

ERN-EUROBLOODNET EXCHANGE PROGRAM



CALL FOR PARTICIPANTS

For ERN-EuroBloodNet members and Affiliated Partners

TO CONTINUING MEDICAL EDUCATION PROGRAM: DIAGNOSIS AND MANAGEMENT OF PAROXYSMAL NOCTURNAL HEMOGLOBINURIA PRECEPTORSHIP

AUSL Romagna- Presidio Ospedaliero di Ravenna, Ravenna, Italy

Coordinated by Prof. Francesco Lanza

5-6 December 2022

The ERN Exchange Mobility Program is coordinated by Ecorys Agency and aims to organize short stays in ERN's Health Care Providers for disseminating expertise on Rare Diseases among Network's members. In order to improve cutting-edge knowledge on Rare Hematological Diseases (RHD), ERN-EuroBloodNet is launching a call for [ERN-EuroBloodNet Members and Affiliated Partners](#) for attending a preceptorship program held in one highly specialized center for: **Diagnosis and Management of Paroxysmal Nocturnal Hemoglobinuria**

Highly specialized centers that will host the preceptorships are chosen across Europe and represent the excellence in RHDs field at international level. Indeed, centers have been chosen among [ERN-EuroBloodNet HCPs members](#).

PNH is a greatly heterogeneous disease characterized by the typical triad of complement-mediated intravascular anemia, some degree of bone marrow failure and very high thromboembolic risk.

Fewer than 40% of patients with PNH receive a diagnosis within 12 months of symptom onset, and 20-25% of all PNH diagnoses can take > 5 years. Diagnostic delay is a source of distress and can affect emotional well-being in patients and their families, possibly causing the impossibility of conducting a good quality life, and to receive an appropriate treatment.

Flow cytometry is the gold standard in diagnosis of PNH by detecting the lack of glycol-phosphatidyl inositol (GPI)-linked protein expression on granulocyte, monocyte and red blood cells. However, it is mandatory to standardize the methodology used to identify circulating blood GPI-deficient cells.

Educational program on

Diagnosis and Management of Paroxysmal Nocturnal Hemoglobinuria

AUSL Romagna- Presidio Ospedaliero di Ravenna, Ravenna, Italy

1. PEDAGOGICAL PROJECT

Context

From theory to laboratory practice and treatment algorithms, from phenotype to genotype. Experimental drugs will be discussed.

Educational objectives

1. There are few practical indications on how to monitor naïve PNH patients, to early diagnose possible severe complications or disease evolution.
The main three topics were:
 - a) Definition of patients' category deserving a specific monitoring schedule
 - b) Indications on monitoring schedule
 - c) Logistic and organization of a given reference center for PNH.
2. To standardize antibody panels, reagents and gating strategies for PNH diagnosis and monitoring.
3. To delineate GPI-deficient phenotypes (type I, type II, and type III cells).
4. To validate high sensitivity analysis for PNH subclones detection and quantitation.
5. To discuss the role of NGS in detecting gene abnormalities in PNH.
6. To discuss treatment options in PNH, including experimental drugs

Contextualised teaching (practical experience)

- Introductory theoretical part: joint clinic-biological presentation.
- Practical experience in the clinics and laboratory practice
- Relevant clinical cases will be discussed



2. PRACTICAL INFORMATION

From 5-6 December 2022 (2 days)

Host Center

[AUSL Romagna- Presidio Ospedaliero di Ravenna, Ravenna, Italy](#)

Number of participants 3

Coordinated by Prof. Francesco Lanza

Teachers

- [Francesco Lanza](#)
- Giovanni Poletti
- Evita Massari

Programme

Day 1

9 am – 5:30 pm

- Discussion of clinical cases
- Focus on clinical trials in PNH
- Management of the disease in the era of COVID pandemic

Day 2

9 am – 5:30 pm

Lab session

- Flow cytometry data,
- Choice of reagents for making a reliable diagnosis of PNH,
- Standardization of lab reagents
- Clinical studies related to flow cytometry assessment in PNH and related conditions.

3. PROFILE OF PARTICIPANTS

This preceptorship will bring together a maximum of **3 participants**

- Participants must be affiliated to a [HCP Member](#) or Affiliated partner of [ERN-EuroBloodNet](#). In the selection, the priority will be given to the permanent staff of the health care provider.
- Interest in developing their medical competences in the clinical area of **Paroxysmal Nocturnal Hemoglobinuria**
- In a position to follow-up the preceptorship with education projects and activities on medical education.
- Available for the whole duration of the preceptorship.
- English speaker.

4. SELECTION PROCEDURE

To participate at this call, candidate must:

- a. **Fulfill the application form available at www.eurobloodnet.eu or in attachment of this email.**

- b. Edit a Curriculum vitae et studiorum.
 - c. Write a cover letter.
 - d. Send the application form, the curriculum vitae and the cover letter to: Dr. Christel Buelens (christel.buelens@ulb.be) and write as object of the email: "Candidature to ERN-EuroBloodNet preceptorships **Diagnosis and Management of Paroxysmal Nocturnal Hemoglobinuria**
 - e. ". If you don't get the confirmation of the receipt within few days, please write again.
- It is mandatory to send the candidature by the **7th of November** at midnight (CET time)
 - A jury among [ERN-EuroBloodNet Members](#) has been established in order to select participants.
 - Gender and geographical balance will be taken into account when making the selection of the group, along with the meritocracy of the CV and the motivations expressed in the cover letter.

5. COSTS COVERAGES

[ERN-EuroBloodNet](#) via [Ecorys Agency](#) is in charge to cover the costs for travel and accommodation of participants. It includes daily allowance to cover subsistence, accommodation, and travel insurance for professional that travels

For any additional information, please write to christel.buelens@ulb.be

If you are interested in participate to [ERN-EuroBloodNet](#) educational formation but your profile does not fully correspond to the requirements of this call for participants, please note that the [ERN-EuroBloodNet](#) will organize other preceptorships on the same topic after summer break.