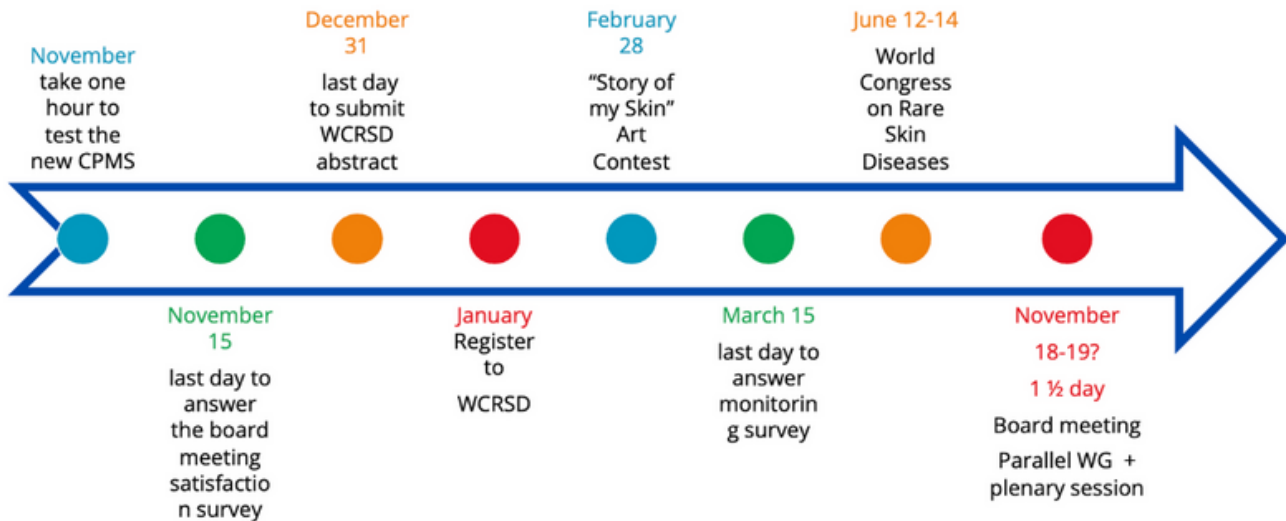


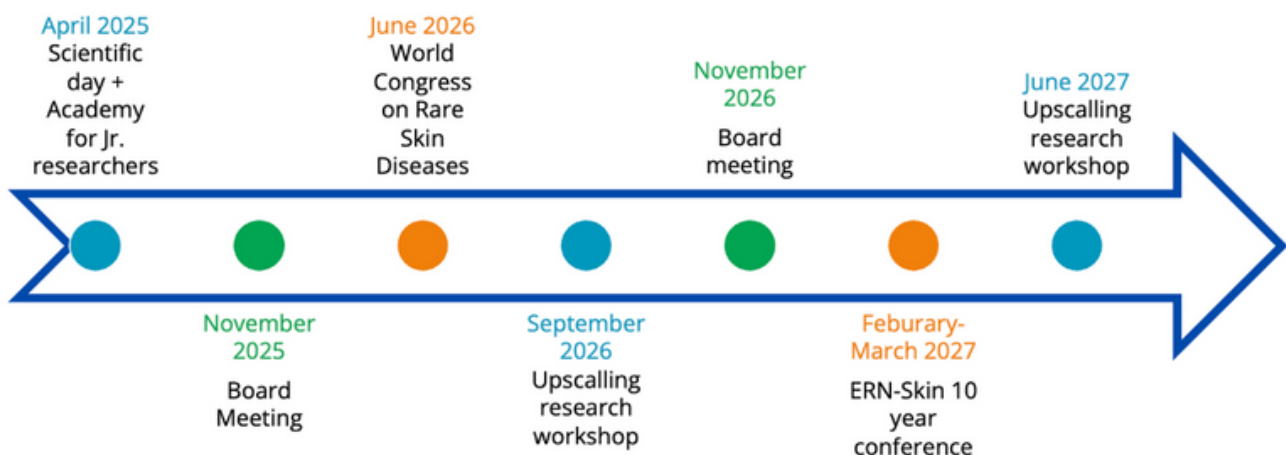
## A few tips

- Update the list of the members of your team engaged in the ERN-Skin <https://ec.europa.eu/eusurvey/runner/Engage-your-HCP>
- Share the ERN-Skin information with every member of your team
  - Unless you specifically ask for it, ERN-Skin information is sent only to the official ERN-Skin healthcare provider / hospital representative, to the ERN-Skin group chairs and ePAGs
- Participate in each thematic group meeting you are engaged with (1 or 2 groups max!) and take responsibility for a task
- Ask for information and support from the ERN-Skin helpdesk
  - to use the CPMS
  - to contribute to ERRAS, the ERN-Skin registry
- Ask your patients to answer the patient satisfaction survey: <https://ern-skin.eu/patient-satisfaction-survey/>
- Keep record of the ERN-Skin activities you participate in so you do not have to spend hours or days when the European Commission monitors or evaluates your activity
- When traveling for the ERN-Skin: do not book yourself your travel and accommodation, always ask before!
- Do not forget to acknowledge the ERN-Skin *"This work is generated within the ERN-Skin"* or *"This work is supported by the ERN-Skin"*
- Participate in the ERN-Skin events and activities (CPMS, registry, ....)






## 2023-2024 ERN-Skin events



## 2025-2027 ERN-Skin events (to be confirmed)



# 2023 Monitoring: A few tips!

-  Write it on your calendar: every year, you have to submit your data by March 15 at the latest
