

Rare Disease Functions/College for Genetics & Rare Diseases Working Group

MISSION

- Unite all bodies (governmental bodies, regional networks, hospital functions and patient organisations) involved in rare diseases by acting as a **national overarching platform** facilitating communication, collaboration, and harmonization of efforts in the field of rare diseases.
- Exchange information on a regular basis on different aspects of rare disease and make it accessible and useful to patients with rare diseases and their relatives, and healthcare providers and this to ensure optimal alignment and stimulate collaboration.
- Raise awareness for rare diseases, including aspects such as medical, psychosocial, ethical, legal and societal aspects, by educating, interacting, and communicating with health care professionals, policy makers and society.
- Enhance, stimulate, and contribute to a strategy for **state-of-the-art holistic**, **multidisciplinary care** for patients with rare diseases and their relatives.
- Stimulate and enhance the impact of rare disease research by acting as a **national** interface for rare disease research