

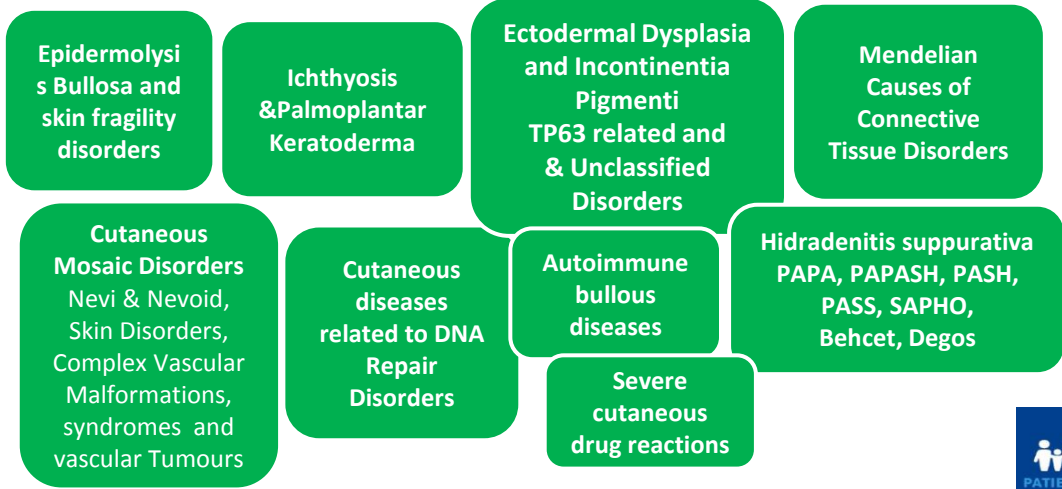
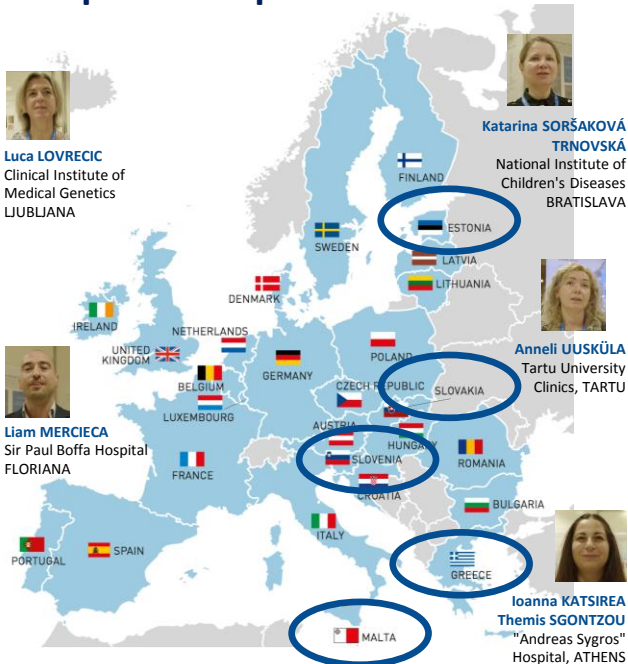
ERN-SKIN

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

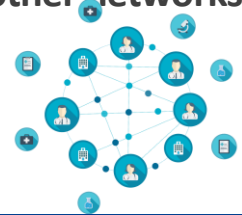
9 thematic Disease Groups

Expert multidisciplinary Management involving over 15 specialities

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



Cooperation + other 23 ERNs, scientific societies other networks



Online resources for Patients and Healthcare professionals

<https://ern-skin.eu/>

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

Enlargement :
2 Associated National Centers
+ 2 National Coordination Hubs

On going main Actions

> Trainings Sessions for medical & paramedical team, scientists & students

<p>1st ERN-Skin training in Finland (May 2017)</p> <p>Helsinki</p>	<p>Italy (November 2018)</p> <p>Roma</p>	<p>France (October 2019)</p> <p>Paris</p>	<p>Belgium (November 2019)</p> <p>Ghent</p>
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- > European and national specific guidelines
- > Specific emergency cards
- > Formation for Patients : leaflets, videos
- > Specific ERN-Skin burden scores for each disease

> Terminology standardization in Dermatology : ORPHACODES for clinical communication, publications and research, health records and registries

+ SPOT App prototype : terminology easy to understand and patient-friendly

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

> European Registries for Dermatology (on going development)



Next Steps ...

- Harmonize patient satisfaction survey
- Develop the ERN-Skin website
- Therapeutic education programs for children, adolescents and adults
- Go on with SPOT App
- DEVELOP THE REGISTRY PROJECT
- INTEGRATE AFFILIATE PARTNERS
- Develop e-learning material
- Organize ERN-Skin Events
- Go on with the activities developed within each thematic group
- Use the CPMS
- Update Orpha Codes