Rare cancers
Medical oncologist Point of View

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Identified factors to explain medical practices

- Initial Medical school education
- **Scientific data**
- Continuous medical education
- Pharma industries
- Financial incitation's & Private or public system
- Organized networks?
Medical decision – for rare cancers?

- Characteristics disease’s & prognostic factors for survival
- Social and cultural values:
  - Practicians uses
  - Patient preferences
- Organisational context:
  - Management care access
  - Economical context
  - Referent centers

Evidence based Medicine

Not Done!
Specific background for rare cancers

- Few knowledge
- No financial supports
- No interests from Agencies & Pharma
- No improvements for survival over time
- No evidence based Medicine & CPG’s
- No clinical trials
- No innovations
- No financial supports
## Incidence & prevalence by sites

### Table 3. Incidence and prevalence of rare and common cancers by site in EU27

<table>
<thead>
<tr>
<th></th>
<th>Incidence rate per 100,000</th>
<th>Standard error</th>
<th>Estimated incident cases in EU27</th>
<th>Incidence distribution (%)</th>
<th>Prevalence per 100,000</th>
<th>Standard error</th>
<th>Estimated prevalent cases in EU27</th>
<th>Prevalence distribution (%)</th>
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<tr>
<td><strong>Common</strong></td>
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<td>380 565</td>
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<td>86 143</td>
<td>15</td>
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<td>21</td>
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<td>0,4</td>
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<td>46</td>
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<td>2</td>
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<td>55</td>
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<td>881 107</td>
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<tr>
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<td>0,1</td>
<td>147 597</td>
<td>100</td>
<td>331,7</td>
<td>1,1</td>
<td>1 658 589</td>
<td>100</td>
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<td>78</td>
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<td>1,4</td>
<td>1 397 655</td>
<td>70</td>
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<td>0,8</td>
<td>465 225</td>
<td>23</td>
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<tr>
<td>All</td>
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<td>1,6</td>
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<td>0,8</td>
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<td>48 077</td>
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<td>62,5</td>
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<tr>
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<td>3565,4</td>
<td>7,2</td>
<td>17 826 767</td>
<td>100</td>
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</table>

Gatta G, Eur J Cancer 2011
• Rare Gynecologic cancers = same problematic than all other rare cancers:
  – Absence of knowledge, curability, few therapeutic options, no very few dedicated clinical trials....
  – Organization of care pathway at all levels
    • Regional, national European & international
The French National Network dedicated to Rare gynecologic Malignant Tumors

National Network including
3 national + 22 regional expert centers

- **Objectives**
  - **Management**: medical strategy decided in dedicated regional multidisciplinary tumor boards
  - **Diagnosis:**
    - systematic second review
    - molecular diagnosis for all patients (ex: FOXL2, SMARCA4...).
  - **Education:**
    - workshops & continuing medical education.
    - information for patients, families and advocacy groups.
    - To elaborate CPG’s
Dedicated website - http://www.ovaire-rare.org

Observatoire des Tumeurs Malignes Rares Gynécologiques
LE SITE DES CENTRES EXPERTS

Les tumeurs malignes rares gynécologiques (TMRG) sont un ensemble de tumeurs qui surviennent en majorité chez des jeunes femmes. Leur prise en charge est très différente de celle des tumeurs gynécologiques habituelles. Une problématique importante dans ces tumeurs est souvent la conservation de la fertilité.

Pour en savoir +

La prise en charge thérapeutique est aujourd'hui facilitée en France par l'existence des Centres Experts Nationaux et Régionaux.

Pour en savoir +

Informations sur les Tumeurs Malignes Rares Gynécologiques et accès aux référentiels →

Réservé aux membres

→ Demande d'avis au Centre Expert

Relecture histologique diagnostique

effet de proposition de prise en charge par une réunion de concertation pluridisciplinaire spécialisée.

→ Études cliniques en cours sur les tumeurs malignes rares gynécologiques

→ Présentations et documents à télécharger
## Observatoire des Tumeurs Malignes Rares Gynécologiques
LE SITE DES CENTRES EXPERTS

