

Feel free to contact us whenever you need information or support in rare disease issues.

Contact address:

Jenni Kuusela, Planning Officer tel. +358 44 7650410 jenni.kuusela@invalidiliitto.fi

Tanja Lehtimäki, Planning Officer tel. +358 40 7281737 tanja.lehtimaki@invalidiliitto.fi

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Invalidiliitto ry Mannerheimintie 107 00280 Helsinki tel. +358 9 613 191 www.invalidiliitto.fi



Finnish Association of People with Physical Disabilities

RARE DISABILITIES UNIT





ber to join the activities. Peer support is the core of the operations, and the events provide an opportunity for the people with rare diseases and their family members to meet others in the same condition.

Do you look for peer support for the challenges of the rare disability situation?

The Invalidilitto peer support operations focus on rare diseases and disabilities. The trained peer support professionals come from various age groups and various parts of Finland. They may have a rare disease themselves or be family members of those involved.

The Rare Disabilities Unit of the Finnish Association of People with Physical Disabilities (Invalidiliiton Harvinaiset-yksik-kö) works to improve the position of people with rare disabilities by disseminating information and organising opportunities for peer support.

What is a rare disease? According to the EU criteria, a disease or disorder is rare if it affects fewer than five in 10,000 people in a given population. In Finland, this means disease and disability groups with less than 2,700 people. The number of rare diseases and disabilities currently known is about 8,000.

The operations of the Rare Disabilities Unit are targeted at people of all ages with a rare disease as well as to their family members. You need not be an Invalidility mem-



With the help of **peer support**, you or your family can receive support and guidance from a person, family or group with personal experience of a corresponding disability, disease or trauma. Peer support is always voluntary.

Rare diseases unit

organises

- peer support events
- diagnostic and thematic meetings
- seminars and other topical events

provides information and guidance to

- people with rare diseases and their family members
- healthcare and social welfare professionals who meet people with rare diseases and disabilities in their work
- those with an interest in the topic

produces information and publishes

- the webpage and newsletter (Harvinaiset uutiset)
- news and blogs on topical issues

collaborates

- on a national level: the rare Disabilities Unit is a member of the Harvinaiset network (www.harvinaiset.fi)
- internationally: *Invalidiliitto* (Finnish Association of People with Physical Disabilities) is a member of the European organisation Eurordis, the European Alliance for Rare Diseases.

