European Reference Networks

JY Blay
Rare cancers are not so rare: The rare cancer burden in Europe

Gemma Gatta a,*, Jan Maarten van der Zwan b, Paolo G. Casali c, Sabine Siesling b, Angelo Paolo Dei Tos d, Ian Kunkler e, Renée Otter b, Lisa Licitra f, Sandra Mallone g, Andrea Tavilla g, Annalisa Trama a, Riccardo Capocaccia g, The RARECARE working group

• 20% of all cancers

• 30% of deaths
Rare cancers are not so rare: The rare cancer burden in Europe

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Fig. 1 – Distribution of number of cancer types (1a) and annual number of diagnoses (1b) in EU27 according to categories of incidence rate.

Fig. 2 – RARECARE estimates of age-specific incidence rates for rare and common cancers in EU 27.
Since 2009 a network of 26 reference multidisciplinary centers aiming to improve the quality of care for sarcoma patients in France was granted by the French National Cancer Institute (Netsarc.org).

NETSARC is associated to a pathology review network (RREPS) and a bone sarcoma network (RESOS).

The outcome of the patients discussed in these 26 NETSARC multidisciplinary tumor board (NMTB) is presented.
Patients in MDT of NetSARC

Soft tissue

Visceral

Bone
The nationwide cohort of 26883 patients with sarcomas & connective tissue tumors treated in NETSARC reference network between 2010 and 2015 in France: major impact of multidisciplinary board presentation prior to first treatment

Jean-Yves Blay, Axel Le Cesne, Nicolas Penel, Emmanuelle Bompas, Florence Duffaud, Christine Chevreau, Maria Rios, Pierre Kerbrat, Didier Cupissol, Philippe Anract, Jean-Emmanuel Kurtz, Celeste Lebbe, Nicolas Isambert, Francois Bertucci, Antoine Thyss, Sophie Piperno-Neumann, Pascale Dubray-Longeras, Francoise Ducimetiere, Jean-Michel Coindre, Antoine Italiano;
Material and methods

- Data of the NetSarc network database include pts characteristics, previous treatment and diagnosis procedures, medical decision, survival and progression.
- Of all patients reviewed in NETSARC MDTB between 2010 and 2015.
- From Jan 2010 to Dec 2015, **20562 newly diagnosed patients** were included in this database, while **6321 patients** with an initial diagnosis prior to this date were included (total 26883).
- The NetSarc database includes pts characteristics, treatment and diagnosis procedures, survival and progression.
- Individual NETSARC centers managed a median of 678 (range 116-3801) pts in 5 yrs.
Patients (All)

• 13,845 women (52%) and 13,038 men (48%),
• Median age of 60y (range 0-103)
• Soft tissue, visceral, and bone tumors represented 17801 (66%), 4625 (17%), 4457 (17%) of pts respectively.
• 995 patients were aged under 18 at diagnosis in NETSARC database (3.7%); 738 (2.7%) age>=85, 130 (0.5%) aged>90
• N=227 different histological and molecular subtypes were documented.
• LMS, GIST, DDLPS and UPS were the most frequent histotypes.
Patients in the next slides

• All patients:
  – Sarcoma
  – Metastases at diagnosis
  – Diagnosis>2009
  – N=13598 patients with local treatment and F.Up
Previous question (ESMO 2016)

• Does presentation of the patient to a NetSARC MDT prior to treatment impact on management and prognosis?
Results

MDT before treatment

• Overall 37% were presented to a Netsarc multidisciplinary board (NMTB) prior to initial treatment

• Between 2010 and 2015, the proportion of pts reviewed in Netsarc MDT prior to surgery increased from 30,3% to 41,6% .
Results (2)

Worse clinical presentation when MDT before treatment

- Metastases at diagnosis 16% vs 10% $p<0.0001$
- Larger tumors: median size 104 vs 91mm $p<0.0001$
- More deep seated: 85.7% vs 76.3% $p<0.0001$
- Higher grade: G1 15.8% vs 12.0%, $p<0.0001$

Also: younger age, more male patients, less visceral sarcomas
Results (3)
Better management when MDT before treatment

• A higher number of pts presented in Netsarc MDTB had
  – Adequate imaging of the tumor before treatment/surgery (87.9% vs 67.8%, \(p<0.0001\))
  – Biopsy prior the first resection (87.0% vs 55.0%, \(p<0.0001\)).
Better adhesion to CPGs when MDT before treatment

- **Primary surgery** performed before vs after presentation to a Netsarc MDT: R0, R1, R2, and R (unk or NE) surgery in:
  - 53.0%, 26.8%, 9.1%, 11.0% (MDT before) vs
  - 34.2%, 32.7%, 17.6%, 15.5% (MDT after) \(p<0.0001\).