### Nouvelle patiente
Nouvel avis de RCP pour une patiente existante

<table>
<thead>
<tr>
<th>Pat. N°</th>
<th>Init.</th>
<th>Date de naissance</th>
<th>Date Inclus.</th>
<th>Médécin</th>
<th>Type d'histologie</th>
<th>Relecture lame</th>
<th>Etat de la RCP</th>
<th>Cons. bio.</th>
<th>Dernières nouvelles</th>
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<td>11/01/2011</td>
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<td>BW</td>
<td>10/02/1973</td>
<td>29/10/2010</td>
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<td>27/10/2010</td>
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<td>Non demandé</td>
<td></td>
<td>x petite</td>
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<td>PL</td>
<td>25/05/1989</td>
<td>12/10/2010</td>
<td>CA</td>
<td>Tumeur à cellules de Sertoli-Leydig</td>
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<td>Non demandé</td>
<td></td>
<td>x petite</td>
</tr>
<tr>
<td>0268</td>
<td>CA</td>
<td>13/03/1946</td>
<td>20/09/2010</td>
<td>CA</td>
<td>Tumeurs des cordons sexuels</td>
<td>Non demandé</td>
<td>Non demandé</td>
<td></td>
<td>en v.</td>
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<tr>
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<td>MM</td>
<td>01/04/1950</td>
<td>20/09/2010</td>
<td>CA</td>
<td>Tumeur de la granulosa forme adulte</td>
<td>Non demandé</td>
<td>Non demandé</td>
<td></td>
<td>en v.</td>
</tr>
<tr>
<td>0196</td>
<td>RV</td>
<td>30/10/1934</td>
<td>20/07/2010</td>
<td>CA</td>
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<td>Non demandé</td>
<td>Non demandé</td>
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<td>en v.</td>
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<td>Non demandé</td>
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<td>en v.</td>
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ESMO PRECEPTORSHIP PROGRAM
Isabelle Ray-Coquard
Decision-making algorithms are available on website for 8 types of tumors

- Stromal and sex-cord T
- Germ-cell T
- Serous & mucinous borderline
- Clear-cell adenocarcinoma
- Mucinous adenocarcinoma
- Low grade serous carcinoma
- Small cell carcinoma
- Carcinosarcoma
1st French Patient Advocacy group

IMAGYN

Support

Awareness

Information

Share and help

Clinical Research

IMAGYN

Published in the Official Journal of 31st May 2014

www.monimagyn.org
Yearly new cases of rare ovarian tumors

<table>
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<tr>
<th>Ovarian Tumor types</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>Cumulated</th>
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<td>202</td>
<td>191</td>
<td>235</td>
<td>216</td>
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<td>93</td>
<td>102</td>
<td>113</td>
<td>125</td>
<td>127</td>
<td>655</td>
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<td>Small cell carcinoma</td>
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<td>8</td>
<td>8</td>
<td>12</td>
<td>7</td>
<td>12</td>
<td>53</td>
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<td>50</td>
<td>42</td>
<td>36</td>
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<td>Low-grade serous carcinoma</td>
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<td>13</td>
<td>14</td>
<td>36</td>
<td>70</td>
<td>85</td>
<td>220</td>
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<td>Clear cell carcinoma</td>
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<td>83</td>
<td>105</td>
<td>123</td>
<td>100</td>
<td>530</td>
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<td>117</td>
<td>109</td>
<td>125</td>
<td>135</td>
<td>610</td>
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<td>472</td>
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<td>5</td>
<td>6</td>
<td>9</td>
<td>13</td>
<td>45</td>
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<td>84</td>
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<td>Total Ovary</td>
<td>553</td>
<td>714</td>
<td>951</td>
<td>1192</td>
<td>1202</td>
<td>1331</td>
<td>5943</td>
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Yearly progression of clinical and diagnosis review

- Multidisciplinary staff meeting
- Multidisciplinary staff meeting with expert pathologic review
- Expert diagnosis review
Expert diagnosis review inducing medical decision change

<table>
<thead>
<tr>
<th>Year</th>
<th>#Yearly new cases</th>
<th># Cases diagnosed by pathologist referees</th>
<th># Cases benefiting from both local and central review</th>
<th># Minor diagnosis discrepancy</th>
<th># Cases for which diagnosis modified therapeutic strategy</th>
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<tr>
<td>2011</td>
<td>553</td>
<td>425</td>
<td>359</td>
<td>28</td>
<td>17 (17/359) (5%)</td>
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<tr>
<td>2012</td>
<td>714</td>
<td>607</td>
<td>355</td>
<td>52</td>
<td>28 (28/355) (8%)</td>
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<tr>
<td>2013</td>
<td>951</td>
<td>810</td>
<td>445</td>
<td>93</td>
<td>40 (40/445) (9%)</td>
</tr>
<tr>
<td>2014</td>
<td>1192</td>
<td>994</td>
<td>658</td>
<td>155</td>
<td>61 (61/658) (9%)</td>
</tr>
<tr>
<td>Total</td>
<td>3410</td>
<td>2383</td>
<td>1817</td>
<td>328 (18%)</td>
<td>146 (146/1817) (8%)</td>
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National network and clinical research: an example

Avastin and weekly paclitaxel use in sEx cord-stromal ovariaN tumORs

A randomized, open label, phase II trial of bevacizumab plus weekly paclitaxel followed by maintenance with bevacizumab monotherapy versus weekly paclitaxel followed by observation in patients with relapsed ovarian sex-cord stromal tumors
International Collaboration

ALIENOR trial: A randomized, open label, phase II trial of bevacizumab plus weekly paclitaxel followed by maintenance with bevacizumab monotherapy versus weekly paclitaxel followed by observation in patients with relapsed ovarian sex-cord stromal tumors.

