

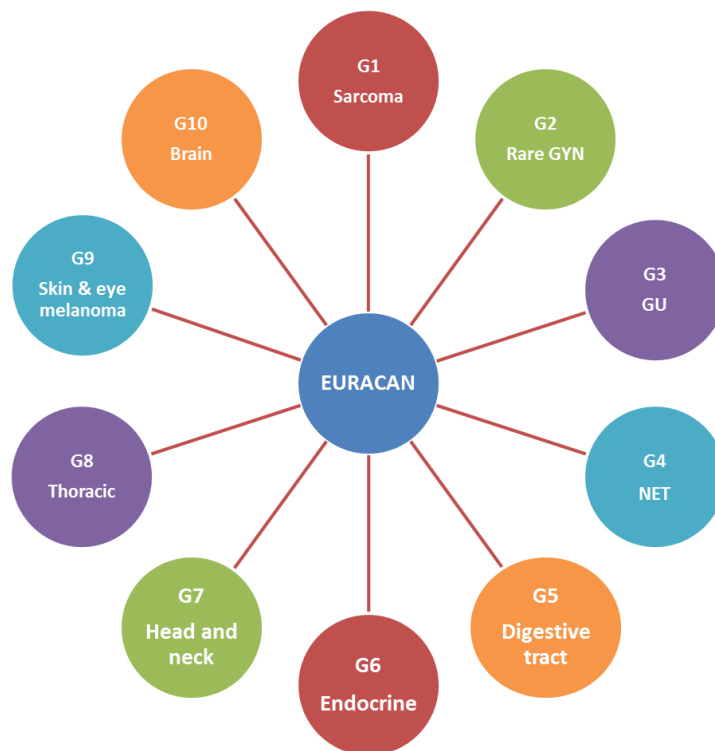


European Reference Network

for rare or low prevalence complex diseases

 **Network**
Adult Cancers
(ERN EURACAN)

EURACAN



Melanoma Patient Network Europe

RARE SOLID ADULT CANCERS

EURACAN KICKED-OFF OFFICIALLY ON 21st and 22nd APRIL 2017 IN LYON, FRANCE

**A special thank-you to the
EURACAN team in Lyon, France
for the use of their slides in this presentation,
and to the
EURACAN team at EURORDIS, France
for the use of their slides in this presentation**

European Reference Networks (ERNs)

**ERNS are virtual networks
involving healthcare providers across Europe
in order to:**

- (1) enable the sharing of expertise and**
- (2) to 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 resources.**

ERNS have been established under the 2011 EU Directive on patients' rights in cross-border healthcare. This Directive makes it easier for patients to access information on healthcare and thus increase their treatment options.

30 million people in the European Union are living with a rare disease

**More than 4.3 million people
in the European Union
are living with a rare cancer ***

Health systems in the European Union aim to provide high-quality, cost-effective care. This is particularly difficult with rare or low-prevalence complex diseases or conditions. Between 5,000 and 8,000 rare diseases affect the daily lives of around 30 million people in the EU.

Despite the rarity of each of the 198 rare cancers, they represent in total about 22% of all cancer cases, including all cancers in children, diagnosed in the EU each year. *

There are 24 ERN Networks Currently

The first ERNs were launched in March 2017, involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 Member States.

24 ERNs are working on a range of thematic issues including bone disorders, childhood cancer and immunodeficiency.

ERNS FOR RARE CANCERS

1. Rare adult cancers (**EURACAN**)

1. Pediatric cancers (**PaedCan-ERN**)

1. Rare haematological cancers
(**EuroBloodNet**)

4. There is also an ERN called **GENTURIS** which is for rare inherited syndromes which may give rise to various cancers, for example Li-Fraumeni Syndrome which can give rise to brain tumours.

EURACAN'S MISSION

EURACAN aims to establish a world-leading, patient-centric and sustainable network of multidisciplinary research-intensive clinical centres focused on RARE ADULT CANCERS (RACs).

EURACAN gathers 66 health care providers in 17 European countries, and 22 associate partners (PAGs, rare disease stakeholders, etc).

EURACAN'S OBJECTIVES

- Increase access **to pathological diagnosis** and associated treatments across all EU MS,
- develop medical **training programmes** to increase and harmonise the **quality of care**,
- **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 and international individuals/networks** involved in cancer care and research and beyond, with other rare diseases stakeholders.



