

RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates 2019

29 November - 1 December

Centro Congressi Fondazione Cariplo

Via Romagnosi, 8, 20121 Milan

DRAFT AGENDA

FRIDAY 29 NOVEMBER

10:30 – 11:00 - Registration and Coffee

- 11:00 – 11:20 Welcome from ESO and ESMO – **F. Peccatori IT - R.A. Stahel, CH**
- 11:40 – 12:00 Networking on rare cancers – **A.M. Frezza, IT**
- 12:00 – 12:20 What can we do politically? – **F. de Lorenzo, IT - K. Oliver, UK**
- 12:20 – 12:40 Open Floor for Discussion

12:40 to 13:00 – Keynote Lectures

- 12:40 – 13:00 Collaborative clinical registries in rare cancers: the ETOP-NTRK registry – **R. Stahel, CH**

13:00 to 14:00 – Networking Lunch

14:00 to 15:50 – Setting the Scene – Moderator Paolo Casali, ESMO / Istituto Nazionale dei Tumori

14:00 – 14:15

Welcome Address – **Paolo Casali, ESMO / Istituto Nazionale dei Tumori**

The JARC Recommendations – **Anna Maria Frezza, Istituto Nazionale dei Tumori**

The patient advocates' contribution:

14:15 – 15:50

- **Francesco de Lorenzo, European Cancer Patient Coalition (ECPC)**

- **Arianne Weinman, EURORDIS - Rare Diseases Europe (Eurordis)**

- **Melanie Brunhofer, Childhood Cancer International Europe (CCI Europe)**

Questions and Answers

15:50 to 16:20 – Coffee Break

16:20 to 18:00 – The Basics of Advocacy – Moderator Kathy Oliver, The International Brain Tumour Alliance (IBTA)

16:20 – 16:50

Presentation of the RCE Advocacy Toolkit – **Kathy Oliver, IBTA**

16:50 – 18:00

Presentation of a Case Study and Discussion

SATURDAY 30 NOVEMBER

09:00 to 11:30 – Treatment and Clinical Trial - Moderator Jean-Yves Blay, EURACAN

Clinical Trials in rare cancers

09:00 – 10:30

- Sponsor perspective - **Gianluca Fincato, Novartis**
- Patient perspective – **Joanne Finnegan, Ocular Melanoma Ireland**
- Clinician perspective - **Paolo Casali, ESMO / Istituto Nazionale dei Tumori**

10:30 to 11:00 – Coffee Break

11:00– 11:30

How medicines get approved – An overarching perspective from the EMA – **Kyriaki Tzogani, EMA**

11:30 to 13:00 – What next for Rare Cancers: A lecture on the opportunities provided by ERNs – Moderator Jean-Yves Blay, EURACAN

11:30 – 13:00

- The EURACAN perspective **Jean-Yves Blay, EURACAN (11:30 – 11:50)**
- The ePAGs perspective **Ariane Weinman, Eurordis (11:50 – 12:05)**
- Melanie Brunhofer, CCI Europe (12:05 – 12:20)**
- Discussion

13:00 to 14:00 – Networking lunch

14:00 to 16:10 – Patient Cafés – Moderator Kathy Oliver, IBTA

14:00 – 16:10

Patient Cafés

16:10 to 16:40 – Coffee Break

16:40 – 18:00 – Session on Diagnosis Treatment and care of RC – Moderator Paolo Casali, ESMO / Istituto Nazionale dei Tumori

16:40 – 17:05

The epidemiology of rare cancers – **Annalisa Trama, Istituto Nazionale dei Tumori**

Questions and Answers

17:05 – 17:30

The pathologic diagnosis in rare cancers – **Angelo Paolo dei Tos, University of Padova**

Questions and Answers

17:30 – 18:00

Rare Cancers clinical perspective – **Paolo Casali, ESMO/ Istituto Nazionale dei Tumori**

Questions and Answers

SUNDAY 01 DECEMBER

9:00 to 10:30 – Advocacy in an interconnected world – Moderator Wendy Yared, Association of European Cancer Leagues (ECL)

- 9:00 – 9:30** Advocacy in the 21st Century: The importance of incorporating Social Media into your efforts – **Sophia Sleeman, 'Young & Cancer' Care Network**
- 9:30 – 10:00** Advocacy in the 21st Century: The importance of effective communication with policymakers – **Wendy Yared, ECL**
- 10:00 – 10:30** Advocacy in the 21st Century: The importance of a powerful campaign – **Melanie Brunhofer, CCI Europe**

10:30 to 11:00 – Coffee Break

Patient Advocate Open Floor

- 11:00 – 12:00** During this session, rare cancers patient advocates could take the floor for 10 minute and introduce their campaigns and pathways for success. This session would provide an interactive approach for attendees who could feel this is their time to put forward their main ideas. Maximum speaking time: 10 min.
- 12:00 – 12:30** The Right to be Forgotten – **Katie Rizvi, Youth Cancer Europe**
- 12:30 – 12:50** Final Discussion & Feedback Forms
- 12:50 – 13:00** Concluding Remarks – **Paolo Casali, ESMO / Istituto Nazionale dei Tumori**