-  Keep record of all your activities
-  Indicate only the activities of the year covered by the monitoring
-  List a congress only if there is a dedicated slot to present ERN-Skin activity
-  List a publication, a clinical trial, an observational study only
  - If it involves at least 2 ERN-Skin members from 2 different Member States
  - If it acknowledges the ERN-Skin



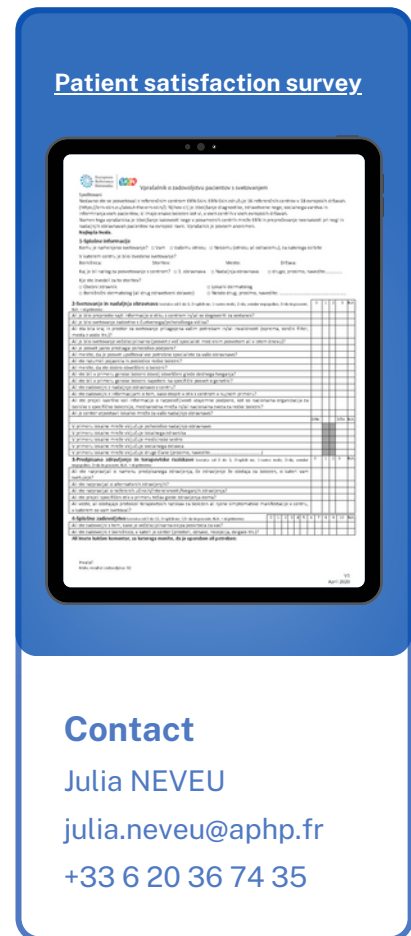
## How to acknowledge the ERN-Skin?

- **In a publication**
  - "This work is generated within the ERN-Skin"
  - "This work is supported by the ERN-Skin"
- **In any other document, add**
  - ERN-Skin logo + the EU flag



# Patient satisfaction survey: What is it?

- It aims to measure the level of patient satisfaction after consultation in an ERN-Skin healthcare provider / hospital (HCP)
- Elaborated by the ePAG group
- The questionnaire has 26 items, in 4 main sections:
  - General information on the patient
  - Consultation and follow-up (19 questions)
  - Treatment prescription and therapeutic research (5 questions)
  - Global satisfaction (2 questions)
- A short blank section is available at the end of the questionnaire to add any comments
- Available in 14 languages
- Online and print version: <https://ern-skin.eu/patient-satisfaction-survey/>



## Patient satisfaction survey timeline

Please find below the patient satisfaction survey timeline which includes the main activities that will take place from November 2023 to March 2025.