- 1125 (15.3%) pts had **secondary resection** after primary surgery performed without previous NetSarc MDT vs 99 (5.5%) in NetSARC centers \(p<0.0001\).

- **Final surgery:**
  R0, R1, R2, and R (unk or NE) surgery in:
  - 57.9%, 25.8%, 6.5%, 9.8% (MDT before) vs
  - 48.8%, 26.9%, 10.6%, 13.7% (MDT after) \(p<0.0001\).
Quality of initial surgery, incident patients (STS & visceral sarcomas operated)

2011 N=724
2012 N=824
2013 N=791
2014 N=888
2015 N=668

2011 N=712
2012 N=806
2013 N=941
2014 N=923
2015 N=670

Outside
NetSarc

R0
R1
R2

Non evaluable
Unknown

ASCO16
Results (5)

Better LRFS when MDT before treatment

Median follow-up 26 months
Better overall and progression free survival after surgery in expert sites for sarcoma patients: a nationwide study of FSG-GETO/NETSARC


Universite Claude Bernard & Centre Léon Bérard, Lyon, France; Gustave Roussy Cancer Campus, Villejuif, France; Centre Oscar Lambret, Lille, France; Department of Medical Oncology, Centre René Gauducheau, Nantes St. Herblain, France; La Timone University Hospital, Marseilles, France; Institut Claudius Regaud, Toulouse, France; Centre Alexis Vautrin, Vandoeuvre-lès-Nancy, France; Medical Oncology Eugene Marquis Comprehensive Cancer Center, Rennes, France; Centre Val d’Aurelle, Montpellier, France; Hopital Cochin Saint Vincent de Paul, Paris, France; Hôpitaux Universitaires de Strasbourg, Strasbourg, France; Dermatology Department, Saint Louis Hospital, Paris, France; Centre Georges François Leclerc, Dijon, France; Institut Paoli Calmettes, Marseille, France; Centre Antoine-Lacassagne, Nice, France; Institut Curie, Paris, France; Centre Jean Perrin/ERTiCa EA 4677, Clermont-Ferrand, France; Centre Léon Bérard, Lyon, France; Institut Bergonié, Department of Pathology, Bordeaux, France; Institut Bergonié, Department of Medical Oncology, Bordeaux, France
Present question (ESMO 2017)

- Does primary surgery the patient within a NetSARC center impacts survival?
Results (4)
Surgery in a Netsarc Center

• **Primary surgery** performed before vs after presentation to a Netsarc MDT:
  R0, R1, R2, and R (unk or NE) surgery in:
  • 49.9%, 28.6%, 6.3%, 14.6% (NETSARC site) vs
  • 25.3%, 32.4%, 21.0%, 21.3% (outside a NETSARC site) (p<0.0001).

• 760 (21.2%) pts had **secondary resection** after primary surgery performed outside NetSarc site vs 221 (6.3%) inside NetSARC centers (p<0.0001).
  • Unknown in 508 [14.2%] vs 288 [8.2%] patients in non NETSARC/vs NETSARC centers

• **Final surgery:**
  R0, R1, R2, and R (unk or NE) surgery in:
  • 55.3%, 25.3%, 4.2%, 15.3% (NETSARC site) vs
  • 42.8%, 24.3%, 11.6%, 21.3% (outside a NETSARC site) (p<0.0001).
Results (5)

LRFS but not MFS nor OS is better in Netsarc centers

Median follow-up 30 months
## Multivariate analysis for RFS

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Multivariate analysis for OS

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Retroperitoneal sarcomas
ERNs are virtual networks involving healthcare providers across Europe to enable the sharing of expertise and to improve access to care for patients across the European Union, especially for complex or rare medical diseases that require highly specialised healthcare and a concentration of knowledge and ressources.
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.

