

# Practical management of epidermolysis bullosa in the newborn: consensus statement from the European Reference Network for Rare Skin Diseases

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- **Introduction** (May El Hachem, Giovanna Zambruno)
- **Care at birth** including diagnosis (May El Hachem, Giovanna Zambruno, Domenico De Rose, Alexandre Lapillone, Cristina Has)
- **Skin care** (May El Hachem, Giovanna Zambruno)
- **Mucous membrane care** including eye, GI and respiratory tracts (Cristina Has and two colleagues from Freiburg)
- **Nutrition** (Nathalia Bellon)
- **Pain management**, supportive and palliative care (Christine Bodemer, Celine Greco, and Elodie Dimarcq)
- **Therapeutic parent education** (Carmen Salavastru)
- **Psychosocial family support** including diagnosis communication (Christine Bodemer, Helene Dufresne and Sarah Dimarcq)
- **Hospital discharge and follow-up** (Hana Bučková)