



# European Reference Network

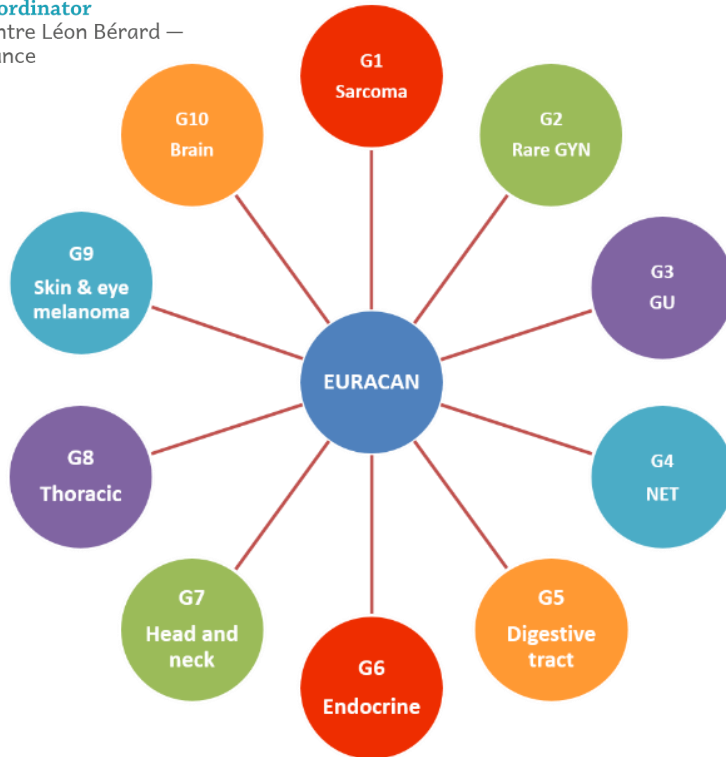
for rare or low prevalence complex diseases

## Network

Adult Cancers  
(ERN EURACAN)

## Coordinator

Centre Léon Bérard —  
France



**10 domains**

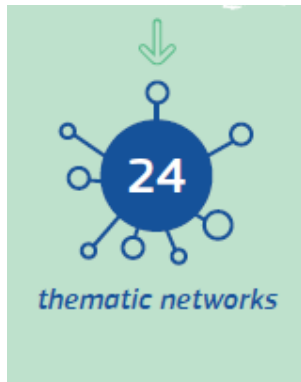
# ERN EURACAN



**17 European countries**

# RARE ADULT SOLID CANCERS

With the support of the EU Health Programme, the first **24 European Reference Networks** started their activities in 2017



ERNs are virtual networks involving

- 300 healthcare providers
- in 26 Member States to share expertise and improve access to care for patients accross the European Union
- Especially for complex or rare medical diseases that require highly specialised healthcare and a concentration of knowledge and ressources.

