ERN on haematological diseases (EuroBloodNet)

Haematological diseases involve abnormalities of blood and bone marrow cells, lymphoid organs and coagulation factors, and almost all of them are rare. They can be subdivided into six categories: rare red blood cell defects; bone marrow failure; rare coagulation disorders; haemochromatosis and other rare genetic disorders of iron synthesis; myeloid malignancies; and lymphoid malignancies.

Preventive programmes are in place in some countries for certain conditions, but there is an urgent need for harmonisation in the field of screening.

Diagnosis of rare haematological diseases (RHDs) requires considerable clinical expertise and access to a broad range of laboratory services and imaging technologies. These tests allow precise disease classification according to WHO criteria using international scoring systems and, where possible, biomarkers.

Given these requirements and the fact that some RHDs are very rare, diagnosis is frequently overlooked or delayed, especially in elderly patients. Treatment is also often difficult due to the specialised infrastructures and teams required and the difficulty accessing specific treatments such as allogenic stem cell transplantation or coagulation factors.

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EuroBloodNet, with the experience gained thanks to the EU-funded European Network for Rare and Congenital Anaemias (ENERCA) and the European Haematology Association (EHA), will seek: to improve access to healthcare for RHD patients; to promote guidelines and best practice; to improve training and knowledge-sharing; to offer clinical advice where national expertise is scarce; and to increase the number of clinical trials in the field.

NETWORK COORDINATOR

Professor Pierre Fenaux
Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis, France