



GENODERMATOSES & RARE SKIN DISORDERS NETWORK

IMPROVE THE QUALITY & SAFETY OF HEALTHCARE
PROMOTE A MULTIDISCIPLINARY MANAGEMENT
DEVELOP A PATIENT-BASED APPROACH
DEVELOP HEALTHCARE PATHWAYS

**Coordinators of the Genodermatoses & Rare Skin
Disorders Network Scientific Committee**



From left to right:

President: Christine Bodmer (France)
President-elect: Maya El-Hachem (Italy)
Past President: Johann Bauer (Austria)



WHO ARE WE?

- A network of **150 teams** in **50 European, Mediterranean and Middle-Eastern countries** involved in rare skin disorders management
- Steered by an **international Scientific Committee**, composed of 34 opinion leaders in the field of rare skin disorders

TOWARDS A EUROPEAN REFERENCE NETWORK

- **Pooling knowledge and expertise across EU** for better access to diagnosis, treatment and provision of affordable, high-quality and cost-effective healthcare
- **56 teams in 18 countries to join the potential ERN-Skin**
- **Disease approach & Transversal approach**
- Involvement of patient groups

COME AND JOIN US!

MORE INFORMATION AVAILABLE AT:

www.genodermatoses-network.org



WHAT DO WE DO?

- **International meetings** bringing together partners **focusing on health care and social support for patients and their families**
- **Working groups** to discuss diagnosis and therapeutic strategies
- **Courses** supporting a multidisciplinary approach & **e-training**
- Promoting the development of national and regional networks
- Increasing **awareness**
- Fostering the development of **dedicated outpatient facilities and centres of expertise** for rare skin disease patients
- Fostering international collaborations and clinical and therapeutic research in the field of rare skin disorders
- Assessing **patients and HCPs needs**: international surveys
- World Interactive Map **Directory of Rare Skin Disorders Medical Resources for Patients and Professionals** available on the website

ADD YOUR TEAM TO THE WORLD DIRECTORY!

MORE INFORMATION AVAILABLE AT:

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SCIENTIFIC COMMITTEE

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