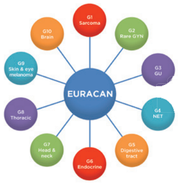
# European Reference Networks for Rare Cancers

European
Reference
Networks

## What is an ERN?

European Reference Networks (ERNs) are networks of national centres of expertise involving nearly 1,000 healthcare providers throughout the European Union (EU) specialising in the treatment of rare and complex diseases. There are 24 ERNs and each corresponds to a broad disease grouping.

EURACAN and EuroBloodNet cover respectively solid and haematological cancers in adults, PaedCan covers paediatric cancers and GENTURIS encompasses genetic tumour risk syndromes.



## How will ERNs help patients?

ERNs facilitate virtual medical consultations on difficult cases for diagnosis and treatments. Expertise travels rather than the patient. Specialised healthcare professionals discuss patients' cases with their colleagues, and securely share images and/or biological samples within and/or outside their country. **Ultimately, this will result in providing timely, adequate and equal access to diagnosis and care for all rare disease/ rare cancer patients in the EU.**

The EU Joint Action on Rare Cancers (JARC) supports the development of ERNs for rare cancers and provides recommendations on rare cancers' policy:

**www.jointactionrarecancers.eu**

## ERNs are patient-centred:

Patient advocates associated with ERNs represent their European Patient Advocacy Group (ePAG) whose diseases are covered by a specific ERN. They are called **"ePAG advocates"** and are involved at the highest level on the ERN Boards/ Steering Committees and work closely with the ERN medical experts. EURORDIS-Rare Diseases Europe provides them with coordinated support.

European
Reference
Network
for rare or low prevalence
complex diseases

Network
Paediatric Cancer
(ERN PaedCan)

EuroBloodNet
European Reference Network in Rare Hematological Diseases

www.genturis.eu

EURORDIS
RARE DISEASES EUROPE

JARC
JOINT ACTION ON RARE CANCERS

# ERNS relevant to rare cancers

## EURACAN: ERN for rare adult solid tumours

This network includes 65 multi-disciplinary expert teams in 16 EU Member States plus Norway. EURACAN is coordinated by Prof. Jean-Yves BLAY and his team at the Centre Léon Bérard, Lyon, France. EURACAN encompasses ten clinical domains as follows, corresponding to the RARECARE list of rare cancers based on the International Classification of Diseases for Oncology (ICD-O):

1. **sarcoma of the soft tissue, bone and viscerae**
2. **rare neoplasms of the female genital organs and placentas**
3. **rare neoplasms of the male genital organs and the urinary tract**
4. **neuroendocrine tumours**
5. **rare neoplasms of the digestive tract**
6. **rare neoplasms of the endocrine organs**
7. **rare neoplasms of the head and neck**
8. **rare neoplasms of the thorax: thymoma, mediastinum and pleura**
9. **rare neoplasms of the skin and eye melanoma**
10. **rare neoplasms of the brain and spinal cord**

**Fourteen ePAG advocates from major European patient organisations are actively involved in all aspects of EURACAN's development.**

**More information:**
**http://euracan.ern-net.eu**

## PaedCan: ERN for paediatric cancers

| | | | |
|---|---|---|---|
| SIOPE<br>Brain Tumour Group | Brain Tumour | Ewing's Tumour | EUROEWING Consortium |
| Germ Cell Tumours | Germ Cell Tumours | Hodgkin's Lymphoma | EHL |
| Histiocyte Society | Langerhans Cell Histiocytosis | Leukemias & Lymphomas | I-BFM |
| SIOPEL | Liver Tumours | Myelodysplasia | EWOG-MDS |
| SIOPEN | Neuroblastoma | New Anticancer Agents | ITCC |
| EICNHL | Non-Hodgkin Lymphoma | Osteosarcoma | EURAMOS |
| SIOP-RTSG | Renal Tumours | Soft Tissue Sarcomas | CWS |
| EpSSG | Soft Tissue Sarcomas | Stem Cell Transplantation | EBMT |
| PanCare | Survivorship & Late Effects | Very Rare Pedatric. Tumours | EXPeRT |
| EURBG | Retinoblastoma | | |

