



European Rare Blood  
Disorders Platform

# **The Registry Module for the Collection of annual counts of patients with Rare Hematological Disorders – EpiBlood**

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Survey template – 2025



European  
Reference  
Network

Hematological  
Diseases (ERN EuroBloodNet)



**Funded by  
the European Union**

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# Myeloid malignancies

Dear expert,

Thank you so much for collaborating with the ENROL Registry mapping of 2025. Please consider that the edition of the submitted data will be available until the 28<sup>th</sup> of April 2026.

**As a reminder, the period to be reported is 1st of January - 31st December 2025.**

Your contribution is mandatory for the subnetworks where your institution is nationally recognized as an ERN Member. However, the opportunity to contribute is also extended to other subnetworks.

Kinds regards,

ENROL Coordination team

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Remember to report only numbers on adult patients ( $\geq 18$  years old)

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## Mastocytosis

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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## Acute myeloid leukemia

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and

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visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

\_\_\_\_\_

Number of new female patients

### Acute promyelocitic leukemia

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

\_\_\_\_\_

Number of new female patients

\_\_\_\_\_

### Myeloid neoplasms with germline presdiposition or inherited

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

\_\_\_\_\_

Number of new female patients

**Myelodysplastic syndrome**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

Number of new female patients

**Myeloproliferative neoplasm (Other than Chronic myeloid leukemia and Hypereosinophilic syndrome)**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

\_\_\_\_\_

Number of new female patients

\_\_\_\_\_

**Chronic myeloid leukemia**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

\_\_\_\_\_

Number of new female patients

\_\_\_\_\_

**Hypereosinophilic syndrome**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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### **Myelodysplastic/myeloproliferative disease**

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Provider for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, including new diagnosis and  
visits to outpatient's clinics, hospital discharges  
and emergencies, coming from national and  
international referrals)

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Number of new male patients

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Number of new female patients

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### **Myeloid neoplasms associated with eosinophilia and abnormality of PDGFRA, PDGFRB or FGFR1**

Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Provider for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, including new diagnosis and  
visits to outpatient's clinics, hospital discharges  
and emergencies, coming from national and  
international referrals)

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Number of new male patients

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Number of new female patients

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Status of the survey

- ☐ Incomplete  
☐ Unverified  
☐ Completed

(Only surveys marked as 'completed' in this  
section will be considered in the analysis)

## Lymphoid malignancies

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Kinds regards,

ENROL Coordination team

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Remember to report only numbers on adult patients ( $\geq 18$  years old)

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### Plasma cell neoplasm

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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### AL amyloidosis

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this

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disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients



Number of new female patients

\_\_\_\_\_

**Dendritic cell neoplasm**

Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care  
Provider for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, including new diagnosis and  
visits to outpatient's clinics, hospital discharges  
and emergencies, coming from national and  
international referrals)

Number of new male patients

\_\_\_\_\_

Number of new female patients

\_\_\_\_\_

**Posttransplant lymphoproliferative disorders (PTLD)**

Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care  
Provider for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, including new diagnosis and  
visits to outpatient's clinics, hospital discharges  
and emergencies, coming from national and  
international referrals)

Number of new male patients

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Number of new female patients

\_\_\_\_\_

**Acute lymphoblastic leukemia**

Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care  
Provider for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, including new diagnosis and  
visits to outpatient's clinics, hospital discharges  
and emergencies, coming from national and  
international referrals)

\_\_\_\_\_

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

### **Follicular lymphoma**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

### **Indolent B-cell lymphomas / Non-follicular**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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### Hairy cell leukemia

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

### Diffuse large B-cell lymphoma, NOS

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside

Number of new female patients

Diffuse large B-cell lymphoma, other than NOS

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

Number of new female patients

Hodgkin Lymphoma

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of new male patients

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside

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Number of new female patients

**Mantle cell lymphoma**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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**Other aggressive B-cell neoplasm**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside

**Mature T-cell neoplasm non-primary cutaneous.1 Leukemic**

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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**Mature T-cell neoplasm non-primary cutaneous.2 Extra nodal**

Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

\_\_\_\_\_

of new patients seen at the Health Care  
Provider for the first time during the reporting  
period, whose disease or condition falls inside

(Number

this group of diseases, including new diagnosis  
and visits to outpatient's clinics, hospital  
discharges and emergencies, coming from  
national and international referrals)

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Number of new male patients

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Number of new female patients

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**Mature T-cell neoplasm non-primary cutaneous.2 Nodal**

Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

\_\_\_\_\_

(Number of new patients seen at the Health Care  
Provider for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, including new diagnosis and  
visits to outpatient's clinics, hospital discharges  
and emergencies, coming from national and  
international referrals)

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Number of new male patients

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Number of new female patients

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**Mature T-cell neoplasms primary cutaneous**

Number of new patients referred to the Health Care

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Providers participating in the ERN diagnosed with this disease group

Health Care

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(Number of new patients seen at the Health Care Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

**Castleman disease**

Number of new patients referred to the Health Care

Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Provider for the first time during the reporting period, whose disease or condition falls inside this group of diseases, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of new male patients

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Number of new female patients

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Status of the survey

☐ Incomplete

☐ Unverified

☐ Completed

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# Red blood cell defects

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Kinds regards,

ENROL Coordination team

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Remember: Pediatric patients are those < 18 years old, while adults are those ≥18 years old.