# European Reference Networks (ERNs)

**EURACAN : ERN for Rare Adult solid Cancers**

**EURACAN gathers**

**66 Health Care Providers in 17 European countries**

**27 Associated partners (Patient Advocacy Groups (PAGs), rare disease stakeholders).**

## 17 European countries



## Countries and institutions participating in EURACAN as of 1 January 2018

**BELGIUM** (Antwerp, Brussels, Leuven, Liège)

**CZECH REPUBLIC** (Brno, Prague)

**DENMARK** (Aarhus)

**GERMANY** (Berlin, Essen, Mannheim, Hamburg–Eppendorf, Marburg, Würzburg)

**FINLAND** (Turku)

**FRANCE** (Lyon, Paris, Villejuif)

**HUNGARY** (Budapest)

**ITALY** (Aviano, Bologna, Candiolo, Firenze, Genoa, Meldola, Milan, Naples, Roma, Siena, Torino, Treviso)

**LITHUANIA** (Kaunas)

**NETHERLANDS** (Amsterdam, Leiden, Maastricht, Nijmegen, Rotterdam, Groningen)

**NORWAY** (Oslo)

**POLAND** (Warsaw)

**PORTUGAL** (Coimbra, Lisboa, Porto)

**SWEDEN** (Karolinska, Uppsala)

**SPAIN** (Barcelona, Sevilla)

**SLOVENIA** (Ljubljana)

**UNITED KINGDOM** (Coventry, London, Oxford, Sheffield)

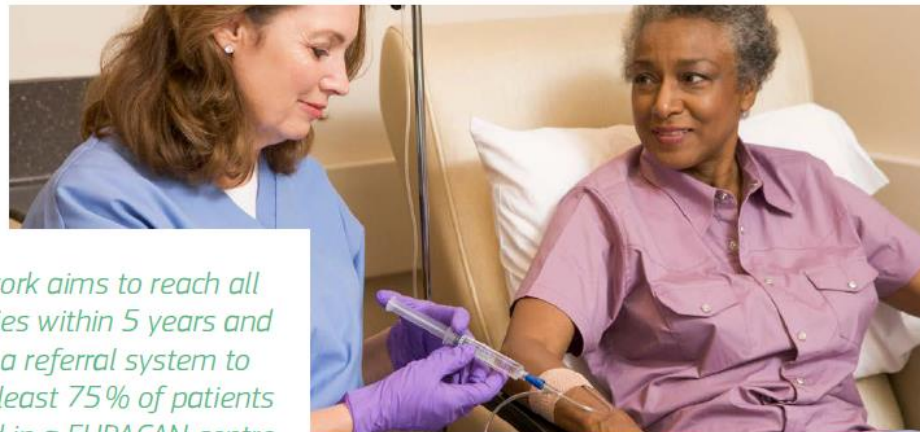
# 66 Health Care Providers

|   |    |   |  |  |    |  |  |
|---|----|---|--|--|----|--|--|
|        | BE | Antwerp<br>Liège<br>Brussels<br>Leuven  | <b>Antwerp University Hospital</b><br><b>CHU of Liège</b><br><b>Institut Jules Bordet</b><br><b>Leuven Cancer Institut</b>   |    | LT | Kaunas   | <b>Hospital of Lithuanian University of Health Sciences</b>  |
|       | CZ | Brno<br>Prague  | <b>Masaryk Memorial Cancer Institute</b><br><b>University Hospital Motol</b>   |   | NL | Amsterdam<br>Rotterdam<br>Leiden<br>Maastricht<br>Amsterdam<br>Nijmegen<br>Gronigen<br>Amsterdam | <b>Academic Medical Center</b><br><b>Eramus MC</b><br><b>Leiden University Medical Center</b><br><b>Maastricht University Medical Center</b><br><b>Netherlands Cancer Institute - AVL</b><br><b>Radboud University Medical Center</b><br><b>University Medical Center Gronigen</b><br><b>VU Medical Center</b> |
|       | DE | Berlin<br>Hamburg Eppendorf<br>Marburg<br>Würzburg<br>Mannheim<br>Essen   | <b>Charité - Universitätsmedizin Berlin</b><br><b>University Medical Center Hamburg-Eppendorf</b><br><b>Univeristy Hospital Marburg</b><br><b>University Hospital Würzburg</b><br><b>Mannheim University Medical Center</b><br><b>University Hospital Essen</b>  |      | DK | Aarhus   | <b>Aarhus University Hospital</b>  |
|       | FI | Turku   | <b>Turku University Hospital</b>   |   | NO | Oslo   | <b>Oslo University Hospital - Norwegian Radium Hospital</b>  |
|       | FR | Lyon<br>Paris<br>Paris<br>Paris<br>Paris<br>Lyon<br>Villejuif   | <b>Centre Léon Bérard</b><br><b>APHP- Consortium Cochin Pominou Descartes</b><br><b>APHP- Hôpital de la Pitié Salpêtrière</b><br><b>APHP- Hôpital Tenon</b><br><b>Institut Curie</b><br><b>Hospices Civils de Lyon</b><br><b>Institut Gustave Roussy</b>   |   | PL | Warsaw   | <b>Maria Skłodowska Curie Institute - Oncology Centre</b>  |
|    | PT | Porto<br>Coimbra<br>Lisboa  | <b>Centro Hospitalar do Porto</b><br><b>Centro Hospitalar e Universitario de Coimbra - EPE</b><br><b>Instituto Portugues de Oncologia de Lisboa Francisco Gentil -EPE</b>  |   | SE | Uppsala<br>Karolinska  | <b>Uppsala University Hospital</b><br><b>Karolinska University Hospital</b>  |
|       | HU | Budapest  | <b>National Institute of Oncology</b>  |   | SI | Ljubljana  | <b>Institute of Oncology of Ljubljana</b>  |
|     | IT | Bologna<br>Firenze<br>Siena<br>Bologna<br>Aviano<br>Naples<br>Candiolo<br>Milano<br>Bologna<br>Roma<br>Milano<br>Milano<br>Meldola<br>Milan<br>Treviso<br>Genoa | <b>AOU- Policlinico S Orsola-Malpighi</b><br><b>AOU - Careggi Firenze</b><br><b>AOU Senese</b><br><b>AUSL di Bologna -</b><br><b>Centro di Riferimento Oncologico di Aviano</b><br><b>CRTR-AOU Federico II</b><br><b>Candiolo Cancer Institute - FPO IRCCS</b><br><b>Humanitas Research Hospital Cancer Center</b><br><b>Istituto Ortopedico Rizzoli</b><br><b>Istituto Fisioterapici Ospitalieri</b><br><b>Fondazione IRCCS Istituto Neurologico Carlo Besta</b><br><b>Fondazione IRCCS Istituto Nazionale dei Tumori</b><br><b>Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori</b><br><b>IRCCS Ospedale San Raffale</b><br><b>Azienda ULSS 2 Mara Trevigiana</b><br><b>IRCCS San Martino - IST</b> |  | SP | Sevilla<br>Barcelona<br>Barcelona  | <b>Complejo Hospitalario regional Virgen del Rocio</b><br><b>Hospital Sant Pau</b><br><b>Integrated unit ICO Hospitalet - HUB</b>  |
|  | UK | London<br>Oxford<br>London<br>London<br>Sheffield<br>London<br>Coventry   | <b>Imperial College Hospitals (NHS) Trust ICHNT</b><br><b>Oxford University Hospitals NHS Foundation Trust</b><br><b>Royal Free London NHS Foundation Trust</b><br><b>Royal Marsden Hospital</b><br><b>Sheffield Teaching Hospital</b><br><b>University College London NHS Foundation Trust</b><br><b>University Hospitals Coventry &amp; Warwickshire NHS Trust</b>   |  |    |  |  |

