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, and skin biopsies. Only experienced dermatologists can differentiate between these complex conditions. The absence of an expert diagnosis is a barrier to treatment. This can be a profound physical and psychological burden for patients.

A comprehensive socio-economic study on the individual burden of diseases will be conducted.

This network brings together leading experts in the field of rare child and adult skin diseases to exchange knowledge, update and develop best practice guidelines, and improve professional training and patient education.

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

ERN Skin will also develop 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 larger cohorts of patients. In addition, a comprehensive socio-economic study on the individual burden of diseases will be conducted.

NETWORK COORDINATOR

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