24 Networks
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.
<table>
<thead>
<tr>
<th>Abbr.</th>
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<tr>
<td>Endo-ERN</td>
<td>European Reference Network on endocrine conditions</td>
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<td>European Reference Network on kidney diseases</td>
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<td>ERN BOND</td>
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<td>European Reference Network on craniofacial anomalies and ENT disorders</td>
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<td>European Reference Network on epilepsies</td>
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<td>ERN EURACAN</td>
<td>European Reference Network on adult cancers (solid tumours)</td>
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<td>ERN EuroBloodNet</td>
<td>European Reference Network on haematological diseases</td>
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<td>European Reference Network on urogenital diseases and conditions</td>
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<td>ERN GUARD-HEART</td>
<td>European Reference Network on diseases of the heart</td>
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<td>ERNICA</td>
<td>European Reference Network on inherited and congenital anomalies</td>
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<td>European Reference Network on congenital malformations and rare intellectual disability</td>
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<td>MetabERN</td>
<td>European Reference Network on hereditary metabolic disorders</td>
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<tr>
<td>VASCERN</td>
<td>European Reference Network on multisystemic vascular diseases</td>
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How ERN are approved

**Key criteria**

- Patient-centred and clinically led
- 10 members in at least 8 countries
- Strong independent assessment
- Fulfilment of Network and Member criteria
- Endorsement and approval by national authorities.
JARC
JARC: Objectives

With regard to RCs in the EU, to improve:
1. Epidemiological surveillance
2. Quality of care through ERNs
3. Clinical practice guidelines
4. Innovation
5. Medical and Patient education
6. Health policy measures
7. Patient empowerment
ERN on paediatric cancer (haematopoietic oncology) (ERN PaedCan)

Paediatric cancer is rare and comes in multiple subtypes. With 20,000 children newly diagnosed with cancer across Europe and 6,000 paediatric cancer patients dying each year, it remains the leading cause of death from disease for children older than 1 year of age.

Average survival rates have improved in recent decades; for some conditions the progress has been dramatic, while for others the outcomes remain very poor. Significant inequalities in survival rates are also a challenge in Europe, with worse outcomes in Eastern Europe.

ERN PaedCan is working to improve access to high-quality healthcare for children with cancer whose conditions require specialist expertise and tools not widely available due to low case volumes and a lack of resources. It builds on previous EU-funded projects ENCCA, PanCare, and ExPOrRNet. ERN PaedCan is building a roadmap of specialist centres to help improve their visibility to healthcare providers and patients. A paediatric oncology tumour board network will be implemented using IT tools to share expertise and advice.

The network aims to increase childhood cancer survival and quality of life by fostering cooperation, research, and training, with the ultimate goal of reducing current inequalities in childhood cancer survival and healthcare capabilities in EU Member States.

NETWORK COORDINATOR
Professor Ruth Ladenstein
St. Anna Kinderspital & St. Anna Kinderkrebsforschung, Austria
ERN on genetic tumour risk syndromes (ERN GENTURIS)

Genetic tumour risk syndromes are disorders in which inherited genetic mutations strongly predispose individuals to the development of tumours. The lifetime risk of cancer can be as high as 100%. While there is considerable diversity in the organ systems that may be affected, individuals affected by these conditions share similar challenges: delay in diagnosis, lack of prevention for patients and healthy relatives, and therapeutic mismanagement. At present, only 20-30% of people with genetic tumour risk syndromes have been diagnosed.

ERN GENTURIS is working to improve identification of these syndromes, minimise variation in clinical outcomes, design and implement guidelines, develop registries and biobanks, support research, and empower patients. The network will educate the public and healthcare professionals, and foster the sharing of best practice across Europe. Access to multidisciplinary care will be improved, with new models and standards for sharing and discussing complex cases. The network is enhancing the quality and interpretation of genetic testing, and increasing patient participation in clinical research programmes.

ERN GENTURIS will cooperate with other ERNs to improve the care of patients with genetic tumour risk syndromes who develop conditions that fall within the expertise of another network.

NETWORK COORDINATOR
Prof. Nicole Hoogerbrugge
Radboud University Medical Center Nijmegen, The Netherlands
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.

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.

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

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
ERN EuraCAN

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 (CtCAnet), as well as several EU research projects.