# ERN on adult cancers (solid tumours) (ERN EURACAN)



More than **300 rare cancers** have been identified. ERN EURACAN covers all rare adult solid tumour cancers, grouping them into 10 domains corresponding to the RARECARE classification and ICD10. The management of rare cancers poses significant diagnostic challenges, sometimes with major consequences for patients' quality of life and outcome. Inappropriate management of these patients may also result in an increased risk of relapse, and risk of death.



*The network aims to reach all EU countries within 5 years and develop a referral system to ensure at least 75% of patients are treated in a EURACAN centre.*

ERN EURACAN is sharing best practice tools and establishing reference centres for rare cancers. It is also establishing regularly updated diagnostic and therapeutic clinical practice guidelines. The network aims to reach all EU countries within 5 years and develop a referral system to ensure at least 75% of patients are treated in a EURACAN centre. It seeks to improve patient survival, produce communication tools in all languages for patients and physicians, and develop multinational databases and tumour banks.

The ERN builds on pre-existing clinical and research networks that have successfully conducted clinical trials through the European Organisation for Research and Treatment of Cancer (EORTC), and established guidelines through EORTC and the European Society for Medical Oncology (ESMO). It also benefits from the work of networks formed by the European Neuroendocrine Tumour Society (ENETS) and Connective Tissues Cancer Network (Conticanet), as well as several EU research projects.

### NETWORK COORDINATOR

Professor Jean-Yves Blay  
Centre Léon Bérard, Lyon, France

# TARGETED Rare Adult Cancers



**EURACAN groups** all rare adult solid cancers into ten “domains” corresponding to the RARECARE list of rare cancers based on the ICD-O (which is a medical classification for cancer).

**These ten domains are also based on pre-existing successful collaborations, in particular for clinical research and expert networks which have been active in the last ten to twenty years.**

