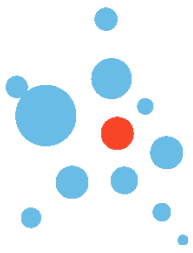




Rare Disorders Denmark

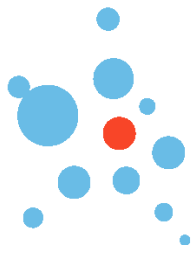
# Why face to face meetings are so important

Lene Jensen, Rare  
Disorders Denmark



# One face to face meeting

- A part of the POLKA project
- First face to face meeting across diagnosis ever
- The center: diagnosis, treatment and counselling for app. 25 rare diseases, 4 doctors, 2 nurses
- Participants in face to face
  - 10 families with children, randomly selected
  - 5 health care professionals (HCP's)

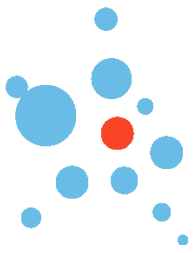


# The discussion

In general: Happy families!

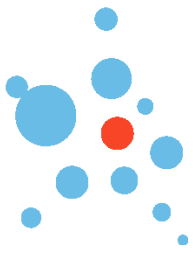
Focus points:

1. To get the diagnosis established and be given direction
2. To be seen and treated as a whole human being – holistic, comprehensive approach
3. The importance of information and coordination



# Room for improvement

- **Examples:**
  - Timing of examinations
  - Relevant information at the right time
  - Better interdisciplinary collaboration
  - Possibility of social counselling at the center
  - E-mail as an official communication instrument



## Said and unsaid

- A lot of nice things said
- Learning from each other
  - Patient to patient
  - Patient to HCP
  - HCP to patient
  - HCP to HCP
- Little things means a lot!

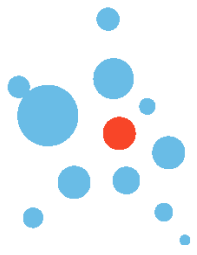




# Could anything have been done differently?

- Find a way to express more direct criticism
- Find a way to let the HCP s give general advise to the patients





Rare Disorders Denmark

# The face-to-face meeting offers great value!

- We can do a lot together as a project
- We can also do something, even though it might not be part of a project

