ERNSKIN

HOW TO IMPROVE HEALTH THROUGH HIGHLY SPECIALISED HCP FOR RARE or LOW PREVALENCE COMPLEX SKIN & MUCOUS MEMBRANE DISORDERS

9 thematic Disease Groups
Expert multidisciplinarity Management involving over 15 specialities

56 HCPs in 18 countries + new HCP candidates
20 patient representatives

Enlargement:
2 Associated National Centers
+ 2 National Coordinatiion Hubs

On going main Actions

> Trainings Sessions for medical & paramedical team, scientists & students
1st ERN-Skin training in Finland (May 2017)
Italy (November 2018)
France (October 2019)
Belgium (November 2019)

> Terminology standardization in Dermatology :
ORPHACODES for clinical communication, publications and research, health records and registries
+ SPOT App prototype easy to understand and patient-friendly

> CPMS :
Clinical Patients Management System on going in each Disease Group

> European Registries for Dermatology (on going development)

Co-funded by the EU

9800 rare skin new patients visited, treated, or followed in our Network (in 2018)

Online resources for Patients and Healthcare professionnals
https://ern-skin.eu/

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Next Steps ...