

Training Course for Rare Cancer Patient Advocates 1-3 December 2018, Milan

PROGRAMME

SATURDAY, 1 DECEMBER 2018

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)

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|-------|-------------------------|---|
| 11:00 | Sarcomas | S. Bielsack, 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)

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|-------|-------------------------------------|--|
| 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)

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|-------|--|-------------------------------|
| 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

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|-------|------------------------|------------------------|
| 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

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|-------|--|---------------------------|
| 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 Borrás Andres |
| 12:40 | Discussion | |

13:00 Lunch (all)

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

Moderators: Ariane Weinman

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|-------|---|---------------------------|
| 14:15 | National cancer Plan – insights from the JARC | Josep Maria Borrás 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

Moderators: 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

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|-------|-------------------------------|--------------|
| 9:00 | Introduction by the moderator | |
| 9:15 | RC Asia | Paolo Casali |
| 9:35 | US presentation | Kathy Oliver |
| 9:55 | Rare Cancers in Latin America | Gemma Gatta |
| 10:20 | Discussion | |

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

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

Moderators: Gilliosa Spurrier

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|-------|--|----------------------|
| 11:15 | Achieving change in RC: ERNs | Kathy Oliver |
| 11:35 | Patient participation in clinical guidelines | Gilliosa Spurrier |
| 11:55 | Patient role in influencing research and clinical trials | Roger Wilson (video) |
| 12:05 | Social media and communication | Conradin Döbeli |
| 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

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|-------|--|--------------------|
| 14:00 | The European Network for Rare Adult Solid Cancer – EURACAN | PG Casali |
| 14:20 | The Joint Action on Rare Cancers - JARC | A Trama |
| 14:40 | The role of Patient Advocates – ECPC perspective | F De Lorenzo (TBC) |
| 15:00 | Debate | |

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