Saturday 1st of December is specifically focused on the ESO-ESMO-RCE Clinical Update on Rare Cancers event. Rare cancers patient advocates are welcome to join sessions of their preferences and discuss ideas with oncologists and researchers.

08:30 Registration and coffee entry

INTRODUCTION (ESO-ESMO-RCE Clinical Updates on Rare Cancers, plenary session)
09:00 Epidemiology and rare cancer networking  
A Trama
09:30 The pathologic diagnosis  
AP Dei Tos
10:00 Clinical decision making in RC  
P. Casali

10:30 Coffee break = 30 Min.

BREAK OUT PRECEPTORSHIP 1 (ESO-ESMO-RCE Clinical Updates on Rare Cancers)
11:00 Sarcomas  
S. Bielack, JY Blay, PG Casali, A. Gronchi
11:00 Rare urogenital cancers  
JA Gietema, N. Nicolai
11:00 Digestive rare cancers  
V. Mazzaferro, F. De Braud, R.Glynne-Jones

13:00 Lunch = 60 Min.

BREAK OUT PRECEPTORSHIP 2 (ESO-ESMO-RCE Clinical Updates on Rare Cancers)
14:00 Rare female genital cancers  
D. Lorusso, I. Ray-Coquard, F. Raspagliesi, M. Seckl
14:00 Rare thoracic cancers  
R. Stahel, M. Garassino, N. Girard, U. Pastorino
14:00 Rare skin tumors and uveal melanoma  
C. Lebbé, L. Licitra, M. Angi, J. Sacco

16:00 Coffee break = 30 Min.

BREAK OUT PRECEPTORSHIP 3 (ESO-ESMO-RCE Clinical Updates on Rare Cancers)
16:30 CNS tumors  
R. Soffietti, M. van den Bent
16:30 Neuroendocrine tumors  
D. Talbot, V. Mazzaferro
16:30 Head and neck cancers w/thyroid cancer  
C. Simon, L. Licitra
SUNDAY, 2 DECEMBER 2018

Patient Advocates parallel session

09:30 Registration

INTRODUCTION: CLINICAL, REGULATORY AND COMMERCIAL CHALLENGES IN RARE CANCERS (PAs parallel session)

Moderators: Isabelle Manneh

10:00 Regulatory perspective Jorge Camarero Jiménez
10:15 Clinical perspective Paolo Casali
10:30 Commercial perspective Jens Tuischer
10:45 Discussion

11:10 Coffee Break (all) = 30 Min.

UNDERSTANDING IMPORTANT RARE CANCER INITIATIVES IN EUROPE (PAs parallel session)

Moderators: Paolo Casali

11:40 Rare Cancers Europe (RCE) Paolo Casali
11:55 Rare Cancers and the ERNs Jean-Yves Blay
12:10 The Joint Action on Rare Cancers (JARC) Annalisa Trama
12:25 Innovative Partnership for Action Against Cancer Josep Maria Borras Andres
12:40 Discussion

13:00 Lunch (all)

UPDATES ON RELEVANT OVERARCHING RARE CANCER AND RARE DISEASE POLICIES IN EUROPE

Moderators: Ariane Weinman

14:15 National cancer Plan – insights from the JARC Josep Maria Borras Andres
14:30 Promotion of rare disease plans in the EU: the patients’ experience Ariane Weinman
14:45 Cancer Registries Carmen Martos
15:00 Discussion
THE EUROPEAN RARE CANCER PATIENT CAFÉ (PAs parallel & brainstorming session)
15:30 - 18:30

*The rare cancer patient café are brainstorming sessions where participants can highlight areas from the previous presentations and propose potential new projects or priorities in these areas for the rare cancers community to address in 2019.*

15:30 – 16:30

16:30 *Coffee break (all) = 30 Min.*

Table 1: topic *Education and training strategic needs for patients advocates* - Moderator Kathy Oliver

Table 2: topic *Patient involvement in clinical trials* - Moderator Isabelle Manneh

Table 3: topic *The Quality of Life of Rare Cancer Patients* - Moderator Ariane Weinman

17:00 – 18:00
*Modestors: Kathy Oliver*

Plenary reporting back and discussion (10’ per table + 30’ discussion)
MONDAY, 3 DECEMBER 2018

RARE CANCER INITIATIVES BEYOND EUROPEAN BORDERS (PAs parallel session)

Moderators: Paolo Casali

9:00   Introduction by the moderator  
9:15   RC Asia  
9:35   US presentation  
9:55   Rare Cancers in Latin America  
10:20  Discussion

10:40  Coffee Break (all) = 30 Min.

ADVOCACY & LOBBYING: SPEAKING UP FOR RARE CANCERS (PAs parallel session)

Moderators: Gilliosa Spurrier

11:15  Achieving change in RC: ERNs  
11:35  Patient participation in clinical guidelines  
11:55  Patient role in influencing research and clinical trials  
12:05  Social media and communication  
12:25  Discussion

13:00  Lunch (all) = 60 Min.

The afternoon sessions are for patient advocates, oncologists and researchers.

RARE CANCERS EUROPE (ESO-ESMO-RCE Clinical Updates on Rare Cancers, plenary session)

Moderators: K. Oliver, P. Casali

14:00  The European Network for Rare Adult Solid Cancer – EURACAN  
14:20  The Joint Action on Rare Cancers - JARC  
14:40  The role of Patient Advocates – ECPC perspective  
15:00  Debate

15:30  (Plenary) Closing remarks with a view to networking  

PG Casali