# 2023-2027 grant: What's new?

+ More engagement of the ERN-Skin healthcare providers / hospitals (HCPs) and patient representatives (ePAGs): 42 HCPs and 8 ePAGs participated to the survey (sent in May 2023) to build the proposal

+ The European Commission engages to less administrative burden and more funding

+ The European Commission encourages ERNs to deliver and healthcare providers / hospitals (HCPs) to engage

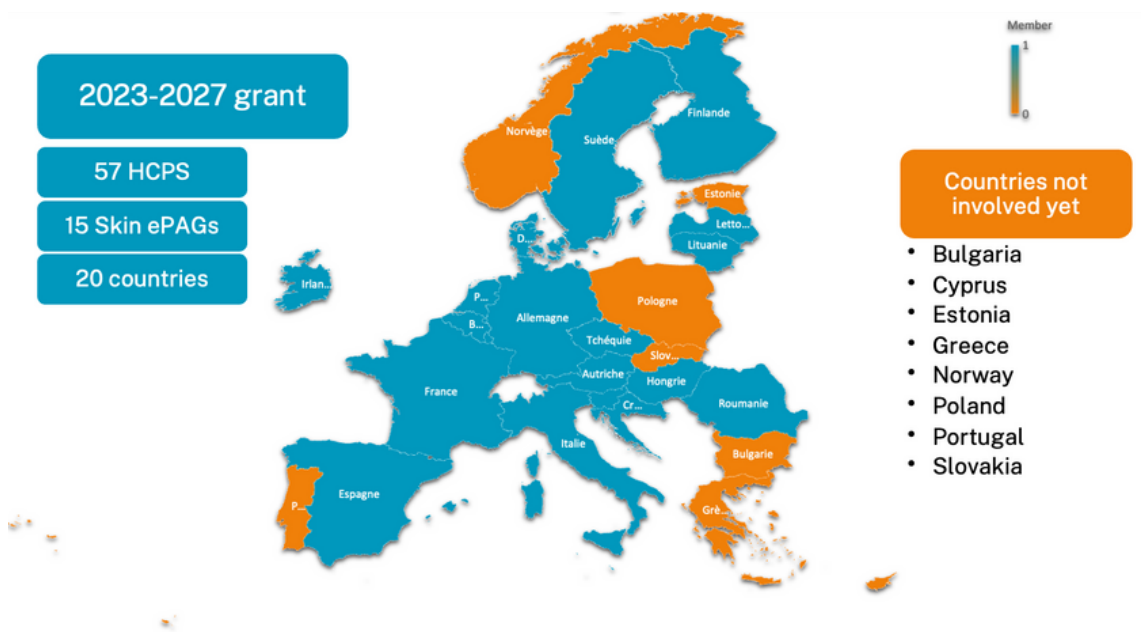
+ Support Ukraine

## 2023-2027 grant: who is involved?

- 57 healthcare providers / hospitals (HCPs)
- 15 patient representatives (Skin ePAGs)
- 20 countries

