Rare Diseases Denmark

# A new Help Line for people living wiht 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

Rare Diseases Denmark

# 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* (hopfully)
  - Geneticist, Lawyer, Physician etc.

Rare Diseases Denmark

# 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**

Rare Diseases Denmark

# 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? ☺