The goal of the ERN PaedCan (coordinated by Prof. Ruth Ladenstein from CCRI, Vienna, Austria) is to improve outcomes of childhood cancer by reducing the current inequalities in different Member States. The main objective of the ERN PaedCan is to provide cross-border best care to rare childhood cancer populations through linking pre-existing reference centres inherent to the established European Clinical Trial Groups (trial groups coordinating treatment in participating centres independent from industry), which will contribute to high-level diagnostic and medical expertise. ERN PaedCan works closely with the patient organisation Childhood Cancer International–Europe (CCI-E) represented by five ePAG advocates, including the Chair.

**More information:**
**http://paedcan.ern-net.eu/ ; ernpaedcan@ccri.at**

# EuroBloodNet:
# ERN for rare haematological diseases including malignant and non malignant conditions

EuroBloodNet encompasses malignant and non-malignant rare haematological diseases. This network includes 66 institutions in 15 EU Member States. The network coordinator for onco-haematology within EuroBloodNet is Prof. Pierre FENAUX, Hospital Saint Louis Paris, France. Non-oncological diseases are coordinated by Prof. Béatrice GULBIS, Hospital Erasme-CUB, Brussels, Belgium. In malignant haematology, EuroBloodNet covers two large oncological clinical domains:

① **myeloid malignancies**
② **lymphoid malignancies**

**Eight ePAG advocates from pan-European haematology patient organisations team up with medical experts, and are members of EuroBloodNet's Board of the Network, Scientific and Strategic Board and Transversal Fields of Action.**

**More information:**
**www.eurobloodnet.eu**

# ERN GENTURIS: ERN on rare genetic tumour risk syndromes

ERN GENTURIS consists of 23 multi-disciplinary expert teams in 12 EU Member States. It is coordinated by Prof Nicoline HOOGERBRUGGE and her team at Radboud University Medical Center in Nijmegen, The Netherlands.

ERN GENTURIS focuses on patients with very high hereditary risk of developing common or rare, benign or malignant tumours, often at an early age. If these patients are diagnosed with cancer, they need different treatments and follow-up in comparison to non-hereditary cancers. ERN GENTURIS comprises four main thematic groups:

① **neurofibromatosis 1, 2 and schwannomatosis**
② **Lynch syndrome and polyposis**
③ **hereditary breast and ovarian cancer**
④ **other rare - predominantly malignant - genetic tumour risk syndromes**

In ERN GENTURIS, there are eight ePAG advocates teamed with medical experts for improving diagnosis and care of patients.

**More information:**
**www.genturis.eu**

# ERNs’ common objectives for paediatric and adult patients with rare cancers:

- Increase access to pathological diagnosis, second opinion, and associated treatments as well as information across all EU Member States
- Implement “roadmaps” for referrals
- Develop and continuously review Clinical Practice Guidelines (CPGs)
- Develop medical training programmes to increase and harmonise quality of care
- Develop and increase the use of patient registries, biobanks and research studies
- Initiate and promote novel translational research programmes and associated tools
- Fully and pro-actively involve patient advocacy groups
- Interact with key national and international medical specialists and networks involved in cancer care and research as well as other rare disease stakeholders

## Support to ePAGs - Patient Advocates

EURORDIS-Rare Diseases Europe, founded in 1997, is a non-profit alliance of over 860 rare disease patient organisations from more than 70 countries (including the 28 EU Member States). EURORDIS has advocated for more than ten years for the establishment of ERNs, which are seen as the way forward to improve equal access to timely and accurate diagnosis and treatment for rare and complex diseases, including rare cancers, for all European patients. In parallel to the establishment of ERNs, EURORDIS has established European Patient Advocacy Groups (ePAGs) to support the involvement of patients in the development of ERNs. EURORDIS provides support and training to all ePAG advocates and works closely with them.

**More information:**
**www.eurordis.org**

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