

ERN-Skin Virtual Board Meeting

2 October 2020

**WELCOME
& THANK YOU FOR JOINING !**

Christine BODEMER, Coordinator of the ERN-Skin



2020 success

Welcome to our 4 new affiliated partners !

The thematic groups produced clinical decision tools

The patient questionnaire is available in 7 languages

The CPMS helpdesk is functional

The registry project is launched

ERN-Skin members successfully apply to EJP-RD program

The COVID-19 and Rare Skin diseases' European study is ongoing in 56 sites

The ERN-Skin private site is operational

The e-training platform is ready

Welcome to our 4 affiliated partners!

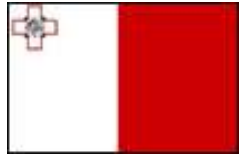


2 coordination hubs

Luxembourg



Malta



2 associated national centers

Latvia



Slovenia



Cooperation agreement on

- CPMS
- Registry
- Meetings
- Clinical guidelines
- Training and education
- Research
- Information
- Capacity building to organize multidisciplinary management for patient with rare skin disorders

Review of the 11 ERN-Skin new applicants

-  Austria (1)
-  Denmark (1)
-  Germany (1)
-  Italy (7)
-  Netherlands (1)

Healthcare Provider Name	Country
Aarhus Universitets Hospital	DK
AOU Città della Salute e della Scienza di Torino	IT
AOU di Modena	IT
AOU Meyer di Firenze	IT
AOU Policlinico Umberto I di Roma	IT
Fondazione IRCCS Casa Sollievo della Sofferenza	IT
Fondazione Policlinico Universitario A. Gemelli - Roma	IT
Medical University of Innsbruck / Tirol Kliniken GmbH	AT
Spedali Civili di Brescia	IT
University Hospital Würzburg is already an ERN-Skin member	DE
University Medical Center Utrecht	NL

The evaluation process until summer 2021



The evaluation rules at the ERN level

Each ERN to review applications against ERN specific criteria set in 2017 by the chairs of each thematic group

- ☑ Number of patients/year
- ☑ Number of new patients/year
- ☑ Number of procedures/year
- ☑ Specialized equipment, infrastructure and information
- ☑ Type of healthcare (multidisciplinary team)

Only the applications which completely fulfill each criterion for each disease included in the application receive a "final favorable opinion".

If an application does not completely fulfill each criterion for a given disease, the applicant receives an "unfavorable draft decision".

If an application includes a disease which is not currently covered by the ERN, the applicant receives an "unfavorable draft decision".

The applicant has then 1 month to review the application and resubmit it.

The ERN-Skin draft opinion

Aarhus Universitets Hospital

- applies for Epidermolysis Bullosa and Ichthyosis & Palmoplantar Keratoderma
- completely fulfills the criteria

AOU Citta della Salute e della Scienza di Torino

- applies for Autoimmune bullous diseases and Ichthyosis
- partially fulfills the ERN-Skin specific criteria for Autoimmune bullous diseases and Ichthyosis
- has to remove Lichen
- has to remove or provide new data or evidence for the diseases which partially fulfills the ERN-Skin specific criteria

AOU Meyer di Firenze

- applies for Ichthyosis / Hidradenitis suppurativa – SAPHO / Xeroderma Pigmentosum / Ectodermal dysplasia including incontinentia pigmenti and p63-associated disorders / Cutaneous mosaic disorders - nevi & nevoid skin disorders and complex vascular malformations and vascular tumours
- completely fulfills the ERN-Skin specific criteria for ichthyosis
- has to remove the diseases which partially fulfills the ERN-Skin specific criteria or provide new data or evidence

The ERN-Skin draft opinion

AOU Policlinico Umberto I di Roma

- applies for one single disease (Lichen sclerosus) not covered by the ERN-Skin

Fondazione IRCCS Casa Sollievo della Sofferenza

- applies for one single disease Ehlers-Danlos syndrome
- completely fulfills the criteria

Fondazione Policlinico Universitario A. Gemelli

- applies for Autoimmune Bullous Diseases and Hidradenitis suppurativa
- completely fulfills the ERN-Skin specific criteria for Autoimmune Bullous Diseases and Hidradenitis suppurativa
- has to remove Lichen Sclerosus et atrophicus, Familial Melanoma

The ERN-Skin draft opinion

Medical University of Innsbruck

- applies for Ichthyosis - Palmoplantar Keratoderma
- completely fulfils the ERN-Skin specific criteria for Ichthyosis
- partially fulfills the criteria for Palmoplantar Keratoderma
- has to remove NF1

Spedali Civili di Brescia

- applies for Ehlers-Danlos syndromes, Autoimmune Bullous skin diseases
- Partially fulfils the criteria for Autoimmune Bullous diseases
- Completely fulfils the criteria for Ehlers-Danlos syndromes
- has to remove Erythropoietic protoporphyria

University Medical Center Utrecht

- applies for Pseudoxanthoma elasticum
- completely fulfills the criteria

Monitoring or how to show the impact of the ERNs...