THE TEN DOMAINS OF EURACAN



Rare adult solid cancers are grouped in 10 domains corresponding to the **RARECARE** classification and the ICD10.

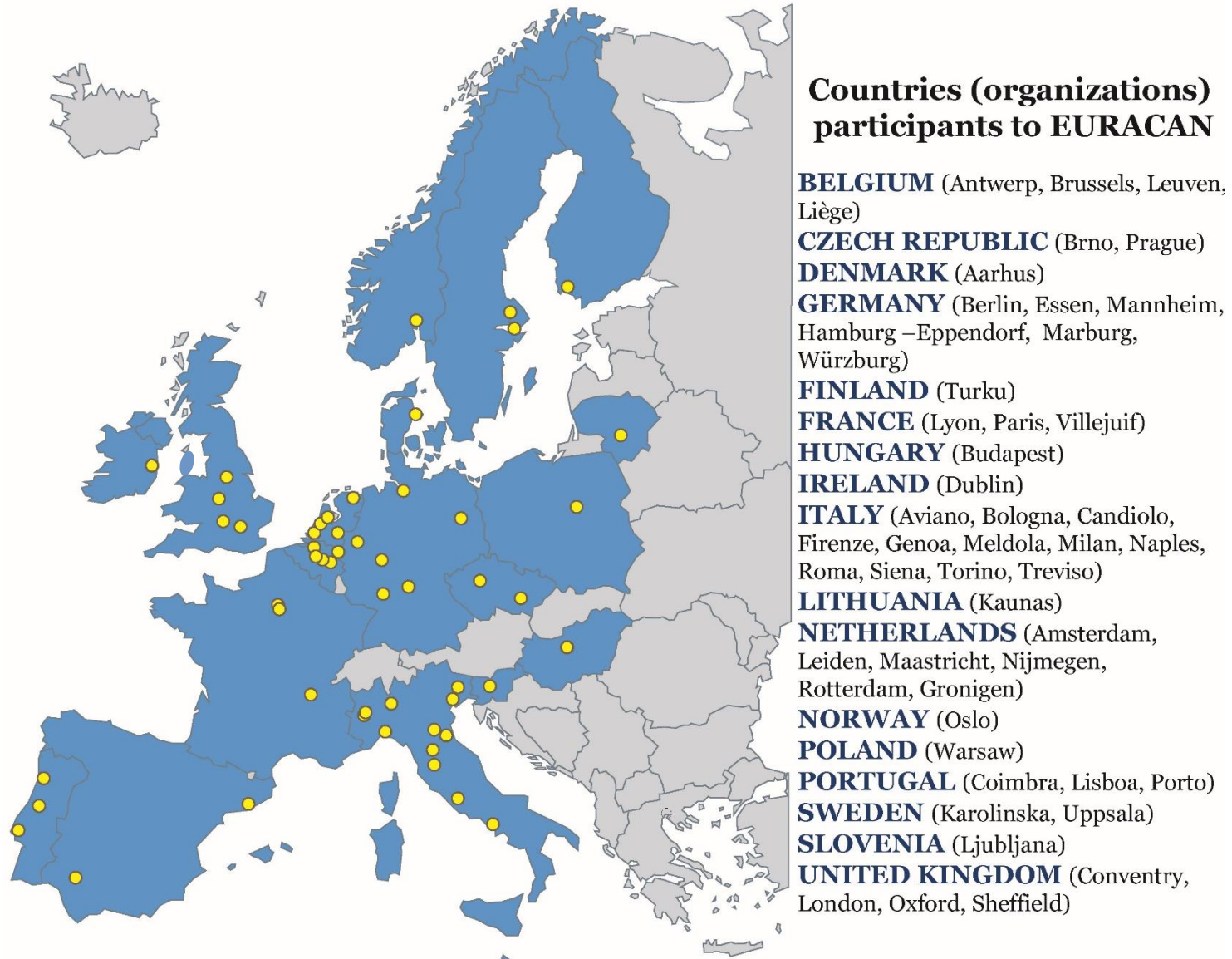
These domains are also based on pre-existing successful collaborations, in particular for **clinical research and expert networks active in the last 10-20 years**

