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:

www.genodermatoses-network.org
Genodermatoses & Rare Skin Disorders Network

Scientific Committee

Hala ABIRACHED-MEGARBAE (LB)
Mohammadreza BARZEGAR (IR)
Johann BAUER (AT)
Christine BODEMER (FR)
Hana BUCKOVA (CZ)
Bert CALLEWAERT (BE)
Anca CHIRIAC (RO)
Violetta CHRISTOPHIDOU-ANASTASIADOU (CY)
Emad EL-GAMAL (EG)
Maya EL-HACHEM (IT)
Ghada EL KAMAH (EG)
Seniz ERGIN (TR)
Angela HERNANDEZ (ES)
Daniel HOHL (CH)
Marcel JONKMAN (NL)
Sarolta KARPATI (HU)

Cezary KOWALEWSKI (PL)
Irene LEIGH (UK)
Branka MARINOVIC (HR)
Juliette MAZEREUW-HAUTIER (FR)
Arti NANDA (KW)
Jemima MELLERIO (UK)
Aïcha SALHI (DZ)
Matthias SCHMUTH (AT)
Eli SPRECHER (IL)
Alain TAIEB (FR)
Spiro TAMS (PS)
Heiko TRAUPE (DE)
Hamida TURKI (TN)
Anders VAHLQUIST (SE)
Pierre VABRES (FR)
Mohammed ZGHAL (TN)
Giovanna ZAMBRUNO (IT)