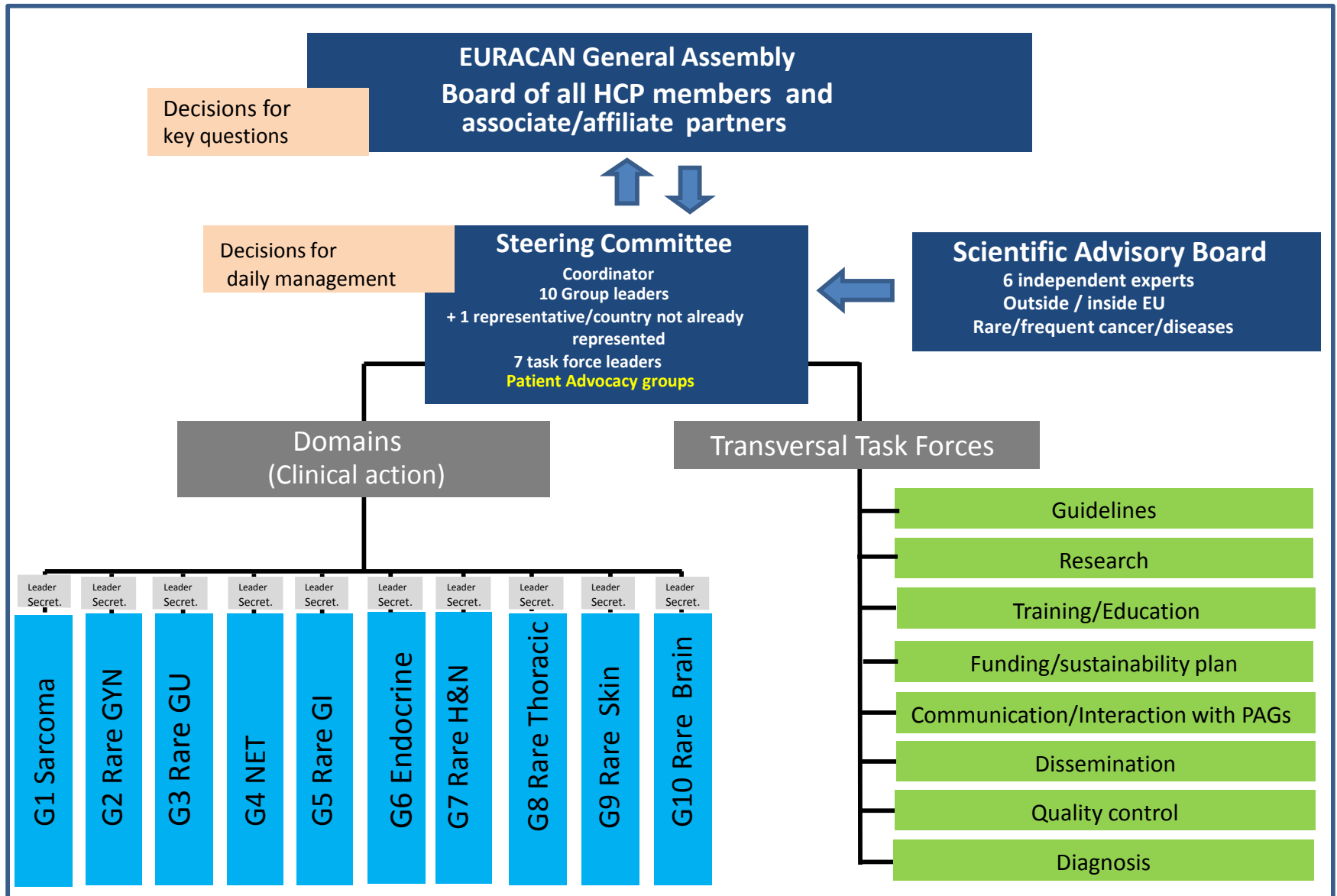
# OBJECTIVES at 5 years

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- **Increase** access to pathological diagnosis and associated treatments across all EU Member States
- **Develop** medical training programmes to increase and harmonise the quality of cares,
- **Involve patient advocacy groups** and assist them in the wide dissemination of educational tools,
- **Implement “roadmaps”** for referral and self-referral of patient to expert centers,
- **Develop and continuously** review Clinical Practice Guidelines (CPGs),
- Initiate and **promote** novel translational research programs (and associated tools – e.g. set of multinational databases and tumour banks),
- **Interact** with key national international actors/networks involved in cancer care and research and beyond, with other rare diseases stakeholders.



