


Rare Diseases Denmark

A new Help Line for people living with rare diseases in Denmark

Signe Kærsgaard Mortensen
Rare Diseases Denmark



Rare Diseases Denmark

Rare Diseases Denmark

- Rare Diseases Denmark is the national alliance of 52 small rare disease societies
 - 12.000 members
 - 200 diagnosis
- Rare Diseases Denmark also hosts NURD –Network for Ultra Rare Diseases
 - 170 diagnosis
 - 560 members – 70 is alone with their diagnosis
- The member societies are mainly run by volunteers: patients and their relatives
- The work of Rare Diseases Denmark is based on volunteers and a minor professional office



The danish Help line reappear

- From governmental organisation to Rare Diseases Denmark
- Anchored in Rare Diseases Denmark
- Partly funded by the private Danish foundation TrygFonden and (hopefully) the Danish Health Authority
- Staffed by our secretariat and volunteers



Volunteers and professionals

- At the "frontdesk"
 - Secretariat employees
 - 3 to 4 volunteers
- Network
 - Approx. 20 volunteer counselors from our member associations
- Panel of Experts – working *pro bono* (hopefully)
 - Geneticist, Lawyer, Physician etc.



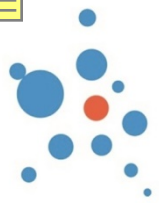
Core activities

- To provide:
 - supportive conversations
 - information about patient organizations and other networks
 - information about living with a rare diseases
- To create and disseminate new knowledge about rare disease and disability groups



Where are we at this point?

- **Stage 1 – developing the organizational model**
 - Mapping the resources
 - Education and training
 - Purchase and translate the datasystem
 - Information campaign
 - And much more...
 - **Stage 2 - establish Helpline**
 - Helpline is to be located in the office of Rare Diseases Denmark
- Our ambition is to handle 200 – 400 inquiries pr. year**



Please share your experience! 😊

- **Organization**

- What do you consider pros and cons of having voluntary and/or professional staff? Do they work together?
- How do you use external experts – if you use them?
- How did you get access to external experts?

- **The phone number**

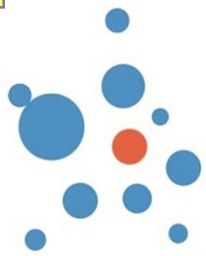
- Do you have a separate number for your Help Line?

- **Advertising**

- How do you advertise your Help Line? (homepage, campaigns, through professionals, social media, otherwise)
- What works for you?

Funding?

- **What is the biggest challenge for your Helpline right now?**
- **What is your best advice for us? 😊**



Rare Diseases Denmark

Please share your experience! 😊

- How is your Help line organised:
 - Staff: Professionals, volunteers?
 - Access to external based experts?
 - Funding?
- How to get in touch with your Helpline:
 - Fixed opening hours?
 - Autonomous phone number /e-mail?
 - Is a personal meeting possible?
- How do you advertise your Helpline
 - Homepage?
 - Campaigns?
 - Through professionals?
 - Otherwise?
- What is the biggest challenge for your Helpline right now?
- What is your best advice for us? 😊