**Randomization:**
- **Arm A:** Paclitaxel 80mg/m² IV, q3W, J8 + J15 every 4 weeks + Bevacizumab 10mg/kg IV, q3W, J4, J11 and J18
- **Arm B:** Observation + Paclitaxel 80mg/m² IV, q3W, J8 + J15 every 4 weeks

**Standard treatment:**
- Bevacizumab 15mg/kg every 2 weeks

**PD:** At the discretion of the investigator

**Sites:**
- Germany: AGO 4
- Belgium: BGOG 2
- France: GINECO 18
- Japon: GOTIC 1
- Italy: MITO 3

**Randomised Patients:**
- France: 10
- Germany: 10
- Italy: 38

ALIENOR - GCIG June 1st 2017
Clinical trials in Germ cell tumours

Novartis: ribociclib, CDK4/6 inh (pRb & cell cycle)

Background: CDK4 & CyclinD2 upregulated GCT

Randomized phase II with LEE011 for patients with immature teratoma in relapse after standard CT

Closed due to low recruitment!
Sarcoma – research program

- Epidemiology not well known (incidence, risk factors)
- Retrospective study on medical practices:
  
  32% management conformed with CPG’s (Ray-Coquard, Ann Oncol 04)

→ problems for diagnosis, management, clinical trials

Dedicated research program for sarcoma tumours
Since 2005 – Prospective - Rhône-Alpes Region

Incidence study → Exhaustive cohort of sarcoma in a specific region

Concordance study for histological diagnosis between initial and second opinion

Medical practice evaluation for STS study

Economical study of sarcoma management costs
Original article

Conformity to clinical practice guidelines, multidisciplinary management and outcome of treatment for soft tissue sarcomas

I. Ray-Coquard¹-³, P. Thiesse¹, D. Ranchère-Vince¹, F. Chauvin¹,², J.-Y. Bobin⁴, M.-P. Sunyach¹, J.-P. Carret⁴, B. Mongodin⁵, P. Marec-Bérard¹, T. Philip¹,²,⁶ & J.-Y. Blay¹,⁴
Overall survival and Conformity of Surgery

Surgical conformity and PFS for STS patients

**Median PFS**
- Conformed surgery: NR
- Non conformed surgery: 45.2

**HR:** conformed vs non conformed: 0.44
**IC 95%:** [0.32, 0.59]
**p ≤0.0001**

- **Adherent to CPG’s**
- **Not adherent to CPG’s**

- **Probability of survival**
- **University / conformed surgery**
- **Private + general S-**
  - **p=0.006**

**Faculté de Médecine Lyon Est**
Dedicated national network for rare cancers Sarcoma - 2010 - 2017

Regional organisation of experts centers
- 3 coordinator centers
- 9 expert centres
- 17 delegate experts centers

- All new diagnosis of STS /GIST and desmoid since 2010
  - systematic central review
  - molecular biology
  - FFPE & frozen samples

Collect of indicators in real time

Shared database (https://netsarc.org)

RRePS – 22 centres (Pathologists)
NETSARC – 29 centres (Clinicians - MS)

- All patients with management discussed in MS since 2010
  - New incident patients
  - Patients in follow up or relapse
  - clinical data
  - participation to clinical trial

Patients With 2nd opinion without MS
Patients With MS without 2nd opinion

Pathologist included in the 2nd opinion report (in conclusion), a recommendation to promote a dedicated MS for management of sarcoma patient «

Dedicated MS from NetSarc asked a systematic 2nd opinion for initial diagnosis for sarcoma patients before to validate proposal of management care

National evaluation of medical practices

Key point: double organization within network (pathologists & clinicians dedicated to sarcoma)
Quality of initial surgery:
New operated sarcoma patients

Résection R0
NetSarc network
Outside Network

Incidents 2011
Incidents 2012
Incidents 2013
Incidents 2014

Outside Network
NetSarc network

R1
R2
Histological discordances

Figure 1: Proportion of diagnostic discordances in three sarcoma networks

In the Evaluation Médicale et Sarcomes study, major discordances were defined as changes between two different histological types, and minor discordances as changes between two different grades. In the Conticanet and RRePPS studies, major discordances were defined as changes between benign and malignant sarcoma or between sarcoma and non-mesenchymal diagnosis (i.e., carcinoma). Minor discordances were defined as changes between two different histological types.

