

ERN on skin disorders (ERN Skin)

Many skin conditions have a severe impact on patients and can be associated with a risk of cancer. Diagnosis of rare and complex skin diseases consists of a full assessment of the skin and mucous membrane, as well as other systems, in addition to skin biopsies. Only experienced dermatologists can differentiate between these complex conditions, and the absence of an expert diagnosis is a barrier to treatment. This can be a profound physical and psychological burden for patients.

ERN Skin brings together leading experts in the field of rare child and adult skin diseases to exchange knowledge, update and develop best practice guidelines, improve professional training and patient education, and set up research programmes.

It aims to improve healthcare organisation with the pooling of resources, including a platform with expert collaborative discussions on difficult cases. For every disease covered, core multidisciplinary teams include at minimum a dermatologist, a nurse, a psychologist, a geneticist, a dietician and a pathologist, along with other specialists as required.

ERN Skin also develops rare skin disease registries, allowing participation in research programmes and clinical trials with well-characterised patients, as well as the stimulation of therapeutic research with sufficiently large cohorts of patients. In addition, a comprehensive socio-economic study on the individual burden of diseases will be conducted.



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