

KAROLINSKA CENTER FOR RARE DISEASES – FOR IMPROVED CARE OF PATIENTS WITH RARE DISEASES

Maria Johansson Soller*, Katja Ekholm, Eva Ekblom, Charlotte Willfors, Charlotta Ingvaldstad-Malmgren, Kristina Gustafsson-Bonnier, Karin Kindberg, Rula Zain.
Karolinska University Hospital, Stockholm, Sweden

Background Rare diseases are often complex multi-organ syndromes. Hence, to obtain necessary support, many rare disease patients need multiple visits and contacts with different health care providers and social services. For many diagnoses, there are no experts in the region and some patients remain undiagnosed. Center for Rare Diseases at the Karolinska University Hospital (KCSD) was formed in 2012.

Aim Our aim is to improve the living conditions for children, adolescents and adults with rare diseases by

- Increasing awareness and knowledge about rare diseases
- Providing information and improve education about rare diseases
- Improving the coordination of health care and facilitating cooperation between experts
- Guidance to patients, health care professionals and society
- Being the national partner of Orphanet and participates in the Rare 2030 Panel of Experts