NETWORK COORDINATOR

Professor Jean-Yves Blay
Centre Léon Bérard, Lyon, France
European Reference Network
for rare or low prevalence complex diseases

Network
Adult Cancers
(ERN EURACAN)

EURACAN

RARE SOLID ADULT CANCERS

CDDF 2018
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).
ERN EURACAN

10 domains

EURACAN

G1 Sarcoma
G2 Rare GYN
G3 GU
G4 NET
G5 Digestive tract
G6 Endocrine
G7 Head and neck
G8 Thoracic
G9 Skin & eye melanoma
G10 Brain

Network
Adult Cancers (ERN EURACAN)

Coordinator
Centre Léon Bérard — France

17 European countries

RARE ADULT SOLID CANCERS
DISTRIBUTION OF MEMBERS BY COUNTRY

COUNTRIES/Towns

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)
IRELAND (Dublin)
ITALY (Aviano, Bologna, Candiolo, Firenze, Genoa, Meldola, Milan, Naples, Rome, Siena, Torino, Treviso)
LITHUANIA (Kaunas)
NETHERLANDS (Amsterdam, Leiden, Maastricht, Nijmegen, Rotterdam, Gronigen)
NORWAY (Oslo)
POLAND (Warsaw)
Portugal (Coimbra, Lisboa, Porto)
SPAIN (Sevilla, Barcelona)
SWEDEN (Karolinska, Uppsala)
SLOVENIA (Ljubljana)
UNITED KINGDOM (Coventry, London, Oxford, Sheffield)
STRENGTHS

- A merger of pre existing expert Networks in the last 10-20 years
- 7 Transversal Task Forces (guidelines, research, training, funding, communication with PAGS, dissemination, quality control and diagnosis)
- A Large coverage
  - 66 Health Care Providers in 17 European countries
  - Associate Partners key in the fields (OECI, EORTC, ESMO, OECI...)
  - Patient Advocacy Groups (PAGs)

- Demonstrated capacity to organize international Multidisciplinary Tumours Boards (MTBs)
- Existing nationwide registries to describe patient management at the national level
- Clinical and basic Research: solid track records
- Development of molecular medicine in rare cancers
OBJECTIVES at 5 years

_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.
SPECIFIC OBJECTIVES

- RAC referral network applying EURACAN standards
- **Develop**, widely spread and implement CPGs
- "roadmaps" for referral and self-referral of patient to expert centers
- develop **communication and educational tools** for both patients and physicians

- Boost RAC R&I capacities
- Enhance collaborative instrumental efforts
- Efficient **sharing and implementation** of EURACAN standards and guidelines in all RAC domains
- Set **multinational databases and tumour banks** for rare tumours, coupled with research projects
SPECIFIC OBJECTIVES

• Define a clear **communication and dissemination strategy** targeting all MS countries with the active support from affiliated and associated members

• Develop a **web-based communication platform**

• Organize dissemination/communication campaigns with

• Perform **training courses** in all languages targeting healthcare providers

• Assessing the **impact of EURACAN** actions on patient health, quality of life, and health care expenditures

• Implement an **efficient governance structure** and associated procedures with an exhaustive representations of all relevant communities

• Develop a **sustainability strategy** including the creation of a legal entity to pursue EURACAN mission beyond the 5-year funding period

• Develop tools to control and demonstrate the **socio-economic and healthcare added-values 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.
**EURACAN General Assembly**
Board of all HCP members and associate/affiliate partners

- Decisions for key questions

**Steering Committee**
- Coordinator
- 10 Group leaders
- +1 representative/country not already represented
- 7 task force leaders
- Patient Advocacy groups

- Decisions for daily management

**Domains** (Clinical action)

**Transversal Task Forces**

- **Scientific Advisory Board**
  - 6 independent experts
  - Outside / inside EU
  - Rare/frequent cancer/diseases

- **Transversal Task Forces**

- **Guidelines**
- **Research**
- **Training/Education**
- **Funding/sustainability plan**
- **Communication/Interaction with PAGs**
- **Dissemination**
- **Quality control**
- **Diagnosis**

**Groups**

- G1 Sarcoma
- G2 Rare GYN
- G3 Rare GU
- G4 NET
- G5 Rare GI
- G6 Endocrine
- G7 Rare H&N
- G8 Rare Thoracic
- G9 Rare Skin
- G10 Rare Brain