# GOVERNANCE



# Groups leaders

|     |  |  |  |
|-----|--|--|--|
| G1  | Sarcoma of the soft tissue, bone and viscerae (Sarcoma domain)   | Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy | <b>Clinical Lead:</b> Paolo CASALI<br><b>ePAG:</b> Estelle LECOINTE & Markus WARTENBERG - Sarcoma Patients EuroNet (SPAEN)   |
| G2  | Rare neoplasm of the female genital organs and placentas (Rare GYN domain)   | Imperial College, London, United Kingdom                     | <b>Clinical Lead:</b> Michael SECKL<br><b>ePAG:</b> Pending confirmation   |
| G3  | Rare neoplasm of the male genital organs, and of the urinary tract (Rare GU domain)  | University Medical Centre, Groningen, The Netherlands        | <b>Clinical Lead:</b> Jourik GIETEMA<br><b>ePAG:</b> Pending confirmation  |
| G4  | Neuroendocrine tumours (NET domain)  | Royal Free London NHS Trust, United Kingdom                  | <b>Clinical Lead:</b> Martyn CAPLIN<br><b>ePAG:</b> Teodora KOLAROVA - International Neuroendocrine Cancer Alliance (INCA) & Catherine BOUVIER - NET Patient Foundation UK |
| G5  | Rare neoplasm of the digestive tract (Rare GI domain)  | M Sklodowska-Curie Memorial Cancer Center, Warsaw, Poland    | <b>Clinical Lead:</b> Lucjan WYRWICZ<br><b>ePAG:</b> James CALDWELL - The Northern Ireland Rare Disease Partnership (NIRDP).   |
| G6  | Rare neoplasm of endocrine organs (Endocrine domain)   | Centre Léon Bérard, Lyon, France                             | <b>Clinical Lead:</b> Christelle de la FOUCHARDIERE<br><b>ePAG:</b> Jo GREY - The Association for Multiple Endocrine Neoplasia Disorders (AMEND)                           |
| G7  | Rare neoplasm of the head and neck: salivary gland tumours, nasopharyngeal cancer, nasal and sinonasal cancers, middle ear (Rare Head and Neck domain) | Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy | <b>Clinical Lead:</b> Lisa LICITRA<br><b>ePAG:</b> Umberto TASSINI - Associazione Italiana Laryngectomizzati (AILAR)   |
| G8  | Rare neoplasm of the thorax: thymoma, mediastinum and pleura (Rare Thoracic domain)  | Institut Curie Paris, France                                 | <b>Clinical Lead:</b> Nicolas GIRARD<br><b>ePAG:</b> Pending confirmation  |
| G9  | Rare neoplasm of the skin and eye (Rare Skin/Eye Melanoma domain)  | Leiden University Medical Centre                             | <b>Clinical Lead:</b> Ellen KAPITEIJN<br><b>ePAG:</b> Iain GALLOWAY - Melanoma Patient Network Europe (MPNE Ocular/Rare)   |
| G10 | Rare neoplasm of the brain and spinal cord (Rare Brain domain)   | Eramus MC, Rotterdam, The Netherlands                        | <b>Clinical Lead:</b> Martin J. van den BENT<br><b>ePAG:</b> Kathy OLIVER - International Brain Tumour Alliance (IBTA)   |

# EUROPEAN PATIENT ADVOCACY GROUPS (ePAGs)

The 24 ERN European Advocacy Groups (ePAGs) are coordinated by the European Organisation for Rare Diseases (EURORDIS), represented by Ariane Weinman in EURACAN.

| Domain | ePAG Representative  | Acronym      | First Name           | Family Name            | Website  |
|--------|--|--------------|----------------------|------------------------|--|
| G1     | Sarcoma Patients Euro Net                                      | SPAEN        | Estelle<br>Markus    | LECOINTE<br>WARTENBERG | <a href="http://www.sarcoma-patients.eu/">http://www.sarcoma-patients.eu/</a>  |
| G2     | Pending confirmation   |              |                      |                        |  |
| G3     | Pending confirmation   |              |                      |                        |  |
| G4     | Int. Neuroendocrine Cancer Alliance,<br>NET Patient Foundation | INCA,<br>NPF | Teodora<br>Catherine | KOLAROVA<br>BOUVIER    | <a href="http://incalliance.org/">http://incalliance.org/</a><br><a href="https://www.netpatientfoundation.org/">https://www.netpatientfoundation.org/</a> |
| G5     | The Northern Ireland Rare Disease<br>Partnership               | NIRDP        | James                | CALDWELL               | <a href="http://www.nirdp.org.uk/">http://www.nirdp.org.uk/</a>  |
| G6     | The Association for Multiple Endocrine<br>Neoplasia Disorders  | AMEND        | Joannah              | GREY                   | <a href="https://www.amend.org.uk/">https://www.amend.org.uk/</a>  |
| G7     | Associazione Italiana Laryngectomizzati                        | AILAR        | Umberto              | TASSINI                | <a href="http://www.ailar.it/">http://www.ailar.it/</a>  |
| G8     | Pending confirmation   |              |                      |                        |  |
| G9     | Melanoma Patient Network Europe                                | MPNE         | Iain                 | GALLOWAY               | <a href="http://www.melanomapatientnetworkeu.org/">http://www.melanomapatientnetworkeu.org/</a>  |
| G10    | International Brain Tumour Alliance                            | IBTA         | Kathy                | OLIVER                 | <a href="http://theibta.org/">http://theibta.org/</a>  |

The ePAG representative across all 10 EURACAN subdomains is Isabelle Manneh-Vangramberen of the European Cancer Patient Coalition (ECPC).