From now on: twice a year

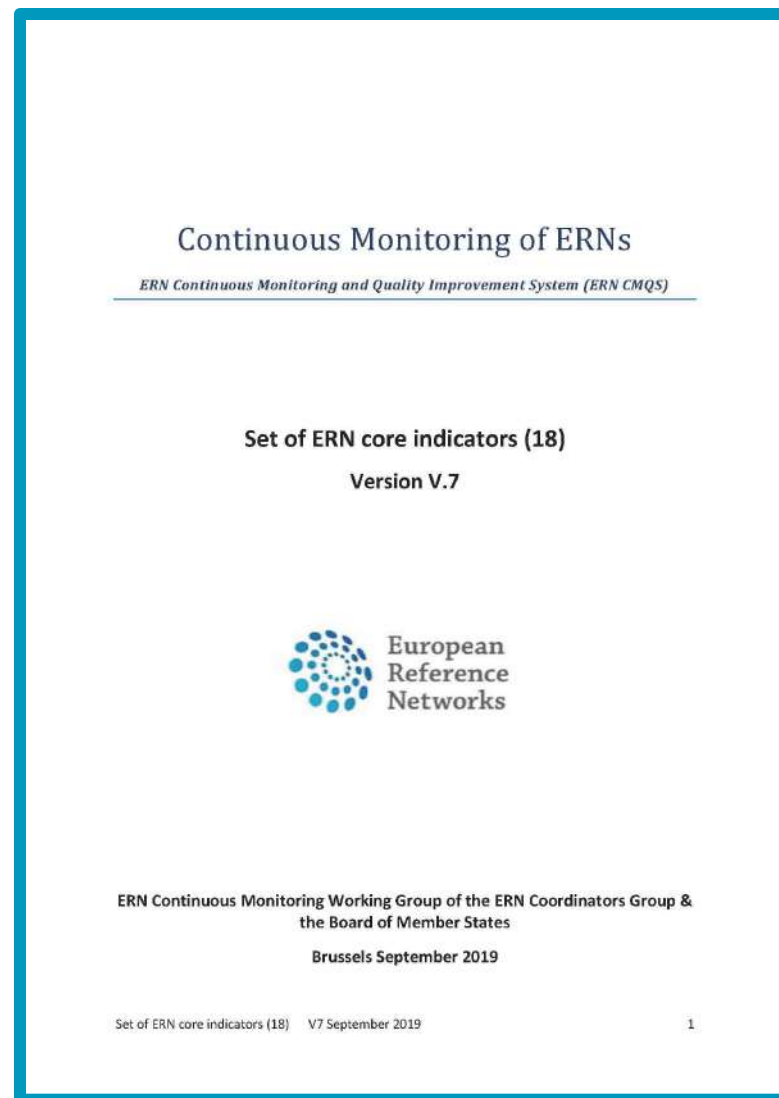
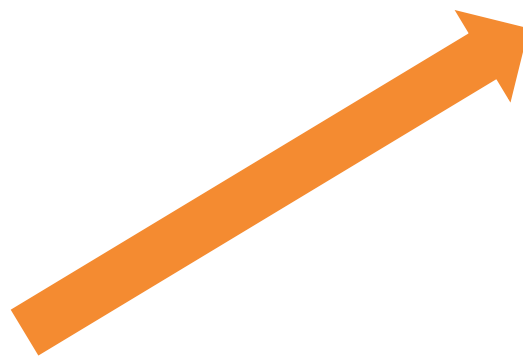
- in March
- in October

Next data collection deadline:

- October 30, 2020
- March 31, 2021
- October 30, 2021

New revised criteria

New ERN-Skin online survey



Clinical practice guidelines/clinical decision tools



EC supports each ERN to

- Develop 2 new clinical practice guidelines/clinical decision tools (CPGs/CDTs)
- Revise 5 ones

The EC has conducted a survey to prioritize 10 diseases per ERN.

Inherited ichthyosis

Palmo-plantar keratoderma

Syndromic Hidradenitis

P63 related ectodermal dysplasias

Cutis laxa

Pseudoxanthoma elasticum

Ehlers-Danlos syndrome

Trichothiodystrophy

Poikiloderma

Bullous pemphigoid

The ERN-Skin thematic group chairs have proposed

ERN-Skin budget for each thematic group

The ERN-Skin negotiated a budget of €15.000 for each thematic group.

NEW ! As e-training is an EC priority, the EC asks each group to use €5.000 specially for e-training.

Each expense should be validated at first by the General Coordination please see the form sent by Catherine

Use your budget by Sept. 30, 2021 !

European Reference Networks | SKIN | ERN-Skin Thematic Group Provisional Budget | 1 January 2020 – 31 December 2021 | European Reference Network for rare or low prevalence complex diseases

Name of thematic group:
Chairs of the thematic group:
First Name - Last Name:
First Name - Last Name:
Amount spent in 2019

Item	Project	Amount
Example: translation	Example: e-training	Example: €215

Provisional budget : 2020-2021
Provisional budget from 1 January 2020 to 31 December 2021: €15 000 (or less depending on the amount spent in 2019)

Project description	Task	Task leader	Deliverable Achievement	Delivery date	Budget - Items	Budget - Amount
Example: emergency documents	Example: literature review	Example: Dr. Xyz	Example: Emergency card	2020/06/30	Meeting of the coordinators and task leaders – emergency chart - Travel and accommodation for 5 people	€2500

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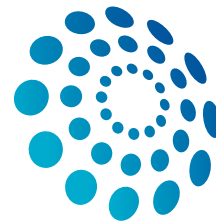
ERN future: negotiation of the EU4Health Programme 2021-2027

Budget voted on the 28th of September

ERN coordinators have contacted their national Members of European Parliament to ask them to support the amendments that would secure future funding for the ERNs.

ERNs have asked funding for

1. Central ERN management
2. Registry
3. CPMS
4. Educational and training
5. Research



European
Reference
Networks



Parlamentum Europaeum

An ERN-Skin scientific day in February 2021 ?

One day on overlapping topics shared by the ERN-Skin groups and/or by other ERNs

- For every ERN-Skin thematic/disease group
- With guest experts

Examples:

- *Albinism management with ERN-Skin and ERN-Eye*
- *Innovative methodologies for clinical studies in rare diseases with all the ERN-Skin thematic groups*

From 9:00 to 17:00
on February 19 or 26 ?