

# Table Of Content

<b>European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5</b> .....	2
<b>Summary</b> .....	3
<b>Work Package</b> .....	4
Coordination of the action .....	4
Dissemination .....	4
Evaluation of the action implementation .....	4
Interactive Directory .....	4
Multidisciplinary Management .....	4
Training .....	4
Patient Education .....	4
Tele dermatology – Clinical Patient Management System .....	4
Cooperation with health care providers from Member States with an insufficient number of patients or lacking technology or expertise .....	4
Deep Phenotyping .....	4
Rare Skin Disorders Registry .....	4
<b>Coordinator, Leader contact and partners</b> .....	7
<b>Outputs</b> .....	8
4.3 Newsletter .....	8
ERN-Skin Activity -Evaluation - Dissemination Report .....	8
1.2.2 List of new health care providers - members and affiliates .....	8
3.1 Clinical Decisions Support Documents .....	8
3.1 Common strategy for recommendations and research programmes .....	8
3.3 Report on collaborative projects with European and International Scientific Societies .....	8
6.5 ERN-Skin patient education programmes and tools .....	8
8.1 List of the 5 health care provider nominees invited to participate in the ERN-Skin courses .....	8
9.4 SPOT App Report .....	8
10.3 Recommendations for a sustainable ERN-Skin registry .....	8
1.1.8 Skin e-PAG minutes .....	8
4.1 ERN-Skin Dissemination Plan .....	8
5.3 2019, 2020, 2021 Course Programme .....	8
5.5 e-learning section on the ERN-Skin website .....	8
7.3 Report on the practical use of CPMS .....	8

# European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5

JA2015 - GPSD [705038]

START DATE: 01/03/2019

END DATE: 28/02/2022

DURATION: 36 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: Multiannual Grant Agreements for European Reference Networks

TOPIC: ERN Specific Grant Agreements 2019 - 2021

EC CONTRIBUTION: 600000 EUR

KEYWORDS: Auto-Immune Skin Diseases, Drug Side-Effect, E-Health, E-Pag, European Reference Network, Genodermatoses, Patient Education, Patient Representatives, Rare Skin Disorders, Skin Tumours, Training

## Project abstract

The ERN-Skin 3-year proposal for third to fifth year of the Framework Partnership agreement (FPA) n°739505 implementation builds upon the ERN-Skin year 1 and 2 achievements. It takes into consideration the recent development of the ERN IT platform (ERN Collaborative Platform and Clinical Patient Management System - CPMS) and the EU policy on ERN. The goals and activities are coherent with the ERN-Skin multiannual plan included into the FPA . By pooling expertise, the planned activities will contribute to achieve the ERN-Skin multiannual goals:

- Strengthen the ERN-Skin operational framework thanks to regular meetings of the ERN-Skin bodies, the management of the Brexit consequences and the integration of members or affiliates
- Cover the largest possible number of diagnosed but also undiagnosed rare and low prevalence skin disorders so that every patient finds a home in the ERN-Skin
- Provide reliable information on diseases and services thanks to the interactive directory update
- Further develop multidisciplinary management and facilitate the mobility of expertise thanks to CPMS and cooperation with other ERNs and scientific societies
- Share and spread harmonized best practices thanks to the adaptation and development of guidelines and recommendations for health care professionals
- Develop health care professional skills thanks to courses, e-trainings and practical trainings
- Empower patients thanks to the development of specific patient education programmes
- Involve Member States with insufficient number of patients or lacking technology or expertise thanks to support to attend courses and access CPMS
- Develop, test and use of the Skin Phenotyping Ontology and Terminology App
- Issue recommendations for an ERN-Skin registry

# Work package

## Work Package 1: Coordination of the action

Start month: 1

End month: 36

Work Package Leader: AP-HP

Build a durable ERN-Skin involving the best experts and covering the largest possible number of diagnosed but also undiagnosed rare and low prevalence skin disorders so that every patient finds a home in the ERN-Skin

## Work Package 2: Dissemination

Start month: 1

End month: 36

Work Package Leader: AP-HP

- Dissemination of information

Update the dissemination plan

Disseminate the project deliverables

Update the ERN-Skin Collaborative Platform and public website in link with each healthcare provider and patients'

Publish a Newsletter

## Work Package 3: Evaluation of the action implementation

Start month: 1

End month: 36

Work Package Leader: AP-HP

- Assess the stakeholders' views

- Monitor the implementation of Year 3 to 5 activities according to the road map

- Ensure the quality of the deliverables: linked to the objective, delivered on time, easily understandable by professionals, patients and general public

