



Hôpital Universitaire Necker-Enfants Malades
ADDRESS: 149 rue de Sèvres - 75 015 Paris - FRANCE

DATE OF UPDATE 15 July 2025

JOB TITLE

ERN-Skin Project Manager

ACTIVITIES

You will work in a stimulating medical environment with a European dimension, ERN-Skin, www.ern-skin.eu. ERN-Skin is a network of medical teams specialised in the care of patients with rare skin diseases. The work of the medical teams is organized into 9 groups of diseases.

With the ERN-Skin coordinator and the coordination team, you will carry out the following activities:

- Coordination of the ERN-Skin Patient Education Programme
- Coordination of the ERN-Skin Orphanet activity
- Coordination of the ERN-Skin e-training activity

MISSIONS

Participation in the organisation and follow-up of disease group's meetings with the scientific project manager

- Meetings' schedule
- Minutes
- Follow-up of the "road map"

Participation in the organisation of ERN-Skin's annual meetings ('Board', 'Scientific Days', etc.)

Coordination of the 'ERN-Skin e-Patient Education Programmes' activity, implementation of online therapeutic education programmes

- Identify available resources and needs for each disease group with medical teams and patient representatives
- Organise a cross-cutting working group
- Support each disease group to deliver age-appropriate online therapeutic education programmes (child, adolescent, adult) with a dedicated roadmap
- Work with the project manager responsible for communication and website for updating and disseminating deliverables

Coordination of the 'ERN-Skin - Orphanet' activity, update of ORPHA codes for rare skin diseases

- Draw up a state of play and prepare a roadmap with each disease group for the update of ORPHA codes
- Link between Orphanet and the disease groups
- Update the list of diseases covered by ERN-Skin

Coordination of the ERN-Skin e-training activity

- Identify available resources and needs for each disease group with medical teams and patient representatives
- Support each disease group to develop of e-training content
- Work with the project manager responsible for communication to update the platform and promote it at European level.

Administrative management

- Carry out day-to-day management operations
- Participate in the administrative and financial management of European projects (budget monitoring, collection and archiving of supporting documents, timesheet management, etc.)
- Search for service providers: quotation request and follow-up
- Organise events (including disease group meetings): invitation and registration management, booking (meeting rooms, travel, hotel, catering), logistical support

QUANTITY OF WORK

Full-time employment / 35 hours per week
12-month fixed-term contract, renewable

WORKING HOURS

From 9:00 a.m. to 5:00 p.m. from Monday to Friday

SKILLS REQUIRED

- Bachelor's degree or Master's degree 5 (management of European projects, political science, public health, etc ...)
- Professional proficiency in English and French

PRE-REQUIREMENTS

Competencies

- Professional proficiency in English and French
- Manage cooperation projects
- Organize events

Qualities

- Rigour, organisational and methodological skills
- Responsiveness and ability to manage multiple tasks simultaneously with different stakeholders
- Ability to work in a team and with a variety of audiences
- Ability to report
- Adaptation and versatility
- Initiative, dynamism
- Self-control, discretion
- Punctuality and assiduity
- Interest in rare diseases

LOCATION: Department of Dermatology (ERN-Skin - Coordination)

PRESENTATION OF THE DERMATOLOGY DEPARTMENT OF HOPITAL UNIVERSITAIRE NECKER- ENFANTS MALADES

- The dermatology department is specialized in the diagnosis and treatment of dermatological diseases (diseases of the skin and mucous membranes, hair, nails).
- The service manages young adults and children, infants and children representing 2/3 of the patients.

ERN-Skin PRESENTATION

- The head of the dermatology department coordinates the ERN-Skin network, www.ern-skin.eu
- ERN-Skin is a network of medical teams specialised in the care of patients with rare skin diseases. The aim of ERN-Skin is to improve access to diagnosis and very high-level care. ERN-Skin brings together 57 hospitals from 20 countries and 15 patient associations.

COMPOSITION OF THE TEAM OF THE ERN-SKIN WITHIN THE UNIVERSITARY HOPITAL NECKER- MALADES CHILDREN:

- Prof. Christine BODEMER, Coordinator
- Marie GUILLOU, Project Manager - Coordination
- Catherine CHAMPSEIX, Project Manager - Scientist
- Valérie DEPRez, Project manager – e-health tools and registry
- Julia NEVEU, Data Analyst - CPMS Project Manager
- Hanae JAALI-CHABOR, Communication and Patient Representatives - Project Manager

HOW TO APPLY?

Send your CV and cover letter to the following address: marie.quillou@fondation-r-touraine.org and christine.bodemer@aphp.fr