# TRANSVERSAL TASK FORCES LEADERS

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|   |                                |                   |
|---|--------------------------------|-------------------|
| <b>Guidelines</b>                                 | Peter HOHENBERGER              | ESMO              |
| <b>Research</b>                                   | Stéphane LEJEUNE               | EORTC             |
| <b>Formation &amp; Education</b>                  | Paolo CASALI                   | ESO               |
| <b>Funding &amp; sustainability</b>               | Bassim HASSAN                  | Oxford University |
| <b>Communication &amp; interaction with PAGs/</b> | Kathy OLIVER                   | IBTA              |
| <b>Dissemination</b>                              | Isabelle MANNEH<br>VANGRAMBEEN | ECPC              |
| <b>Quality control</b>                            | Josef LOVEY                    | OECI              |
| <b>Diagnostic</b>                                 | Paolo DEI TOS                  | Azienda ULSS2     |

# Associate Partners



**EANO**  
EUROPEAN ASSOCIATION  
OF NEURO-ONCOLOGY



**ECCO**  
EUROPEAN  
CANCER  
ORGANISATION



EUROPEAN  
CANCER  
PATIENT  
COALITION



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DI MILANO



# European Reference Network

for rare or low prevalence complex diseases

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# GUIDELINES

In this scope, each domain started working towards the harmonization of existing guidelines across Europe.

At this stage 2 sarcoma guidelines have already been updated in collaboration with the ESMO (European Society on Medical Oncology):

- **Gastrointestinal stromal tumours and Soft tissue and visceral sarcomas**
- **Bone sarcomas**

# Gastrointestinal Stromal tumours and Soft Tissue and visceral sarcomas

The updated [ESMO-EURACAN guidelines on Gastrointestinal stromal tumours and Soft tissue and visceral sarcomas](#) have been published online on 29/05/2018 in Annals of Oncology. These guidelines are also available directly on the [ESMO.org](#) and [OncologyPRO](#) websites.

## Annals of Oncology:

STS: <https://academic.oup.com/annonc/advance-article/doi/10.1093/annonc/mdy096/5004451>

GIST: <https://academic.oup.com/annonc/advance-article/doi/10.1093/annonc/mdy095/5004450>

## ESMO website:

STS: <http://esmo.org/Guidelines/Sarcoma-and-GIST/Soft-Tissue-and-Visceral-Sarcomas>

GIST: <http://esmo.org/Guidelines/Sarcoma-and-GIST/Gastrointestinal-Stromal-Tumours>

## ESMO OncologyPRO website:

STS: <http://oncologypro.esmo.org/Guidelines/Clinical-Practice-Guidelines/Sarcoma-and-GIST/Soft-Tissue-and-Visceral-Sarcomas>

GIST: <http://oncologypro.esmo.org/Guidelines/Clinical-Practice-Guidelines/Sarcoma-and-GIST/Gastrointestinal-Stromal-Tumours>





# Bone sarcomas

[ESMO-PaedCan-EURACAN Bone Sarcomas guidelines have been published online in Annals of Oncology.](#)

[These guidelines are also available directly on the ESMO.org and OncologyPRO websites.](#)

**Annals of Oncology:**

[https://academic.oup.com/annonc/article/29/Supplement\\_4/iv79/5115250](https://academic.oup.com/annonc/article/29/Supplement_4/iv79/5115250)

**ESMO website:** <https://www.esmo.org/Guidelines/Sarcoma-and-GIST/Bone-Sarcomas>

**ESMO OncologyPRO website:**

<https://oncologypro.esmo.org/Guidelines/Clinical-Practice-Guidelines/Sarcoma-and-GIST/Bone-Sarcomas>



**European  
Reference  
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for rare or low prevalence  
complex diseases

 **Network**  
Paediatric Cancer  
(ERN PaedCan)



**European  
Reference  
Network**

for rare or low prevalence  
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 **Network**  
Adult Cancers  
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# RESEARCH

# EORTC protocol 1553

(NCT02834884)

