Sandro Pignata
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MITO and ENGOT CHair
Results of the questionnaires to the groups before the strategic in 2016

| Domains where ENGOT should be more active | • Alternative funding to pharma (EU...)  
• Translational projects  
• Rare tumours  
• Megadatabase  
• Mentoring and participation of small groups  
• Public relations |
| Things to be improved | • Small and less active groups  
• Global collaboration out of Europe. More flexibility in the rules?  
• Rare diseases |

[Graph showing data: ALIENOR, France, Germany]
Rules & political discussions

• This working group will meet 1 or 2 times per year and calls will be organized when needed.
• This business should not conflict with the educational activities of ESGO or with the European network of centers
• This should not repeat what is ongoing in GCIG (papers, guidelines,...)
• Collaboration with GCIG welcome

• This is only research!!
The TOC bank is now officially the ENGOT bank.
Umbrella Trial: Rare Epithelial Ovarian Cancer
A project of the ENGOT Phase I/II clinical trial initiative (Nicole Concin)

Arm A: Standard Chemotherapy
optional
(Caelyx, Paclitaxel, Topotecan, Gemcitabine)

Experimental Arm B

Experimental Arm C

Experimental Arm D

Experimental Arm E

Cross-over of standard arm A permitted

Primary endpoint
- PFS by RECIST

Secondary endpoints
- Safety
- PRO
- ORR
- DOR
- DCR at 6 and 12 m
- OS
- PK
- Experimental

Clear cell, Low-grade serous, Low-grade endometrioid

TUMOR BIOPSY
blood, plasma, serum
SCREENING

Continous blood, plasma, serum
TREATMENT

TUMOR BIOPSY
blood, plasma, serum
PROGRESSION
How the rare cancer group started

Dear Friends,

as discussed during the recent strategic meeting in Copenhagen, a special focus on research in rare cancers should be given in the next 2 years.

As first action I ask you to complete this table and send it to the ENGOT office. I also ask you if in your group there is one person in charge of the promotion of research in rare tumors or if you are planning or willing to nominate. In this case please share this information with us and send us name and email.

The description of the activities should be very brief, only the title is enough. We will present the results of this survey in Valencia.

Thank you in advance

Sandro Pignata

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<thead>
<tr>
<th>Tumor</th>
<th>Group and Group rep</th>
<th>Ongoing</th>
<th>Planned</th>
<th>Lookink for collab</th>
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61 projects!!!!
Plan for collaboration of ongoing proposals (a proposal for putting together very similar projects)
Sex Cords Stromal

• Registries - Retrospective studies
  • AGO (CORSETT) retrospective and prospective
  • MITO9 retrospective and prospective
  • GINECO (TMRG)
    • Substudy 1 retrospective: initial management & elaboration of a nomogram to define risk of progression (n = 653)
    • Substudy 2 Prospective on long term effects (need to see patients in cs and cardiac exploration, plus blood tests to be organized) financial support only for French patients
  • NCRI (prospective?) RaNGO: study of specified rare gynaecological cancers to facilitate in-depth analysis of their clinical and biological behaviours
  • ISGO aromatase inh activity retrospective but focus on clinical activity

• Clinical trials
  • AGO HR+ gyn cancer (CDK4/6 + AI) phase II trial → collab to be defined /umbrella proj
  • GINECO AMRH2 Ab (+ ADCC) for AGCT, phase I trial (on going) → coll model Alienor

Meta analysis
Combined substudies
Validation series
<table>
<thead>
<tr>
<th>Topics</th>
<th>Groups with databases</th>
<th>Groups Willing to share data</th>
<th>Groups Willing/candidate to coordinate a subtopic or already on going?</th>
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The intent is to select 1-2 collaboration that can be presented at next ENGOT in April 2018 and to promote collaboration in each of the topics.
Roadmap

• next meeting in march 2018,

• Tasks identified for the next meeting are:
  • Rules the role of the rare tumour representative and general organization of the group (Jalid Sehouli)
  • Database to be used for registry where national registry are not yet active (possibility to adopt REdcap as common system)
  • Approval of the documents for bio banking
  • Approval of the ongoing projects in collaboration
GCIG activities

• Rare tumour working group (Chairs J Ledermann & C Scott)

  • 20 GCIG recommendations/guidelines for rare tumors (2014)
    • To delineate control arm & develop clinical trial in such rare population
  • Clinical trials on-going/ completed (MeOC, Alienor, NICC, ...)
  • Proposed new trials
    • Growing list of proposals....... 
  • Registries (Redcap, French TMRG, SCOOHT...)

• Interaction with translational group for prospective studies:
  • e.g OCCC project (sharing tumour blocks between JGOG & GINECO) for WGS & RNAseq
International Context

- GCIG rare tumour working group
- Euracan organization
- ESGO rare tumours task force
- ENGOT rare tumour plan
Negative spiral for rare cancers

It’s time to work on it.