RRePS—Réseau de Référence en Pathologie des Sarcomes.
COST ECONOMIC IMPACT OF CENTRALIZED HISTOLOGICAL REVIEWS IN PATIENTS WITH SARCOMA, GIST, AND DESMOID TUMORS

➢ Out of the 2,425 patients that underwent histological review, 341 patients had a major discordance in their diagnosis (14%)

➢ N = 10 patients were excluded from the model due to missing data
Access to Expertise and innovation ?
Territorial inequalities?

Cartography and flux of patients to MTB in France
How to improve survival in sarcoma (rare cancer) patients?

- More favorable patients (screening, hygiene measures, fighting vulnerabilities)
- More scientific guidelines (“evidence based guidelines”)
- Top level physicians (medical practices)
- Efficient structures (hospital volume, quality program)
- More specific drugs ‘Imatinib model’
THE EFFECT OF ADJUVANT CHEMOTHERAPY ON RELAPSE-FREE SURVIVAL IN PATIENTS WITH OSTEOSARCOMA OF THE EXTREMITY


1984 - academic study
70 patients
No benefit in OS
Drug non expensive
Standard of care

2007 - academic study
662 patients
Benefit in OS
Drug expensive
Non available in France
Negative spiral for rare cancers

- Few knowledge
- No evidence-based Medicine
- No Standard of Care
- No clinical trials
- No innovations
- No improvements for survival over time
- No interests from Agencies & Pharma
- No financial supports

Rare Gynecologic cancers = same problematic than all other rare cancers
How to change the future?

• 5\textsuperscript{th} OCCC GCIG in Tokyo 2015
  – Have fixed standard of care in 1\textsuperscript{st} line & relapse
  – Have highlighted the need for investigational treatments
  – New prognostic factors including molecular factors

• New organizations for management & clinical research
  – Dedicated cancer network (eg French model)
    • Education for physicians, care givers and public
    • Motivate Patients advocacy group
  – European network for rare cancer (ENGOT, ESMO, ESO, EURACAN)
  – International collaboration (GCIG, WSN)
Prospective clinical data bases / observational studies
Risks of the new EU Data protection regulation: an ESMO position paper endorsed by the European oncology community

recommendations

In summary, patients should have the right to donate their data and tissues to health research. Patient consent for use of data or tissues for health research should be a fully informed, withdrawable, more or less broad, 'one-time' process, which truly implements the patient's rights, rather than creating burdensome, possibly harmful consequences to the patient's community. The patient shall retain access to the tissue and data donated, hence ensuring him/her to obtain relevant information related to his/her condition. On the contrary, denial of this right would make patients less free, because they would be denied a civil right, i.e., to contribute to research, which advances knowledge and leads to new ways of improving their health and that of other patients. There need to be put in place legal provisions to protect data confidentiality, reviewing mechanisms to ensure retrospective researches and biobanks, and a system allowing full transparency of research processes and storage of patient tissue in biobanks. Cancer registries should be able to register cancer cases and patient data without the requirement of patient consent, in order to provide society and health administrators with exhaustive health data for public health policy decisions.

The European Cancer community urges all EU decision makers to save research, as well as to protect the right of patients to donate their data and tissues to advance research and find cures. EU decision makers are urged to change the European Parliament Amendments 194 and 194 to Articles 81 and 83, as they would impair public health research within and across EU Member States. A balance between the right to privacy and the right to health can be achieved by reasonably addressing all concerns, while fully complying with those relating to confidentiality and ethical use of personal health data.
The «one-time consent»

REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

of 27 April 2016

on the protection of natural persons with regard to the processing of personal data and on the free
movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation)

(Text with EEA relevance)

One time consent

(33) It is often not possible to fully identify the purpose of personal data processing for scientific research purposes at
the time of data collection. Therefore, data subjects should be allowed to give their consent to certain areas of
scientific research when in keeping with recognised ethical standards for scientific research. Data subjects should
have the opportunity to give their consent only to certain areas of research or parts of research projects to the
extent allowed by the intended purpose.
EURACAN

European Reference Network
for rare or low prevalence complex diseases

Network
Adult Cancers
(ERN EURACAN)

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
Rarity will be the future
Take home message

• Rare tumors are frequent!
  – Prognosis & clinical presentation really different
  – Thinking to rarity before surgery!
  – Fertility & of adjuvant treatment

• Management decision making:
  – Expert Pathologists
  – Multidisciplinary expert staff
  – Dedicated Rare Cancer Network→ French experience

• Physicians & patients advocacy groups parternship → Authorities & gouvernements

• Tumoral minority is the future of the oncology
• European Cooperation +++++
• European networks of reference for rare diseases: we need you to be sure they will be dedicated to rare cancers!