

## RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates January 2021 On-line training programme

### Rare Cancers on the EU Agenda

Date and time: Thursday 14 January, 16.00 - 17.40

#### About Rare Cancers on the EU Agenda:

“Rare Cancers on the EU Agenda” is a virtual meeting where participants will be introduced to the upcoming ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancer [training](#) (16-17 January), and they will learn about the latest cancer policy developments within the European agenda, the role of the European Reference Network on Rare Adult Solid Cancer, the role of the national centres of expertise from a patient perspective, and how to develop a successful advocacy campaign.

### Agenda

Chair: **Kathy Oliver**

Co-chair: **Paolo Casali**

**16.00 - 16.20:** Welcome and introduction to the ESO-ESMO-RCE Clinical Update on Rare Adult Solid Cancer training – **Paolo Casali, Rare Cancers Europe**

**16.20 - 16.40:** The new EU Agenda on Cancer and the role of the European Reference Network EURACAN – **Jean-Yves BLAY, EURACAN**

**16.40 - 17.00:** The role of patients advocates to raise awareness on rare cancers – **Kathy Oliver, The International Brain Tumour Alliance**

**17.00 - 17.20:** How to develop a successful advocacy campaign – **Antonella Cardone, European Cancer Patient Coalition**

**17.20 - 17.40:** Open floor for discussion and conclusions – **Paolo Casali, Rare Cancers Europe**

## **PATIENT CAFÉ**

### **COVID-19 and cancer: lessons learned, pathway for the future**

*Date and time: Monday 18 January, 16.30 - 18.15*

#### **About the COVID-19 Patient Café:**

The “COVID-19 and cancer: lessons learned, pathway for the future” patient café is composed of three brainstorming sub-sessions where the participants will highlight rare cancer challenges magnified during the COVID-19 pandemic and develop recommendations to ensure that the rare cancer community will be ready to face possible future pandemics or healthcare crises in a more prepared way. The three sessions aim to collect recommendations from a “patient perspective”, “patient organisation perspective”, and “physician perspective”.

## **Agenda**

*Moderator: Kathy Oliver*

**16.30 - 16.40:** Welcome and presentation of COVID-19 challenges by three perspectives: patients, patient organization, and physicians

#### **Topic 1: Patient Perspective**

**16.40 - 16.45:** Introduction to topic – **Kathy Oliver, The International Brain Tumour Alliance**

**16.45 - 17:05:** Discussion

**17.05 - 17:10:** Conclusion

#### **Topic 2: Patient organization perspective**

**17.10 - 17.15:** Introduction to topic – **Markus Wartenberg, Sarcoma Patients EuroNet**

**17.15 - 17:35:** Discussion

**17.35 - 17.40:** Conclusion

#### **Topic 3: Physician perspective**

**17.40 - 17.45:** Introduction to topic – **Fedro Peccatori, European School of Oncology**

**17.45 - 18.05:** Discussion

**18.05 - 18.10:** Conclusion

#### **Conclusions**

**18.10-18.15:** overall conclusions – Moderator

## **PATIENT CAFÉ**

### **Patient involvement in clinical research**

*Date and time: Tuesday 19 January – Thursday 21 January*

#### **About the patient involvement in clinical research Patient Café:**

The “patient involvement in clinical research” patient café is composed of three different brainstorming topics in online sessions which are organised over two days with the aim to give participants the opportunity to attend all three sessions. The sessions aim to provide training on “patient involvement in clinical trials”, “patient involvement in clinical registries”, and “patient involvement in tumour banks”. Each brainstorming session will conclude with concrete outcomes which will be collected and used to develop Rare Cancers Europe recommendations for each of the themes discussed.

### **Agenda**

#### **Topic 1: Patient involvement in clinical trials**

*Moderator: Jan Geissler*

*Date and time: Tuesday 19 January, 16.00 - 17.00*

- 10': Welcome and presentation of what is a clinical trial and the relevance of patient input – **Jan Geissler, Chronic Myeloid Leukaemia Advocates Network**
- 10': How can patient advocates be more involved in clinical trials? – **Markus Wartenberg, Sarcoma Patients EuroNet**
- 30': Discussion – the patient's perspective on how to design a patient-centric clinical trial
- 10': Conclusion: Draw the relevant recommendations on how to improve patient involvement in clinical trials – *Moderator*

#### **Topic 2: Patient involvement in clinical registries**

*Moderator: Ariane Weinman*

*Date and time: Wednesday 20 January, 16.30 - 17.30*

- 5': *Welcome - Moderator*
- 10': What are clinical registries and why is patient involvement crucial? – **Annalisa Trama, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano**
- 10': Challenges faced by patient advocates re: clinical registries – **Ariane Weinman, EURORDIS**
- 30': Discussion – the patient's perspective on how to involve patients in clinical registries:
- 10': Conclusion: Draw the relevant recommendations on how to improve patient involvement in clinical registries – *Moderator*

### Topic 3: Patient involvement in tumour banks

*Moderator:* **Jayne Bressington**

*Date and time:* Thursday 21 January, 16.30 - 17.30

5': Welcome - Moderator

10': What is a tumour bank and the role played by patients – **Prof. Andy Hall, RareCan**

10': The patient experience in creating tumour banks – **Jayne Bressington, GIST Cancer UK**

30': Discussion – the patient's perspective on how patients can be involved in creating tumour banks

10': Conclusion: Draw the relevant recommendations on how to involve patients in creating tumour banks – *Moderator*