THE TEN DOMAIN LEADERS

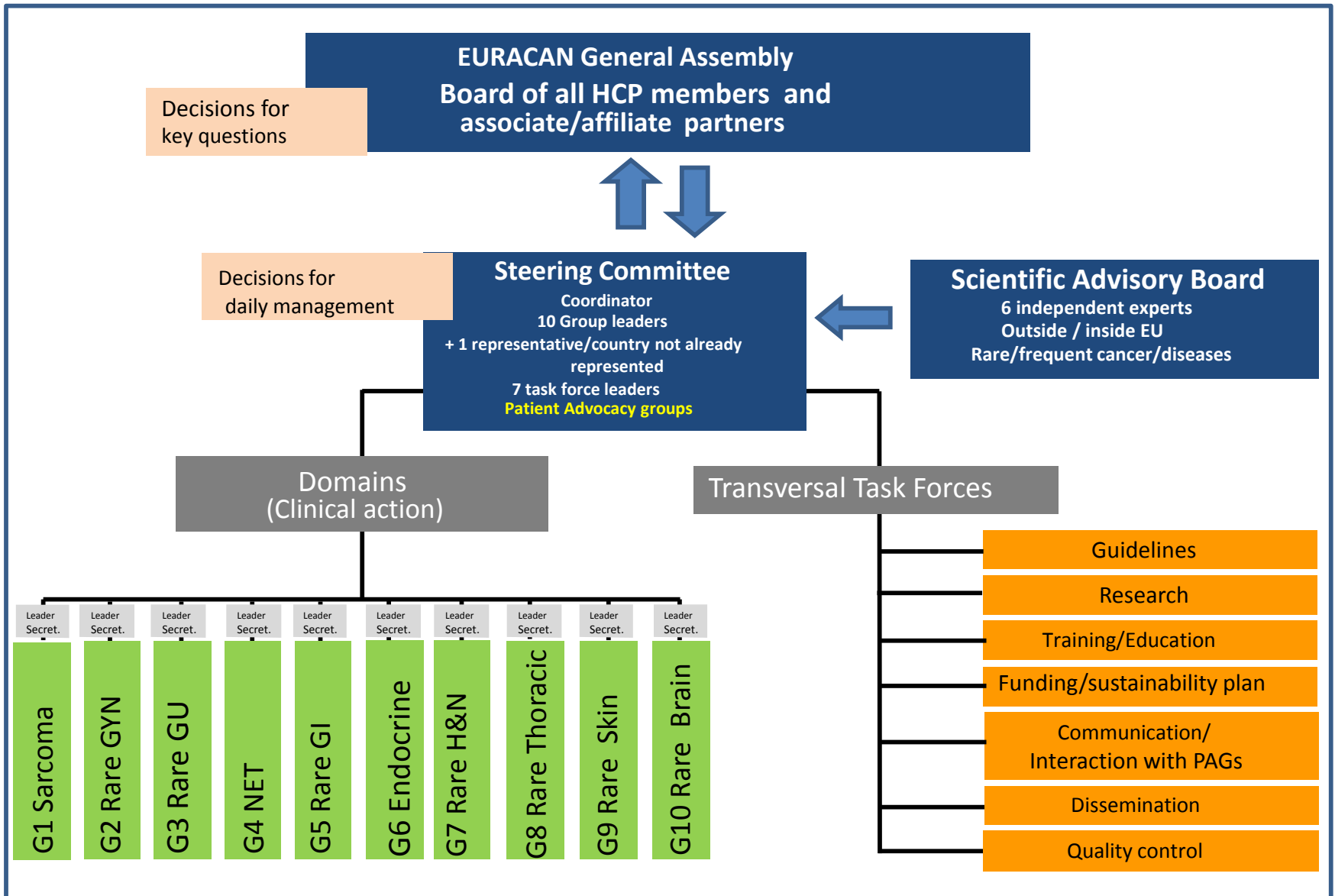
G1 Sarcoma - CASALI Paolo	Istituto Nazionale dei Tumori, Milan, Italy
G2 Rare GYN - SECKL Michael	Imperial College London, United Kingdom
G3 Rare GU - GIETEMA Jourik	University Medical Center Groningen, The Netherlands
G4 NET - CAPLIN Martyn	Royal Free London NHS Trust, United Kingdom
G5 GI - WYRWICZ Lucjan	M Sklodowska-Curie Memorial Cancer Center, Warsaw, Poland
G6- Endocrine - BAUDIN Eric	Gustave Roussy- Villejuif, France
G7 Rare Head and Neck - LICITRA Lisa	Istituto Nazionale dei Tumori, Milan, Italy
G8 Rare Thoracic - GIRARD Nicolas	Hospices Civils de Lyon, France
G9 Rare Skin/Eye melanoma - SCHADENDORF Dirk	University Hospital Essen, Germany
G10 Brain tumours - VAN DEN BENT Martin J.	Eramus MC, Rotterdam, the Netherlands