- Disseminate a questionnaire on patient satisfaction

- Take corrective measures if problems have arisen

## Work Package 4: Interactive Directory

Start month: 1

End month: 36

Work Package Leader: AP-HP

Update of the HCPs services in cooperation with Orphanet

## Work Package 5: Multidisciplinary Management

Start month: 1

End month: 36

Work Package Leader: AP-HP

- Identify available guidelines and recommendations at the ERN-Skin level, at the ERN level, at the Scientific Societies level, at patient support group level
- Elaborate an ERN-Skin methodology for developing / accrediting these guidelines and recommendations
- Use template proposed by the EC in the framework of the call for tender "Taxonomy and templates for ERN documents"

## Work Package 6: Training

Start month: 1

End month: 36

Work Package Leader: AP-HP

- Identification of the hosting countries
- Elaboration of the programme with the chairs of each thematic and transversal group
- Practical organisation of the including practical and e-training

## Work Package 7: Patient Education

Start month: 1

End month: 36

Work Package Leader: AP-HP

- Identify available patient education tools for each group of diseases
- Elaborate an ERN-Skin methodology for developing / accrediting these education programmes
- Use template proposed by the EC in the framework of the call for tender "Taxonomy and templates for ERN documents"

## Work Package 8: Tele dermatology – Clinical Patient Management System

Start month: 1

End month: 36

Work Package Leader: AP-HP

- Organisation of panels on the CPMS
- Registration of new healthcare providers on the CPMS

## Work Package 9: Cooperation with health care providers from Member States with an insufficient number of patients or lacking technology or expertise

Start month: 1

End month: 36

Work Package Leader: AP-HP

Launch an open call to identify at least 5 teams from Member States with an insufficient number of patients or lacking technology or expertise to participate in the 2019, 2020, 2021 ERN-Skin

## Work Package 10: Deep Phenotyping

Start month: 1

End month: 36

Work Package Leader: AP-HP

Develop, test and use the SPOT App at the ERN-Skin and ERN level

## Work Package 11: Rare Skin Disorders Registry

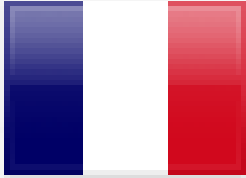
Start month: 1

End month: 36

Work Package Leader: AP-HP

- Identification of the available registries at the local, national and international level
- Meeting and conference call of the ERN-Skin registry group and the European Rare Diseases Registry Infrastructure
- Development of the ERN-Skin registry in link with the European Rare Diseases Registry Infrastructure

## COORDINATOR



ASSISTANCE PUBLIQUE - HOPITAUX DE PARIS (APHP)

Avenue Claude Vellefaux 1- Carré Historique de l'Hôpital Saint-Louis  
75010 Paris

France

WEBSITE: <http://www.aphp.fr>

## PARTNERS

No partners related to the current project

## 4.3 Newsletter

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Published on: 06/11/2020

ERN-Skin life: news on each thematic and transversal group, focus on the Skin e-PAG, information on training, meetings.

## ERN-Skin Activity -Evaluation - Dissemination Report

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Report on the ERN-Skin achievements – Evaluation Report Dissemination Report

## 1.2.2 List of new health care providers - members and affiliates

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Health care providers complying with ERN-Skin specific criteria and endorsed by their national authorities + affiliated partners

## 3.1 Clinical Decisions Support Documents

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Guidelines / recommendations / healthcare pathways for each thematic group of diseases



## 3.1 Common strategy for recommendations and research programmes

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Complementary and multidisciplinary approach to the road map for the elaboration of guidelines and research programmes

## 3.3 Report on collaborative projects with European and International Scientific Societies

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Report on the interaction between the EADV Task Forces, the EDF research networks, the ESPD, the ILDS and other European and international networks

## 6.5 ERN-Skin patient education programmes and tools

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Patient education programmes and tools accredited by the ERN-Skin

## 8.1 List of the 5 health care provider nominees invited to participate in the ERN-Skin courses

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

List of the health care provider nominees from Member States with insufficient number of patients or lacking technology or expertise to provide highly specialized services, eligible to participate in the 2019, 2020, 2021 ERN-Skin Courses

## 9.4 SPOT App Report

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Report on the test, launch and use of the final SPOT App

## 10.3 Recommendations for a sustainable ERN-Skin registry

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Expected on: 28/02/2022

Recommendations for a sustainable ERN-Skin registry

## 1.1.8 Skin e-PAG minutes

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Published on: 06/11/2020

Recommendations of ERN-Skin Patient Representatives

## 4.1 ERN-Skin Dissemination Plan

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Published on: 06/11/2020

Dissemination plan of the ERN-Skin

## 5.3 2019, 2020, 2021 Course Programme

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Published on: 06/11/2020

2019, 2020, 2021 Course Programmes

## 5.5 e-learning section on the ERN-Skin website

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Published on: 06/11/2020

Hosting and inclusion of the videos recorded during the 2019, 2020, 2021 ERN-Skin courses

## 7.3 Report on the practical use of CPMS

AP-HP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 3 to 5 (ERN-Skin)

Published on: 06/11/2020

Report on the virtual consultations for the ERN-Skin panels