**Leaders and Secretaries**

- Leader
- Secret.
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<tr>
<th>Domain</th>
<th>Leader Name</th>
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<td>CASALI Paolo</td>
<td>Istituto Nazionale dei Tumori, Milan, Italy</td>
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<td>SECKL Michael</td>
<td>Imperial College London, United Kingdom</td>
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<td>GIETEMA Jourik</td>
<td>University Medical Center Groningen, The Netherlands</td>
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<td>G4 NET</td>
<td>CAPLIN Martyn</td>
<td>Royal Free London NHS Trust, United Kingdom</td>
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<td>G5 GI</td>
<td>WYRWICZ Lucjan</td>
<td>M Sklodowska-Curie Memorial Cancer Center, Warsaw, Poland</td>
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<td>BAUDIN Eric</td>
<td>Gustave Roussy- Villejuif, France</td>
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<td>LICITRA Lisa</td>
<td>Istituto Nazionale dei Tumori, Milan, Italy</td>
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<td>G8 Rare Thoracic</td>
<td>GIRARD Nicolas</td>
<td>Institut Curie, Paris, France</td>
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<td>G9 Rare Skin/Eye melanoma</td>
<td>SCHADENDORF Dirk</td>
<td>University Hospital Essen, Germany</td>
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<td>G10 Brain tumours</td>
<td>VAN DEN BENT</td>
<td>Eramus MC, Rotterdam, The Netherlands</td>
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<td></td>
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# Transversal Task Forces Leaders

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<tr>
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<td>Research</td>
<td>Stéphane Lejeune</td>
<td>EORTC</td>
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<td>Paolo Casali</td>
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<td>Oxford University</td>
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<td>Communication &amp; interaction with PAGs</td>
<td>Kathy Oliver</td>
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<td>Dissemination</td>
<td>Isabelle Manneh Vangrambeeen</td>
<td>ECPC</td>
</tr>
<tr>
<td>Quality control</td>
<td>Josef Lovey</td>
<td>OECI</td>
</tr>
<tr>
<td>Diagnostic</td>
<td>Paolo Dei Tos</td>
<td>Azienda ULSS2</td>
</tr>
</tbody>
</table>
THRESHOLDS
### Thresholds Definitions for the Calculation of Thresholds

**Minimum number of patients / year** = patients seen in the centre whatever the reason, consulting or treated = new opening files.

**Number of new patients / year** = new files + discussed in a MDT.

**Number of procedures / year** = number of discussions in MDT (if one patient is discussed 2 times in the year, it will count 2 times).

<table>
<thead>
<tr>
<th>Rare or Complex Disease(s), Condition(s) or Highly Specialised Intervention(s)</th>
<th>Minimum Number of Patients (Visited, Treated or Followed) Per Year</th>
<th>Number of New Patients Per Year</th>
<th>Number of Procedures Per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1: Sarcoma of the soft tissue, bone and visceralae</td>
<td>240</td>
<td>100</td>
<td>180</td>
</tr>
<tr>
<td>G2: Rare neoplasm of the female genital organs and placentas</td>
<td>140</td>
<td>50</td>
<td>140</td>
</tr>
<tr>
<td>G3: Rare neoplasms of the male genital organs, and of the urinary tract.</td>
<td>100</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td>G4: Neuroendocrine tumors.</td>
<td>250</td>
<td>80</td>
<td>150</td>
</tr>
<tr>
<td>G5: Rare neoplasm of the digestive tract</td>
<td>130</td>
<td>48</td>
<td>130</td>
</tr>
<tr>
<td>G6: Rare neoplasm of endocrine organs</td>
<td>50</td>
<td>20</td>
<td>100</td>
</tr>
<tr>
<td>G7: Rare neoplasm of the head and neck: Salivary gland tumors, nasopharyngeal cancer nasal and sinonasal cancers, middle ear</td>
<td>200</td>
<td>100</td>
<td>150</td>
</tr>
<tr>
<td>G8: Rare neoplasm of the thorax: Thymoma, mediastinum and pleura</td>
<td>75</td>
<td>30</td>
<td>75</td>
</tr>
<tr>
<td>G9: Rare neoplasm of the skin and eye</td>
<td>90</td>
<td>45</td>
<td>90</td>
</tr>
<tr>
<td>G10: Rare neoplasm of the brain, spinal cords</td>
<td>250</td>
<td>100</td>
<td>250</td>
</tr>
<tr>
<td>G1.1. Bone sarcoma</td>
<td>40</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>G1.2. Soft tissue and visceral sarcoma</td>
<td>200</td>
<td>80</td>
<td>150</td>
</tr>
</tbody>
</table>
IV. KNOWLEDGE AND EXPERTISE FOR THE NETWORK AND HEALTHCARE PROVIDER APPLICANTS

8a. Please state the activity (minimum thresholds) that Healthcare Providers within the Network will need to meet to maintain competence and expertise, as applicable.

