



Rare Disorders Denmark



**Rare Disorders Denmark**

An alliance of  
Danish rare disease organisations

[www.raredisorders.dk](http://www.raredisorders.dk)

## Focus on rare disorders

Rare Disorders Denmark is an alliance of more than 30 national patients' organisations which represent people born with serious, rare diseases or disabilities.

As representatives of people with rare disorders we produce expert knowledge about their problems and conditions.

In Rare Disorders we aim to put focus on the common problem areas for people with rare disorders.

We:

- Take part in the public debate
- Present our viewpoints to politicians and authorities
- Create knowledge and documentation about rare diseases through research, reports and conferences
- Publish the magazine *Rare Disorders*, which focuses on current problem areas for people with rare diseases

Bjarne and Bette both have Crouzon Syndrome which causes craniofacial deformities.



Johanne and Stine are twins. Johanne (bottom) is born with galactosaemia, a rare metabolic disorder.



## Treatment and Research

In Rare Disorders we advocate the interests of people with rare diseases. Two of our major focus areas are:

### **Coherent treatment**

Many people with rare diseases experience that their treatment is insufficient, uncoordinated and varying according to their geographical setting.

Rare Disorders work to improve the organisation of this treatment. We are continually in dialogue with politicians and professionals significant for people with rare diseases.

### **Research in rare diseases**

Research in rare diseases and development of diagnosis and treatment possibilities are neglected areas. The costs are high, research has limited resources and knowledge, and the marketing of drugs is often delayed by complicated and slow procedures.

It is necessary to work out a joint Danish strategy in this area and in Rare Disorders we are actively working on this problem.

## Cooperation for better conditions

Rare Disorders cooperate closely with other organisations which aim to promote patients' interests in Denmark.

We take part in European cooperation as a member of Eurordis (European Organisation for Rare Disorders) which represents the rare disease groups in Europe.

The purpose is to improve the quality of life for people with rare diseases in all European countries. Among other things, we work to carry out the objective of the EU regulation 141/2000 which states that patients with rare conditions should be entitled to the same quality of treatment as other patients.

### Facts

20-30.000 people in Denmark suffer from a rare disease.

In Denmark, a disease is defined as rare if it has a prevalence of less than 1.000.

Most of these diseases are serious and often life threatening. In many cases no method of treatment exists. The diseases may cause

- internal deformities
- external deformities
- psychomotoric problems
- mental disability
- reduced life span

Knowledge about these diseases is often limited because they are so rare.

## The real experts

The rare disease groups are often isolated because of their low prevalence. The patients' organisations are experts on how to live with a rare disorder, and they represent important resources.

The mutual exchange of ideas and experiences is very central in Rare Disorders. It is a way for the organisations to learn from each other.

In Rare Disorders spread knowledge to the organisations through seminars about treatment of rare disorders, patient safety, health care, genetic counselling, social conditions etc.



### Rare Disorders Denmark

KMS

Rare Disorders Denmark was founded in 1985 as KMS – The Danish Alliance for Rare Disorders.

In 2005, KMS changed its name to Rare Disorders.

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**Member organisations**

Association of Children with Undiagnosed Disabilities  
Danish Association for Neurofibromatosis Recklinghausen  
Danish Cystic Fibrosis Association  
Danish Mitochondrial Society  
Gaucher Association Denmark  
Huntington's Disease Denmark  
National Society for Congenial Bladderectopia  
Prader Willi Syndrome Association Denmark  
PV - The Association of Polycythemia Vera in Denmark  
Restricted Growth Association of Denmark  
The Danish Alpha 1 Association  
The Danish Angelman Syndrome Organization  
The Danish Apert Syndrome Association  
The Danish Association for Albinism  
The Danish Association for Crouzon Syndrome  
The Danish Association for Dysmelia  
The Danish Association for Immunodeficiencies  
The Danish Association for Sotos Syndrome  
The Danish Association for Galactosaemia  
The Danish Ehlers-Danlos Society  
The Danish Haemophilia Society  
The Danish National Association for Marfan Syndrome  
The Danish Rett Syndrome Association  
The Danish Spielmeier-Vogt Association  
The Danish Spina Bifida and Hydrocephalus Association  
The Danish Tourette Syndrome Association  
The Danish Tubercous Sclerosis Association  
The Danish Von-Hippel-Lindau Association  
The Danish Wilson Patient Association  
The Osteogenesis Imperfecta Society of Denmark  
UniqueDenmark