The Rare Disabilities Unit is a member of Eurordis, the European Alliance for Rare Diseases. We also operate in a network of associations and cooperate with the public sector.





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Finnish Association of People with Physical Disabilities

RARE DISABILITIES UNIT Services for the rare disease community



Facts and peer support

The Rare Disabilities Unit, part of the Finnish Association of People with Physical Disabilities (FPD), aims at improving the status of people with rare diseases by providing up-to-date information and opportunities for peer support. The rarer the disease, the more difficult it is usually to get information, guidance and peer support.

What is a rare disease?

A rare disease hampers a person's functional ability in everyday life in a number of ways. Rare diseases are characterised by a broad range of disorders and symptoms, whose effects on functional ability vary from patient to patient. Rare diseases can be hereditary, progressive or life-threatening, and include a large number of complex syndromes. The origin of certain diseases is completely unknown. Although the research and diagnostics of rare diseases is developing, much remains to be done in order to promote established treatment methods and rehabilitation.

The European Union defines a disease or disorder as rare if it affects fewer than five in 10,000 citizens. In Finland, this means disease and disability groups involving less than 2,700 people. Depending on the definition used, there are between 6,000 and 8,000 rare diseases and disabilities worldwide.



RARE DISABILITIES UNIT Finnish Association of People with Physical Disabilities

Information and support

FPD's Rare Disabilities Unit

- provides information and publications
 - guides, such as diagnostic and rehabilitation guides
 - newsletter on rare diseases (Harava)
 - website and bulletins
 - expert articles
- organises
 - meetings for diagnostic groups
 - meetings on various themes
 - regional meetings
 - peer events
 - lectures, informative events
- provides guidance and counselling
 - for rare disease patients and their families
 - for professionals who meet rare disease patients in their work
 - for other interested parties.