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## Autoimmune hemolytic anemia

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_  
disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care

Providers participating in the ERN diagnosed with this disease group

#### Health Care

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Alpha-thalassemia and related diseases

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Beta-thalassemia and related diseases

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this 

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 disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **Sickle cell disease and related diseases**

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Number of total patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of total patients seen at the Health Care  
Provider during the reporting period (no matter if  
they come for the first time or not), whose disease  
or condition falls inside this group of diseases,  
whatever their age, including visits to outpatient's  
clinics, hospital discharges and emergencies, coming  
from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming from  
national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Hemoglobinopathy (Other than thalassaemia and sickle cell disease)

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Hereditary spherocytosis

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed  
with this \_\_\_\_\_  
disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Hereditary elliptocytosis

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)



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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Hereditary stomatocytosis

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming  
from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **Rare constitutional hemolytic anemia due to a red cell membrane anomaly (Other than Hereditary Spherocytosis, Hereditary elliptocytosis, Hereditary Stomatocytosis)**

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Number of total patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of total patients seen at the Health Care  
Provider during the reporting period (no matter if  
they come for the first time or not), whose disease  
or condition falls inside this group of diseases,  
whatever their age, including visits to outpatient's  
clinics, hospital discharges and emergencies, coming  
from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)  
Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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#### **Rare constitutional hemolytic anemia due to pyruvate kinase deficiency (PKD)**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this 

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disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **Rare constitutional hemolytic anemia due to an enzyme disorder (Other than PKD)**

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this 

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 disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming  
from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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Status of the survey

- ☐ Incomplete  
☐ Unverified  
☐ Completed

(Only surveys marked as 'completed' in this  
section will be considered in the analysis)

# Bleeding-Coagulation disorders

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Your contribution is mandatory for the subnetworks where your institution is nationally recognized as an ERN Member. However, the opportunity to contribute is also extended to other subnetworks.

Kinds regards,

ENROL Coordination team

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Remember: Pediatric patients are those < 18 years old, while adults are those ≥18 years old

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## Typical hemolytic-uremic syndrome

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_  
disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this

group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients

\_\_\_\_\_

Number of new adult patients

\_\_\_\_\_

Number of new male patients

\_\_\_\_\_

Number of new female patients

\_\_\_\_\_

### Atypical hemolytic-uremic syndrome

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_ disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of pediatric patients

\_\_\_\_\_

Number of adult patients

\_\_\_\_\_

Number of male patients

\_\_\_\_\_

Number of female patients

\_\_\_\_\_

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Rare hemorrhagic disease due to coagulation factors defects (Other than hemophilia and VWD)

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Hemophilia A

Number of total patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of total patients seen at the Health Care  
Provider during the reporting period (no matter if  
they come for the first time or not), whose disease  
or condition falls inside this group of diseases,  
whatever their age, including visits to outpatient's  
clinics, hospital discharges and emergencies, coming  
from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming from  
national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Hemophilia B

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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**Von Willebrand Disease**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_

disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **Rare hemorrhagic disorder due to a constitutional platelet anomaly**

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

Page 7

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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**Rare hemorrhagic disorder due to an acquired platelet anomaly**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of pediatric patients

Number of adult patients

Number of male patients

Number of female patients

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients

Number of new adult patients

Number of new male patients

Number of new female patients

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**Rare thrombotic disorder due to a coagulation factors defect**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_  
disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

\_\_\_\_\_  
(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Rare thrombotic disorders due to a quantitative platelet anomaly (Low)

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this 

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 disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Rare thrombotic disorders due to a quantitative platelet anomaly (High)

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this 

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 disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics,

hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients

\_\_\_\_\_

Number of new adult patients

\_\_\_\_\_

Number of new male patients

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Number of new female patients

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Status of the survey

☐ Incomplete

☐ Unverified

☐ Completed

(Only surveys marked as 'completed' in this section will be considered in the analysis)

## Bone marrow failure and hematopoietic disorders

Dear expert,

Thank you so much for collaborating with the ENROL Registry mapping of 2025. Please consider that the edition of the submitted data will be available until the 28<sup>th</sup> of April 2026.

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Kinds regards,

ENROL Coordination team

Remember: Pediatric patients are those < 18 years old, while adults are those ≥18 years old

### Paroxysmal nocturnal hemoglobinuria

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_ disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases,

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whatever their age, including visits to outpatient's  
clinics, hospital  
discharges and emergencies, coming from national  
and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming  
from national and international referrals.)