<table>
<thead>
<tr>
<th>Rare or Complex Disease(s), Condition(s) or Highly Specialised Intervention(s)</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Minimum Number of Patients (Visited, Treated or Followed) Per Year</td>
</tr>
<tr>
<td>G2.1. GTD</td>
<td>60</td>
</tr>
<tr>
<td>G2.2. Rare ovarian tumors</td>
<td>80</td>
</tr>
<tr>
<td>G3.1. Testicular cancer</td>
<td>60</td>
</tr>
<tr>
<td>G5.1 Peritoneal tumors</td>
<td>20</td>
</tr>
<tr>
<td>G5.2. Biliary tract cancer</td>
<td>70</td>
</tr>
<tr>
<td>G5.3. Anal cancer</td>
<td>40</td>
</tr>
<tr>
<td>G8.1: Thymoma and thymic carcinoma</td>
<td>60</td>
</tr>
<tr>
<td>G8.2. Mesothelioma</td>
<td>50</td>
</tr>
<tr>
<td>G9.1. Ocular melanoma</td>
<td>60</td>
</tr>
<tr>
<td>G9.2. Rare skin cancers (MCC, Adnexal...)</td>
<td>30</td>
</tr>
<tr>
<td>G6.1: Refractory thyroid cancer</td>
<td>35</td>
</tr>
<tr>
<td>G6.2. Adrenal cancer</td>
<td>15</td>
</tr>
</tbody>
</table>
AREAS OF EXPERTISE
<table>
<thead>
<tr>
<th>Main Thematic Group</th>
<th>Related Rare Or Complex Disease(s), Condition(s)</th>
<th>Related Code / ICD / Orphacode Group of Codes*</th>
<th>Prevalence**</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1: Rare neoplasm of connective tissue</td>
<td>G1: Sarcoma of the soft tissue, bone and viscera</td>
<td>C46-C49, C40-C41</td>
<td>from 9 to 47/100000/year</td>
</tr>
<tr>
<td>G2: Rare neoplasm of the female genital organs and placenta</td>
<td>G2: Trophoblastic disease, Rare malignant gynecological cancer</td>
<td>C51-C58</td>
<td>0.86 to 15/100000</td>
</tr>
<tr>
<td>G3: Rare neoplasms of the male genital organs, and of the urinary tract</td>
<td>G3: Testis and annexes, extragonadal germ cell tumors</td>
<td>C62, C60, C61, C64-C68</td>
<td>3.4 to 87.7/100000</td>
</tr>
<tr>
<td>G4: Rare neoplasm of the neuroendocrine system</td>
<td>G4: Neuroendocrine tumors</td>
<td>C17, C25.4</td>
<td>20/100000</td>
</tr>
<tr>
<td>G5: Rare neoplasm if the digestive tract</td>
<td>G5: Biliary tract, peritoneal cancer, &amp; mesothelioma and anal carcinoma</td>
<td>C21-C24</td>
<td>2.86 to 8.16/100000</td>
</tr>
<tr>
<td>G6: Rare neoplasm of endocrine organs</td>
<td>G6: Thyroid and adrenal cancers</td>
<td>D35, C73-C75</td>
<td>1 to 62/100000</td>
</tr>
<tr>
<td>G7: Rare neoplasm of the head and neck</td>
<td>G7: Salivary gland tumors - nasopharyngeal cancer; nasal and sinonosal cancers</td>
<td>C07, C08, C11, C30.0, C31, (salivary gland type tumors of C00-C06, C09-C14, C30.0, C31, C32)</td>
<td>0.2 to 13/100000</td>
</tr>
<tr>
<td>G8: Rare neoplasm of the thorax</td>
<td>G8: Thymoma, mediastinum and pleura, pleural mesothelioma</td>
<td>C37-C38, C45</td>
<td>1.4 to 3/100000</td>
</tr>
<tr>
<td>G9: Rare neoplasm of the skin and eye melanoma</td>
<td>G9: Rare skin cancers and eyes melanoma</td>
<td>C44, C69</td>
<td>2.7 to 6/100000</td>
</tr>
<tr>
<td>G10: Rare neoplasm of the brain, spinal cords</td>
<td>G10: Glial and non glial tumors</td>
<td>C69-C72</td>
<td>1 to 26/100000</td>
</tr>
</tbody>
</table>
FIRST YEAR
1st March 2017 – 28th February 2018

