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ERN on Rare and Undiagnosed Skin Disorders

JA2015 - GPSD [705038]

START DATE: 06/03/2017

END DATE: 05/03/2022

DURATION: 60 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: European Reference Networks

TOPIC: ERN-2016 - European Reference Networks – Framework Partnership Agreement

EC CONTRIBUTION: 0 EUR

KEYWORDS: Auto-Immune Skin Diseases, Clinical Outcomes, Cross-Border Healthcare, Drug Side-Effects, E-Health, Genodermatoses, Guidelines, Rare Skin Disorders, Registries, Skin Tumours, Therapeutic Education, Training

PORTFOLIO: Rare diseases

Project abstract

Situation

The ERN-Skin aims to enhance high-level patient management for rare complex and undiagnosed skin disorders, by improving the: quality, safety, access to highly specialized healthcare. These diseases share: frequent misdiagnosis; lack of training of paramedics; frequent systemic involvement; poor recognition as a handicap; poor social integration.

Objectives

1. Better exchange of expertise; 2. Improved healthcare organization by pooling the resources; 3. Update/ develop guidelines in cooperation with overlapping ERNs; 4. Improved training of caregivers; 5. Patient/family therapeutic education; 6. Widespread general public information and recognition of the disease as a handicap, 7. Deep phenotyping for a common scientific language; 8. Development of an e-health platform allowing telemedicine and registries (research); 9. Comprehensive socio-economic study

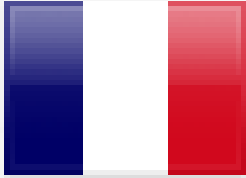
Methods

1. Governance thought to ensure maximum geographical and target groups representativity and outreach across the EU; 2. Sub-thematic groups (specific clinical outcomes) and transversal groups (deep phenotyping, e-health& registries, training, common clinical outcomes); 3. Theoretical and practical courses for specialists and paramedics across the network and other ERNs covering different same symptoms; 4. Set up of a Patient Representative Council, representing all patient groups; 5. Communication and information: dissemination of Minutes, Reports in/outside the network; development of tools (website, newsletters, etc...); periodic meetings; 6. Support of European scientific societies

3rd HP relevance

ERN-Skin will facilitate access to better and safer healthcare for EU citizens by identifying centers with the necessary expertise and resources to treat rare diseases with skin involvement, as well as by sharing knowledge for an improved healthcare offer. ERN-Skin has a strong focus on developing innovative e-health tools for HCPs, thus facilitating cross-border access to expertise for effective patient management

COORDINATOR



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PARTNERS

No partners related to the current project