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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **Blackfan -Diamond Anemia**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

Number of new female patients

**Dyskeratosis congenita and related disorders**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_  
disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Fanconi Anemia

Number of total patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of total patients seen at the Health Care  
Provider during the reporting period (no matter if  
they come for the first time or not), whose disease  
or condition falls inside this group of diseases,  
whatever their age, including visits to outpatient's  
clinics, hospital discharges and emergencies, coming  
from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming from  
national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Rare constitutional aplastic anemia (Other than BDA, FA, SD)

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

\_\_\_\_\_

**Shwachman-Diamond syndrome**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this \_\_\_\_\_

disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Idiopathic Aplastic Anemia

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

Page 7

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

## Red Cell Aplasia

Number of total patients referred to the Health  
with this \_\_\_\_\_  
disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of pediatric patients

Number of adult patients

Number of male patients

Number of female patients

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients

Number of new adult patients

Number of new male patients

Number of new female patients

**Constitutional Megaloblastic Anemia**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of pediatric patients

Number of adult patients

Number of male patients

Number of female patients

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients

\_\_\_\_\_

Number of new adult patients

\_\_\_\_\_

Number of new male patients

\_\_\_\_\_

Number of new female patients

\_\_\_\_\_

### **Congenital dyserythropoietic anemia type II**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

Number of pediatric patients

\_\_\_\_\_

Number of adult patients

\_\_\_\_\_

Number of male patients

\_\_\_\_\_

Number of female patients

\_\_\_\_\_

Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

### **Congenital dyserythropoietic anemia (Other than type II)**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this 

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 disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics,

hospital discharges and emergencies, coming from national and international referrals.)

Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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Status of the survey

☐ Incomplete

☐ Unverified

☐ Completed

(Only surveys marked as 'completed' in this section will be considered in the analysis)

## Hemochromatosis and other iron related disorders

Dear expert,

Thank you so much for collaborating with the ENROL Registry mapping of 2025. Please consider that the edition of the submitted data will be available until the 28th of April 2026.

As a reminder, the **period to be reported is 1st of January - 31st December 2025.**

Your contribution is mandatory for the subnetworks where your institution is nationally recognized as an ERN Member. However, the opportunity to contribute is also extended to other subnetworks.

Kinds regards,

ENROL Coordination team

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Remember: Pediatric patients are those < 18 years old, while adults are those ≥18 years old

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### Acquired idiopathic sideroblastic anemia

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care



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Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)



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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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**Constitutional sideroblastic anemia (Other than Severe congenital hypochromic anemia with ringed sideroblastic)**

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

Number of new female patients

### **Congenital atransferrinemia**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Aceruloplasminemia

Number of total patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

(Number of total patients seen at the Health Care  
Provider during the reporting period (no matter if  
they come for the first time or not), whose disease  
or condition falls inside this group of diseases,  
whatever their age, including visits to outpatient's  
clinics, hospital discharges and emergencies, coming  
from national and international referrals)

Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming from  
national and international referrals.)

Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### Microcytic anemia with liver iron overload

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### IRIDA syndrome

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed  
with this 

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disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **Severe congenital hypochromic anemia with ringed sideroblasts**

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)



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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **Rare Acquired deficiency anemia (Plummer - Vinson syndrome)**

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming  
from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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### **HFE related hereditary hemochromatosis (Symptomatic form of hemochromatosis type 1 - OMIM 235201)**

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Number of total patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of total patients seen at the Health Care  
Provider during the reporting period (no matter if  
they come for the first time or not), whose disease  
or condition falls inside this group of diseases,  
whatever their age, including visits to outpatient's  
clinics, hospital discharges and emergencies, coming  
from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)  
Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

### **HFE related hereditary hemochromatosis (Other than type 1)**

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Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care Providers participating in the ERN diagnosed with this disease group

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(Number of new patients seen at the Health Care Providers for the first time during the reporting period, whose disease or condition falls inside this group of diseases, whatever their age, including new diagnosis and visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

## Porphyria

Number of total patients referred to the Health Care Providers participating in the ERN diagnosed with this 

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 disease group

(Number of total patients seen at the Health Care Provider during the reporting period (no matter if they come for the first time or not), whose disease or condition falls inside this group of diseases, whatever their age, including visits to outpatient's clinics, hospital discharges and emergencies, coming from national and international referrals)

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Number of pediatric patients

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Number of adult patients

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Number of male patients

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Number of female patients

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Number of new patients referred to the Health Care  
Providers participating in the ERN diagnosed with this  
disease group

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(Number of new patients seen at the Health Care  
Providers for the first time during the reporting  
period, whose disease or condition falls inside this  
group of diseases, whatever their age, including  
new diagnosis and visits to outpatient's clinics,  
hospital discharges and emergencies, coming  
from national and international referrals.)

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Number of new pediatric patients

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Number of new adult patients

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Number of new male patients

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Number of new female patients

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Status of the survey

- ☐ Incomplete  
☐ Unverified  
☐ Completed

(Only surveys marked as 'completed' in this  
section will be considered in the analysis)