

# Social Profiles

## a dialogue tool



## Rare Disorders Denmark\*

Rare disease patients and their families often navigate in unknown territory. Even if medical guidelines for their disease exist, they normally do not mention social and educational matters and the public services within the social and educational area are often inadequate.

Because the disease is rare, social workers, teachers and care takers have no knowledge of the consequences and necessary support. The real experts as to what is needed, is located among the patients and their societies.

Rare Disorders Denmark has developed a tool, Social Profiles, for the dialogue between the rare disease patients and professionals.

Social Profiles:

- gives a short description of the diagnosis and its characteristics in lay terms
- provides a check list for relevant support which should be considered in a life time perspective, for instance:
  - Necessary considerations in general, e.g. assistive technology and interior special design
  - Special needs of the small child, the larger child and the youngster, e.g. needs for extra resources in day care, special resources at school and special vocational guidance
  - Special needs of adults, e.g. special programmes in order to obtain labour market contact or special housing
  - Contact to the relevant patient society

The Social Profiles have been developed in a process involving the rare disease patient soci-

eties and government authorities. The profiles exist for 15 rare diagnosis, more to come.

The Social Profiles consist of verified facts only and are published at the website [www.sjaeldenborger.dk](http://www.sjaeldenborger.dk) (meaning: [www.rare-citizen.dk](http://www.rare-citizen.dk)). The professionals can find the Social Profiles, when they Google the disease and the rare patient and her family can bring the Social Profile to the professional at the first meeting.

The Social Profiles have been developed within a state funded project of 420.000 € over a 4-year period, also containing

- Upgrading of skills for patient society advisers
- Virtual tool kit for rare patient societies
- Raising awareness about rare disease patients in order to avoid stigmatisation.

# Visit [www.sjaeldenborger.dk](http://www.sjaeldenborger.dk)



Here you find Social Profiles of the following disorders:

- Apert Syndrome
- Crouzon Syndrome
- Dwarfism
- Ehlers-Danlos syndrome
- Galactosaemia
- Haemophilia
- Marfan Syndrome
- Mitochondrion
- Möbius Syndrome
- Prader-Willi Syndrome
- Primary Immunodeficiency
- Rett Syndrome
- Spinal Cord Disease
- Tourette Syndrome
- Von Hippel-Lindau Syndrome
- Von Recklinghausen's Neurofibromatosis
- Wilson's Disease

Please be aware that the site and all Social Profiles are in Danish

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