## SPECTA: Screening Cancer Patients for Efficient Clinical Trial Access

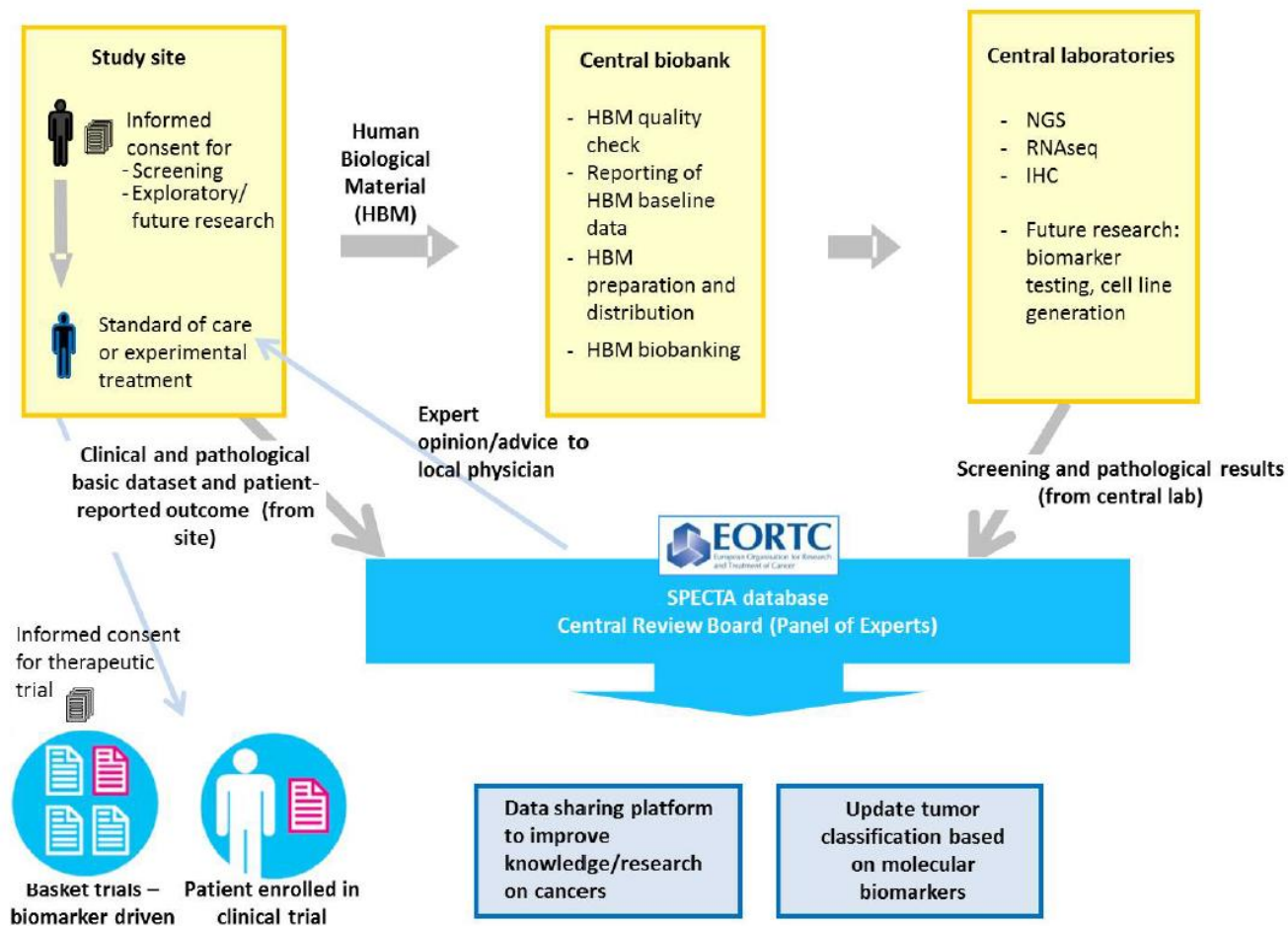


Figure 1: Description of the processes

## **EORTC protocol 1553**

(NCT02834884)

**SPECTA: Screening Cancer Patients for  
Efficient Clinical Trial Access**



EORTC research project 1843

for EURACAN

« ARCAGEN »

# EORTC research project 1843: ARCAGEN

**Objectives** : To establish a **clinical genomic screening platform for rare tumors** by characterizing the genomic alterations of rare cancers using a next-generation sequencing (NGS) panel (Foundation One, CDx)

- **In 1000 rare cancers from different tumor domains of EURACAN.**
  - 100 retrospective
  - 900 prospective
- For a retrospective part of the study, the tumor banks available within the EURACAN network will be used (estimated to be 100 cases). Prospective patient enrollement will be performed using the EURACAN-EORTC network.



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# Training/education

# Training/education

In the framework of EURACAN and the **JARC** European School of Oncology implemented new e-sessions on Rare Adult Solid Cancers

- Annual basis
- Ultimate goal : to strengthen the educational coverage of a group of cancers which may be neglected in spite of their collective incidence.
- Rare adult solid cancers are represented by EURACAN which provides a corresponding educational session within this Course

<http://www.e-eso.net/pages.do?methodcall=view&id=2>

# Training/education

Preceptorships have been conceived looking at the educational needs of **clinical oncologists** willing to open up to rare adult solid cancers as well as **patient advocates**. They will be multidisciplinary and clinically oriented

- **2<sup>nd</sup> ESO-ESMO-RCE clinical update on Rare Adult Solid Cancers 2-4 December 2017 Milan, Italy**

- **3<sup>rd</sup> ESO-ESMO-RCE Preceptorships & Clinical Update on Rare Adult Solid Cancers - 3 December 2018 - Milan, Italy**