DISTRIBUTION OF EURACAN MEMBERS BY COUNTRY



EURACAN GOVERNANCE



EURACAN BOARDS AND COMMITTEES

Board / Committee	Chair	ePAG representative
Transversal Task Forces		
Guidelines	TBD	ePAG rep (TBD)
Research	Stephane Lejeune (EORTC)	ePAG rep (TBD)
Training and education	TBD	ePAG rep (TBD)
Funding and sustainability plan	TBD	ePAG rep (TBD)
Communication and Interaction with PAGs	TBD	Kathy Oliver (IBTA) and Isabelle Manneh-Vangramberen (ECPC)
Dissemination	TBD	Kathy Oliver (IBTA) and Isabelle Manneh-Vangramberen (ECPC)
Quality control	TBD	ePAG rep (TBD)

COORDINATION TEAM

Centre Léon Bérard – Lyon, France

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Administrative Affairs: Magali Bayssière
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What are ePAGs and what do they do for EURACAN?

European Patient Advisory Groups (ePAGs):

FORUM for dialogue, unity and solidarity to optimise involvement of patients

REPRESENTATIVENESS to engage with the application and governance of rare diseases ERNs

OPEN to member and non-member patient groups in the European Union

ALIGNED with rare disease ERN scope: 24 ePAGs to support all 24 ERN applications to optimise the patient voice in ERNs

COMPOSED OF ELECTED ePAG representatives and member organisations

DEMOCRATICALLY established where there is an ERN application and progressively expanded (a work in progress; to be fine-tuned)

ePAG REPRESENTATIVES' ROLES IN ERNs

Key roles (Governance)	Key objectives (Care)
<ul style="list-style-type: none">• Present and represent the patient voice, providing patient experience• Communicate and connect with our community	<ul style="list-style-type: none">• Ensure transparency in quality of care, safety standards, clinical outcomes and treatment options.• Promote a patient-centric approach in both delivery of clinical care, service improvement and strategic development and decision-making.
Key roles (Monitoring & Evaluation)	Key objectives (research)
<ul style="list-style-type: none">• Review effectiveness of network empowering patients, evaluate how network acts on feedback received	<ul style="list-style-type: none">• Contribute to the definition of research priority areas based on what is important to patients and their families.• Ensure that patients are embedded in the research activities performed within the ERN, including involvement in the assessment of clinical trials and in ethics committees.

THE EURORDIS MATCHMAKER INITIATIVE

An online tool, launched in September 2016 to connect patient organisations to ERNs

Aim of Matchmaker:

- **ENGAGE** patient organisations across the EU and beyond EURORDIS' membership to join an ERN
- **MATCH** patient organisations with ERNs according to their thematic groupings and across ERNs
- **CREATE** a network of patient organisations for each ERN eventually covering all rare diseases and Member States
- **MAP** patient organisations across the EU
- **CONNECT** ePAG representatives with ePAG member organisations and vice versa
- **FACILITATE** collaboration and discussions between ePAG representatives, ePAG member organisations and clinicians to ensure fair representation of the patient voice in ERNs

EUROPEAN REFERENCE NETWORKS

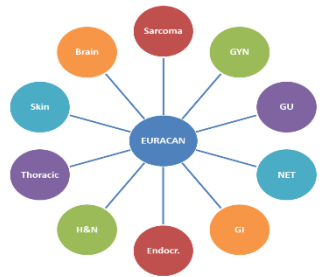
SHARE. CARE. CURE.

“Over the next five years, as the ERNs reach full capacity, thousands of EU patients suffering from a rare or complex condition can expect to benefit.” (EU leaflet on ERNs)

ec.europa.eu/health/ern



THANK YOU FOR LISTENING



EURACAN
European network for
Rare adult solid Cancer



EURORDIS
Rare Diseases Europe

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ePAGs:**

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