

**ERN-Skin IPPK Thematic Group Meeting**  
**– Minutes–**  
**during ERN-Skin Board Meeting on 11/12/2025**

Shortly discussed changing name to ERN-Skin - Epidermal Differentiation Disorders (EDD) group.

**Activities & Progress Update | 2nd Coordination Period (Sept 2023–Aug 2027)**

**Scope**

The IPPK Thematic Group addresses inherited palmoplantar keratodermas and epidermal differentiation disorders (including ichthyoses, Darier disease and Hailey-Hailey disease). Its mission is to harmonize care, education, research, and patient involvement across ERN-Skin.

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**Clinical Case Discussion (CPMS)**

- **From two to three CPMS sessions per year**, with multiple panels per session (one case per panel).
- **Status:** Fully implemented and ongoing.

**Training & Education (Health Professionals)**

- **Case-based e-education:** Development of EDD clinical cases (e.g. congenital and lamellar ichthyosis).
  - **Status:** Three cases planned for begin 2026.
- **E-training modules (students/residents/dermatologists):**
  - **Status:** Four modules near completion; final audio and editing pending.
- **Scientific Webinar** : organised on 26th May 2026 (from 1:00 – 2:00 pm CET), subject and speaker to be confirmed

**Patient Education & e-Learning**

- **Recorded webinars/interviews** on mental health, family planning, comorbidities, aging, and social burden.
  - **Status:** Preparation ongoing; first recordings in 2026, continuation in 2027
- **Practical patient tools:** Translation and adaptation of existing materials (e.g. topical treatment instructions, itch-relief techniques), with short practical videos planned end 2026/2027 depending on funding
- **New patient resources:**
  - Ichthyosis: social and reimbursement aspects across Europe.
  - PPK: development of first dedicated educational tools.
  - **Status:** Data collection and prioritization ongoing (2026).

**Guidelines & Clinical Decision Tools**

- **Ichthyosis management guidelines:** Updated version published (2025); patient-friendly summary prepared – waiting for BJD permissions.
- **Skin-at-School tool:** Existing Dutch program; translations and cultural adaptations in progress.
- **Darier disease:** Severity score (Delphi ongoing); guideline draft completed.

- **Hailey-Hailey disease:** Guideline development planned (2026–2027), in collaboration with the EB group.

### **Patient Journeys & Involvement**

- Active participation in ERN-Skin ePAG initiatives (mental health, pediatric aspects, palliative care).
- Dedicated ichthyosis patient journey activities planned for 2026

### **Research Upscaling**

- **Quality of life & psychosocial research:**
  - Short ichthyosis-specific QoL questionnaire (ethical approval ongoing).
  - Studies on social media, reproductive dilemmas, and artificial intelligence (ongoing/submitted).
- **Cohort studies:**
  - Phenotype-genotype studies, joint involvement, comorbidities, mild PC/PPK phenotypes.
  - Several new multicenter cohorts initiated or in preparation.
- **Classification & outcomes:**
  - Updated international ichthyosis classification published (2025).
  - Core Outcome Set (COS) for inherited ichthyosis ongoing (Delphi until mid-2026).
  - COS for inherited PPK initiated (funding required).

### **Therapy & Registry**

- **Biologic repurposing in ichthyosis:** International series published (2024).
- **Clinical trials:** BEDD trial in preparation, pending funding.
- **ERN registry:** Participation ongoing; contracts in progress.

### **Overall:**

The IPPK group is making sustained progress across **clinical care, education, guidelines, patient engagement and research**, with multiple high-impact outputs delivered and several key initiatives entering decisive phases in **2026–2027**.