



The Vall d'Hebron Research Institute (VHIR) is a public sector institution that promotes and develops the research, innovation and biosanitary teaching of the Vall d'Hebron University Hospital. Through the excellence of our research, we identify and apply new solutions to the health problems of society and we contribute to spread them around the world.



HR EXCELLENCE IN RESEARCH

In April 2015, the **Vall d'Hebron Research Institute (VHIR)** obtained the recognition of the European Commission **HR Excellence**.

This recognition proves that VHIR endorses the general principles of the European Charter for Researchers and a Code of Conduct for the Recruitment of Researchers (**Charter & Code**).

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## Coordinator – European Rare blood disorders Registries

The University Hospital Vall d'Hebron is highly specialized in rare diseases on a Regional, national and international level with its recent incorporation as full member of 20 of the 24 European Reference Networks (ERN).

ERN-EuroBloodNet, <https://eurobloodnet.eu/>, the ERN dedicated to Rare Hematological Diseases (RHD), currently consists of 96 healthcare-providers from 14 Member States, with important interactions with patient groups covering those conditions.

The ERN-EuroBloodNet coordination hub based in Barcelona, led by Dr Mañú Pereira, head of the Rare Anemia Disorders research lab, directly leads the strategy on the development of European patient's registries, with the aim to collect sufficient data on patients affected by these rare diseases to promote the epidemiological surveillance.

In this context, we are looking for a motivated, self-driven and committed Scientific Coordinator who will lead the development of the different patients' registries coordinated in the Rare Anemias Disorders Research Line:

The European Rare Blood Disorders Platform (ENROL): <https://eurobloodnet.eu/enrol/what-is-enrol/>, built in line with the recommendations of the European Platform on Rare Disease Registration (EU RD Platform).

The Rare Anaemia Disorders European Epidemiological Platform (RADeep): <https://www.radeepnetwork.eu/>, collaborating with 13 member states across Europe to collect data.

### JOB DESCRIPTION

#### Education and qualifications:

#### Required:

- University degree in area of science / health (Biology, Biosciences, Medicine, Epidemiology)
- Master / PhD (or 5 years of proven expertise in the area)
- Fluent (spoken and written) English



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## Experience and knowledge:

### Required:

- Experience with the management and exploitation of patients registries, the FAIR standards, international codification, challenges of interoperability and alignment of eCRFs...
- Experience leading consortia with international stakeholders and ability to find solutions in case of conflicting interests between partners
- An analytical mindset with problem-solving skills
- An easy-going person with human qualities
- Ability to work effectively with a dynamic team and to work independently with tight deadlines

### Desired:

- Experience in the field of hematology
- Understanding of GDPR, legal agreements (MTA, Data sharing agreements) and experience with ethics documents (preparation of submission file for ethics)

## Main responsibilities and duties:

- Leading the implementation of the European Patients Registries coordinated by VHIR, or in which VHIR is involved : strategic planning, conducting Steering committee and scientific meetings, proposing priorities, raising risks and developing risk mitigation strategies.
- Looking for new funding sources, being in touch with Pharma industry and national / European stakeholders
- Preparing and delivering presentations at different meetings (occasional travel in the European Union will be required).
- Overseeing the strategical approach of the implementation of the registries in the group, and their links with other Research projects funded by the European Union (GenoMed4All <https://genomed4all.eu/>, Synthema <https://synthema.eu/>, Impact-AML)
- Contributing to the development of research protocols for epidemiological surveillance of Rare Hematological Diseases in Europe
- Contributing to scientific reports and deliverables for Sponsors



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### Labour conditions:

- Full time position (40 h week, from Monday to Friday) based in Vall d'Hebron Research Institute
- Start: Immediately
- Permanent contract
- Gross annual salary: Remuneration will depend on experience and skills. (Salary ranges are consistent with our Collective Agreement pay scale)

### What can we offer?

- Incorporation to Vall d'Hebron Research Institute (VHIR), a public sector institution that promotes and develops the biomedical research, innovation and teaching at Vall d'Hebron University Hospital (HUVH), the biggest hospital of Barcelona and the largest of Catalan Institute of Health (ICS).
- A scientific environment of excellence, highly dynamic, where high-end biomedical projects are continuously developed.
- Continuous learning and a wide range of responsibilities within a stimulating work environment.
- Individual training opportunities.
- Flexible working hours.
- 23 days of holidays + 9 personal days.
- Flexible Remuneration Programme (including dining checks, health insurance, transportation and more)
- Corporate Benefits: platform through which you can obtain significant discounts on travel, culture, technology, gastronomy, sports... among many others.
- Healthy Offering: choose from a variety of wellbeing focused activities to be the healthiest you.

### How to apply:

Applicants should submit a full Curriculum Vitae and a cover letter with the reference "Scientific Manager Registries" to the following email addresses: [claire.diot@vhir.org](mailto:claire.diot@vhir.org) and [seleccio@vhir.org](mailto:seleccio@vhir.org)