

CENTRE FOR RARE DISORDERS

Centre for Rare Disorders in Norway is a multidisciplinary, nationwide competence centre offering information, counselling and seminars on around 70 rare disorders.

We cover medical, social and pedagogical aspects, and our services are aimed at patients/persons with a rare disorder and their families, as well as professionals working with these disorders.

Anyone may contact the centre; a referral or advance appointment is not required.

INFORMATION

The centre acquires and coordinates specialist knowledge on, and experience with, designated rare disorders. This information is distributed via counselling, courses, information booklets, videos and our website.

A MULTIDISCIPLINARY ORGANISATION

We are a multidisciplinary organisation staffed with medical professionals such as doctors, medical geneticist, specialist nurses, psychologists, educator, social workers, bioengineer, physiotherapists, nutritionists and others who can advise on any matter relating to one of the centre's diagnoses.

We also work closely with medical professionals responsible for treating those with one of our diagnoses.

COUNSELLING

Centre for Rare Disorders offers counselling and guidance to patients and their families and to professionals via:

- phone and e-mail enquiries
- meetings at the centre or at the treating hospital
- meetings in the patient's local environment
- video conferences
- courses

COURSES & E-LEARNING

Centre for Rare Disorders arranges courses for patients, their families and professionals. The courses last for 1 to 5 days, held at various locations throughout the country. They offer medical information related to specific diagnoses, and also address more general issues, such as everyday life in kindergarten/at school/at work, nutrition, physical activities, national health benefits, rights and privileges

Sharing experiences is an important part of these courses.

We also develop and offer e-learning courses, enabling patients, relatives and professionals to learn about rare disorders whenever and wherever they want. This is especially convenient for health professionals and school and kindergarten staff, when in need to prepare for receiving a person/child with a rare disorder.

INFORMING THE PATIENT'S LOCAL ENVIRONMENT

In regional health services, there is usually a lack of knowledge about rare disorders. Hence, it is essential that we supply competence through information meetings held in the patients' local area. We strive to ensure that the transition from one stage of life to the next is planned well in advance, so that necessary adjustments may be implemented.

PATIENT PARTICIPATION

Centre for Rare Disorders collaborates with patients, their families and patient organisations. The centre has a Centre Council where patients (represented by patient organisations) and professionals offer feedback and make suggestions for the centre's activities and development.

RESEARCH AND DEVELOPMENT

Research activities at the centre are run through collaboration between patient organisations and specialist health care environments in Norway and abroad. New international research and results from our centre's projects are communicated to patients and involved health care specialists.

Our employees regularly attend national and international conferences, and contribute to research through scientific publications.

Some current research activities:

The Centre for Rare Disorders is responsible for several projects aiming at investigating different aspects of the challenges involved in living with a rare disorder.

As an example, one current project explores experiences of support in the local and specialist health care system in parents of children with Bardet-Biedl syndrome.

Another project is testing an online intervention programme for young people with appearance concerns related to living with a visible difference (UNG Face It / YP Face It).

Yet another project investigates the impact of appearance-altering surgery on young people with rare craniofacial conditions and their parents.

ORGANISATION

Organisationally, the Centre is a department in the Oslo University Hospital, and is also one of 10 competence centres constituting the "Norwegian national advisory unit on rare disorders" (NKSD).

The centre is a national undertaking and works on behalf of the Norwegian directorate of health.

Centre for Rare Disorders

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