

The background features a solid red horizontal band across the middle. Above this band, there are several light blue circles of varying sizes. Below the band, there is a faint, semi-transparent image of two hands shaking, symbolizing partnership or agreement.

How can civil society and patient organisations join forces to improve the health and social situation of PLWRD?

Lene Jensen, Rare Diseases Denmark

RARE DISEASES DENMARK – DATING PROFILE:

- Age: almost 40
- Profession:
 - National alliance and platform for Associations
 - Advocate, knowledge holder and Helpline supplier for all PLWRD
- Volume: 55 member Associations + NURD = 600 different diagnosis, board of representatives and executive committee + small, professional secretariat
- Looking for: anyone who can help adress all unmet needs along the rare patient journey



CIVIL SOCIETY AS A RESSOURCE

- A driver for change
 - Frontrunner
 - Advocate
 - Critical voice
 - Bridge builder
- Creating insight and support
 - Expert knowledge
 - Supplier
 - And so much more...



THE DYNAMICS BETWEEN EUROPE AND NATIONAL LEVEL

- The European trampoline (2008, 2009, 2011, 2014, 2018, 2022, ?)
- The National Alliance as a full partner
- Concrete example: the Danish Helpline
 - Reference: The Danish National Strategy
 - Part of evaluation → excellent grades!
 - A strong case for raising the necessary (public) funds
- Even though: room for improvement
 - Non-binding mandate for the Monitoring Group
 - No budget, no action plans
 - 2024: mostly a contact agency...



A NEW EUROPEAN ACTION PLAN FOR RARE DISEASES

- We need to tighten the European bar dunes
 - To give Civil society a better springboard
 - To create a framework
- We need the European Reinforcement
 - To integrate health, social care, research and data management policies
 - To promote access to Diagnosis and Treatment, Patient Empowerment and Cross Border Healthcare
 - To create clear, measurable goals
 - To set the course for anyone who can help adress all unmet needs along the rare patient journey

