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European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2

JA2015 - GPSD [705038]

START DATE: 01/03/2018

END DATE: 28/02/2019

DURATION: 12 month(s)

CURRENT STATUS: Finalised

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

PROGRAMME PRIORITY: -

CALL: EUROPEAN REFERENCE NETWORKS SPECIFIC GRANT AGREEMENTS
COVERING YEAR 2018

TOPIC: ERN Specific Grant Agreements Year 2

EC CONTRIBUTION: 200000 EUR

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

Project abstract

ERN-Skin-2 proposal builds upon the ERN-Skin first year achievements and takes into consideration the recent development of the ERN IT platform (ERN Collaborative Platform and Clinical Patient Management System) and the EU policy regarding ERN. The ERN-Skin year 2 goals and activities are coherent with the ERN-Skin multiannual plan included into the Framework Partnership Agreement (FPA) and they contribute to achieve the ERN-Skin multiannual goals. The objectives are to:

- Strengthen the ERN-Skin operational framework thanks to regular meetings and conference calls of the ERN-Skin bodies
- Further develop teledermatology thanks to the organisation of 3 panels and the registration all HCPs on the Clinical Patient Management System
- Update information on resources for patients and healthcare providers thanks to the interactive directory update
- Pool expertise thanks to:
 - update and upload of information and documents on the ERN-Skin collaborative platform
 - update of the ERN-Skin directory in cooperation with Orphanet
 - update of the ERN-SKIN website and development of new sections including one on updated list of guidelines
 - organisation of the second ERN-Skin course as well as the first practical training, complemented by e-training
- Involve Member States with insufficient number of patients or lacking technology or expertise to provide highly specialized care thanks to the support for travel and accommodation for 5 HCPs from these member States to participate in the 2018 ERN-Skin course
- Integrate more partners, members or affiliates, from Member States not yet represented in the ERN-Skin
- Strengthen collaborative relationships with overlapping ERNs & Scientific Societies

Work package

Work Package 1: Governance

Start month: 1

End month: 12

Work Package Leader: APHP

- Coordination of the network
- Cooperation with e-PAG
- Organisation, preparation and follow-up of meetings and conference calls
- Dissemination of information
- Update of the ERN-Skin Collaborative Platform and public website
- Newsletter
- Liaison between partners

Work Package 2: Interactive Directory

Start month: 1

End month: 12

Work Package Leader: APHP

Update of the HCPs services in cooperation with Orphanet

Work Package 3: Multidisciplinary Management

Start month: 1

End month: 12

Work Package Leader: APHP

Analysis of available guidelines for each sub-thematic group with patient representatives and overlapping ERNs
Conference calls or meetings with ERN-Skin and other ERNs
Information exchange with scientific societies

Work Package 4: Information

Start month: 1

End month: 12

Work Package Leader: APHP

ERN-Skin website update in link with each healthcare provider website and the Geneskin website

Work Package 5: Training

Start month: 1

End month: 12

Work Package Leader: APHP

Organisation of the 2nd ERN-Skin course (Nov. 24, Rome, Italy) including practical and e-training.

Work Package 6: Patient Education

Start month: 1

End month: 12

Work Package Leader: APHP

Analysis and harmonization of existing patient education programmes

Work Package 7: Tele dermatology

Start month: 1

End month: 12

Work Package Leader: APHP

- Organisation of 3 panels on the CPMS
- Registration of all HCPs on the CPMS

Work Package 8: Cooperation with health care providers from Member States with an insufficient number of patients or lacking technology or expertise

Start month: 1

End month: 12

Work Package Leader: APHP

Identification of 5 teams from Member States with an insufficient number of patients or lacking technology or expertise to participate in the 2018 ERN-Skin

Work Package 9: Deep Phenotyping

Start month: 1

End month: 12

Work Package Leader: APHP

- Revision and improvement of the classifications, the choice and definitions of terms
- Development of a common language shared by other ERNs/Scientific networks.
- Discussion among ERNs for test/validation of the description

Work Package 10: Rare Skin Disorders Registry

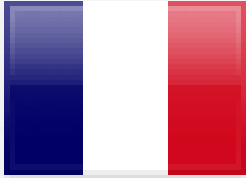
Start month: 1

End month: 12

Work Package Leader: APHP

- Finalization of the mapping of the existing databases to avoid duplication and facilitate the re-use of data
- Identification of solutions to develop a sustainable ERN-Skin registry in link with the European Rare Diseases Registry Infrastructure

COORDINATOR



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PARTNERS

No partners related to the current project

4.3. Bi-Annual Newsletter

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

ERN-Skin life: news on each of the sub-thematic and transversal groups, focus on the Patient Representative Council

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

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 26/06/2019

Hosting and inclusion of the videos recorded during the 2018 ERN-Skin course

6.3. Strategy report for harmonised patient education programmes and tools

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 26/06/2019

Strategy for harmonised patient education programmes and tools.

7.3. Report on the practical use of CPMS

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 26/06/2019

Virtual Consultations for the 3 ERN-Skin panels

8.1. List of the 5 HCP nominees invited to participate in the 2018 ERN-Skin course (travel

and accommodation covered)

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 26/06/2019

List of the HCP nominees from Member States with insufficient number of patients or lacking technology or expertise to provide highly specialised services, eligible to participate in the 2018 ERN-Skin Course.

9.2. Deep Phenotyping meeting minutes

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 26/06/2019

Minutes of the meeting of the "Deep Phenotyping" transversal group

10.2. Registry Report

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 26/06/2019

Minutes of the meeting of the "e-health and registry" group focusing on registry issues

1.1.1. ERN-Skin Activity & Evaluation Report

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Report on the ERN-Skin achievements – Evaluation Report

1.1.3. Executive Committee meeting minutes

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Validation of the working plan of each sub-thematic group

1.1.5. Sub-thematic groups meeting minutes

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Validation of the Year 3 working plan

1.1.8. PRC minutes

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Recommendations of ERN-Skin Patient Representatives

1.2.1. List of specific criteria

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Specific criteria defined for each of the 4 new sub-thematic groups

1.2.2. List of new HCP (organization) members and affiliates

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

HCP (organization) complying with ERN-Skin specific criteria and endorsed by their national authorities + affiliated partners

2.3. List of diseases covered by each health care provider included in the interactive directory

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

New functionality of the interactive directory with a list of diseases covered by each health care provider

3.1.3. Strategy for updated guidelines at 5 years

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Strategy for updated guidelines at 5 years for each sub-thematic group of diseases

3.2.4. Common strategy for recommendations and research programmes

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

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

3.3.1. Report on collaborative projects with European and International Scientific Societies

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Report on the interaction between the EADV Task Forces, the EDF research networks, the ESPD, the ILDS.

4.1. ERN-Skin Dissemination Plan

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Dissemination plan of the ERN-Skin

4.2. Updated Website second version

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Website update

5.3. Programme of the 2018 Course

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Programme of the 23 Nov. 2018 course in Rome, Italy

5.4. Strategy for the development of practical training in each country

APHP

European Reference Network for Rare, Low Prevalence, Diagnosed and Undiagnosed Skin Disorders - Year 2 (ERN-Skin-2)

Published on: 22/05/2019

Analysis of the services available in the 18 partner countries to develop practical training