## Countries which are not involved yet:

- Bulgaria, Cyprus, Estonia, Greece, Norway, Poland, Portugal, Slovakia

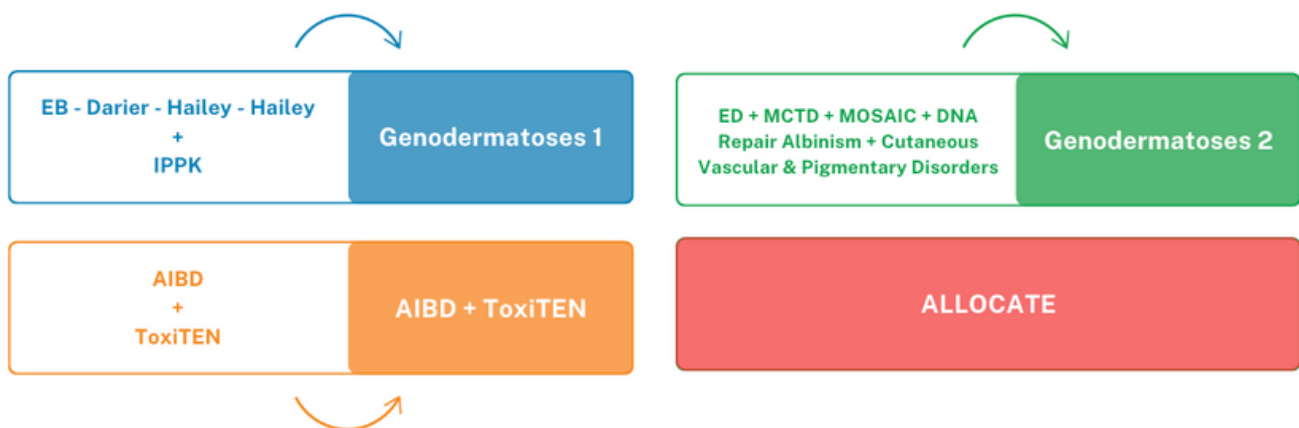


# New thematic group organization

In the survey launched in May 2023, to build the 2023-2027 proposal we proposed new thematic group organization and new “labelling” in order to:

- Get together the healthcare providers / hospitals (HCPs) working on similar topics and reach a “critical mass”
- Have more efficient meetings
- Show more the diseases and their designation, rather than some of their pathophysiological mechanisms (which may remain as a sub-title) to make it understandable for patients looking for information and for our administrations

In short, we keep the 9 initial thematic groups with a dedicated budget but incorporate them in larger groups:



## What about the coordination of the larger groups?

We propose that each larger group is chaired by a leader team including the 2 coordinators of the previous thematic groups: to be efficient, to enable mutual assistance between the coordinators.

# Large group organization

We will have now 4 large groups including the 9 previous thematic groups and covering the following diseases:

Genodermatoses-1	
EB/IPPK	Inherited Epidermolysis Bullosa and skin fragility syndromes – Darier – Hailey-Hailey – Ichthyoses – Palmoplantar Keratoderma
Genodermatoses-2	
ED group + genetic disorders of nails	Ectodermal Dysplasias, ED Hypohidrotic/anhidrotic form, Incontinentia Pigmenti and p63-associated disorders
MCTD group	Mendelian Causes of Connective Tissue Disorders: Ehlers-Danlos, Cutis Laxa, Pseudoxanthoma, Elasticum, Buschke--Ollendorf, scleroderma-like diseases
DNA-repair group + Albinism	Xeroderma pigmentosum, Trichothiodystrophy, Cockayne, Rothmund-Thomson, Albinism
MOSAIC group	Nevi & Nevoid Skin Disorders, Superficial Complex Vascular Malformations and vascular Tumors, overgrowth syndrome, etc...
AIBD/ TOXITEN group	
AIBD group	Autoimmune Bullous Diseases & Cutaneous Autoimmune Diseases (Pemphigus, Pemphigoid gestationis..., Cutaneous Lupus, Morphea, Lichen...)
ToxiTEN group	Severe cutaneous drug reactions, Stevens Johnson and Toxic Epidermal necrolysis
ALLOCATE group	
ALLOCATE group	Hidradenitis Suppurativa – PAPA – PAPASH – PASH – PASS – SAPHO – Behçet – Degos.

## What does the ERN-Skin cover for each thematic group?

- 2025 and 2027 workshops/meetings
- Practical e-training - complements the e-training with didactic clinical cases accessible only for students completing ERN-Skin e-learning
- e-education patient program
- Clinical practice guidelines & clinical decision tools development or update
- Support from an ERN-Skin group manager (C. Champseix)

# How to become an ERN-Skin beneficiary?

*We offer this option to one of the thematic group chair for a smoother budget use*

- You are an official ERN-Skin healthcare provider / Hospital (HCP)
- You officially agree to implement the thematic group road map for which you receive a budget under your own responsibility and in accordance with the ERN-Skin agreement, and after validation of the action by the thematic group.
- You sign a consortium agreement with all the other ERN-Skin beneficiaries
- You are responsible for the technical implementation of the thematic group road map for which you receive a budget
- You manage and report on that budget according to the European Commission rules
- You keep information related to your participation stored in the European Commission portal
- You submit to the ERN-Skin coordination team in good time
  - financial documents and statements
  - contribution to the deliverables and technical reports
  - any other documents required by the European Commission such as documents to prove the proper implementation of the action, the costs declared, etc.
- You inform the European Commission and all the beneficiaries of any event likely to affect or delay the implementation of the action