PROGRESS TOWARDS OBJECTIVES
**TO STRUCTURE THE ERN**

- **Designated representatives** in the various Network bodies
- **Operational meetings**: monthly Steering Committee meetings
- **Signed Terms of Reference**

**TO PROMOTE EURACAN INITIATIVE**

- **Secured Intranet: ERN Collaborative Platform (ECP)**. This tool is essential for the wide dissemination of information amongst members and Associate partners and to secure international communication between them. Members can publish (Library), discuss (Forum), Schedule (agenda), Vote (Poll) and endorse (Like).

- **Website**: [http://euracan.ern-net.eu/](http://euracan.ern-net.eu/) It is a public-facing website for our ERN to publish content to promote our activities and share background information with partners, patients, media and other stakeholders. Development: the webpage is online and we will carry on populating it gradually. The website is available in 10 Member State languages

- Facebook: [https://www.facebook.com/EURACAN/](https://www.facebook.com/EURACAN/)

- Twitter: [https://twitter.com/ERN_EURACAN](https://twitter.com/ERN_EURACAN)
**TO SHARE AND PROMOTE HEALTHCARE BEST PRACTICE**

- **Clinical Practice Guidelines** are being produced or updated by each domain. Prof Hohenberger has been gathering information on all guidelines available in each country through the lead of the TTF guidelines and the WP6 of the JARC.

- **Informative material** developed or updated for general practitioners and researchers: ongoing.

- **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/](https://cpms.ern-net.eu/login/)

- In the framework of EURACAN and the JARC, the ESO implemented new e-sessions on rare cancers made available: [http://www.e-eso.net/pages.do?methodcall=view&id=2](http://www.e-eso.net/pages.do?methodcall=view&id=2)
  
  - 2nd ESO-ESMO-RCE clinical update on Rare Adult Solid Cancers **2-4 December 2017 Milan, Italy**
  
  - *University post-graduate course* clinical oncology
    - **Head & Neck cancers** 5-9 February 2018 Milan, Italy
    - **Sarcoma** 22-26 January 2018 Milan, Italy
**TO IMPLEMENT THE FUNDING: SUSTAINABILITY APPROACH**

- **Evaluation of the collaboration with the EIT health Rare Cancer Project.** Linkage has been established co-funding agreed for the 2nd EURACAN annual meeting to be held in Oxford on April 4-5-6, 2018.

- **Potential Collaboration with CancerAID application, Australia.** Cost effective input of EIT health funding into the adoption of a free patient App for connectivity in EURACAN. Telconferences and ongoing to scope the application. We see this as a key branding and sustainability issue, and is a deliverable aimed for the next quarter.
SECOND YEAR
1st March 2018– 28th February 2019

ACTIVITIES RELATED TO EACH OBJECTIVE
TO STRENGTHEN AND WIDEN THE STRUCTURE AND QUALITY CONTROL SYSTEM OF THE ERN

- Improving quality control, developing scorecards, questionnaires, quality procedures, piloting and reporting tools

TO SHARE, PROMOTE AND HARMONIZE HEALTHCARE BEST PRACTICES

- Harmonized CPGs: to pursue the work initiated in year 1
- Implementation of WHO classifications: diagnosis TTF
  - implementing all domain trainings
- Referencing EURACAN databases, resources, registries
TO PROMOTE EURACAN INITIATIVE

Communication tools: Facebook, Twitter, EURACAN leaflet, domain leaflet, newsletter, slide library, translation of communication supports.

TO STIMULATE RESEARCH ON RAC, IMPROVE RAC PATIENT DIAGNOSIS AND SUPPORT ERN SUSTAINABILITY

- Development of Third party collaborations to support sustainability
- Inventory and coordination of research funding activities
EURACAN

RARE SOLID ADULT CANCERS

CDDF 2018
COORDINATION TEAM
Centre Léon Bérard – Lyon, France

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