ERN on Haematological diseases (ERN-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.

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

In its first five years ERN-EuroBloodNet, in close collaboration with the European Hematology Association (EHA), has successfully conducted multiple transversal and RHD disease-specific actions aimed at improving access to healthcare for RHD patients; promoting guidelines and best practice; improving training and knowledge-sharing; offering clinical advice where national expertise is scarce; and increasing the number of clinical trials in the field. The involvement of ePAGs and patient associations from the outset contributes to patients' empowerment, therapeutical education and advocacy training, in keeping with ERN-EuroBloodNet's patient-centred approach.

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