# Training/education

- The European school of Oncology in collaboration with the University of Milan, has also launched a series of Post-graduate Courses for an international audience of clinical oncologists interested in advancing their knowledge and skills on rare adult solid cancers
- Two courses have been already scheduled at the beginning of 2018
  - *University post-graduate course* clinical oncology
    - **Head & Neck cancers** 5-9 February 2018 Milan, Italy
    - **Sarcoma** 22-26 January 2018 Milan, Italy



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# Clinical Patient Management System CPMS

# Clinical Patient Management System

- The Clinical Patient Management System (CPMS) is the secure web-based application provided by the EC to support ERNs in the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders (<https://cpms.ern-net.eu/login/>)
- Physicians members of EURACAN, can ask for their patient case to be reviewed. To do so an ERN coordinators convene 'virtual' advisory boards of medical specialists across different disciplines, using a dedicated IT platform (CPMS) and telemedicine tools.



# Communication & Dissemination



**How can Health Care Providers (HCP) non-members of an ERN be aware of this European initiative?**

In order to raise awareness on the ERNs, the Commission has carried out communication actions in particular through dedicated webpages on Europa portal [https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)

🌟 **Press release**, for instance in occasion of the Rare diseases Day 2018, see example: <https://www.theparliamentmagazine.eu/articles/opinion/rare-disease-research-european-reference-networks-are-good-start>

🌟 **specific communication materials** both available in all EU languages

- [Brochure](#)
- [flyers](#)
- [Videos](#)

# Similar objectives for Eurocan and protons network...

- **ERN main objectives are**
  - To share expertise
  - To improve access to care for patients accross Europe
  - Especially for complex /rare medical diseases
  - That require highly specialised healthcare and a concentration of knowledge and ressources.
- **Similarly, protons treatments require**
  - A high level of expertise to be shared
  - An improvement of access for patients accross the EU
  - While they are mainly dedicated to complex medical disease requiring a high level of expertise, knowledge and resources for both adults and children

# Similar objectives for Eurocan and protons network...

- Meticulous and rigourous large prospective studies are lacking to improve our knowledge on protons : which patients do have a real benefit ?
- As a consequence, there is a need to
  - Treat larger numbers of patients
  - Implement “roadmaps” for them through UE
  - Evaluate them prospectively and properly with a long-term follow-up
- More facilities are needed
  - To cover all the needs in both adults and children and to evaluate efficiency/toxicities on large numbers
  - To develop clinical, translational and fundamental reseach using “model based” studies

# EURACAN/PAEDCAN objectives could be applied to European proton project

- **Increase access to protons** across all EU Member States for patients WHO need it
- **Develop** medical training programmes to increase and harmonise the quality of cares : radiation oncologists, physicists, radiation therapists have to be trained and harmonise their practice in protons
- **Involve patient advocacy groups** and assist them in the wide dissemination of educational tools concerning protons
- **Implement “roadmaps” for referral and self-referral of patient to expert centers**
  - which patients should be sent with high priority to protons facilities ?
  - Clinical Patient Management System could be implemented for protons (i.e : treatment planning can be shared between different institutions)
- **Develop and continuously** review Clinical Practice Guidelines (CPGs)
- **Promote** European Research Programs and associated tools (multinational databases, storage of planning treatment as well as strict prospective follow-up of the patients to better evaluate long-term benefits of protons )

# Thank you for your attention





## Research

### Sarcomas

**Collaborative TRANSCAN application** titled "*Patient-derived xenograft and organoids for testing anticancer drugs and identifying novel actionable targets in rare soft tissue sarcomas*" was submitted and approved at the first evaluation step.

### Digestive tract

### Training/education

The domain has actively participated in the world-wide research initiative on anal cancer (IIRC). The pilot study in postoperative management of biliary cancer was initiated and enrollement started;

# Data Protection information

- The data collected and stored by an ERN member, who is physically providing care to the patient, will be held according to the rules and processes for collecting and storing patient data in the ERN member's institution. This storage falls outside the legal ambit of the ERN and is covered by the internal rules of the organisation and the national legislation of the country in which it is established.
- When data is made available for sharing in an ERN consultation between ERN members, it is shared through the ERN Clinical Patient Management System (CPMS).

# Data Protection information

- The European Commission has contracted with an external provider for this system, and accordingly has accepted the role of data co-controller for the de-identified data held on that system.
- The responsibility is shared with the provider of the CPMS who is also a data co-controller for the CPMS. This means that they share the responsibility for ensuring that data sharing facilitated by the CPMS is covered by adequate standards of security.

# Physician legal liability

🌟 In terms of legal liability for the quality care, under both the Directive and the Regulation this remains the responsibility of the legal entity providing the care. The advice provided within an ERN between healthcare professionals does not attract either a legal or financial responsibility outside the one already existing between the treating physician and the patient.