



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

February 2022 - Agenda

## A crucial time for the European rare cancer policy landscape: Europe's Beating Cancer Plan and Cancer Mission

Tuesday 8 February, 16.00 - 17.30 CET

### About the session:

Structured in a meeting format, the *A crucial time for the European rare cancer policy landscape: Europe's Beating Cancer Plan and Cancer Mission* session will focus on two key initiatives that demonstrate the European Commission's continued focus on cancer. Published in February 2021, [Europe's Beating Cancer Plan](#) is of crucial importance to the work of Rare Cancers Europe and the broader rare cancer community. The Cancer Plan [Implementation Roadmap](#) was published in November 2021, and added detail and concrete timelines for the different flagship initiatives and other initiatives within the plan. In addition, the European Commission's [Cancer Mission](#), operating under the Horizon Europe programme, has the objective of improving the lives of more than 3 million people by 2030 through prevention, cure and for those affected by cancer including their families, to live longer and better. Through both the Cancer Plan and Cancer Mission, there are tremendous engagement opportunities for the European rare cancer community and this session is aimed at equipping patient advocates with the knowledge to capitalise on this.

### Agenda & Speakers

*Chairs:* **Paolo Casali & Ariane Weinman**

- 16:00 – 16:15** Welcome and introduction to Rare Cancers Europe's activities  
**Paolo Casali, Rare Cancers Europe & European Society for Medical Oncology (ESMO)**
- 16:15 – 16:30** Europe's Beating Cancer Plan and its implementation roadmap: what will this change for rare cancers?  
**Ariane Weinman, European Organisation for Rare Diseases (EURORDIS)**
- 16:30 – 16:45** How will rare cancer patients benefit from the Cancer Mission?  
**Bettina Ryll, Member of the first Cancer Mission Board**
- 16:45 – 17:05** Political engagement: ensuring the needs of rare cancer patients are reflected in the policy agenda
- Case study: **Dorica Dan, Romanian Rare Cancers Association (Romania)**
  - Case study: **Francesco De Lorenzo, Italian Federation of Cancer Patients Organisations (Italy)**
  - Case study: **Jo Gumbs, OcuMel (UK)**
  - Case study: **Lise-lott Eriksson, Swedish Blood Cancer Association (Sweden)**
- 17:05 – 17:30** Q&A session & conclusions  
**Moderated by Paolo Casali & Ariane Weinman**

## PATIENT CAFÉ

### Rare cancers in the new COVID-19 era

Wednesday 9 February, 15.30 - 17.45 CET

#### About the session:

Structured in a patient café format, the *Rare Cancers in the new COVID-19 era* session will include three brainstorming sub-sessions, with participants taking each topic in turn and developing recommendations to ensure the European rare cancer community responds to the challenges posed by the pandemic. The first sub-session is centred on raising awareness on the importance of COVID-19 vaccination. The second sub-session will look at best practices around creating and maintaining digital patient communities during the pandemic, taking into account recent trends. The final sub-session will see contributions from different stakeholders within the rare cancer community, who will share their experiences and best practice examples with participants.

#### Agenda & Speakers

*Chairs:* **Wendy Yared & Radu Ianovici**

**15:30 – 15:35** Welcome and introduction to the session  
**Wendy Yared, Association of European Cancer Leagues (ECL)**

#### Topic 1: COVID-19 vaccination in rare cancer patients

**15:35 – 15:45** Collecting evidence for advocacy: best practice example from IBTA's patient survey on COVID-19 vaccination  
**Kathy Oliver, The International Brain Tumour Alliance (IBTA)**

**15:45 – 16:05** Discussion

#### Topic 2: Rare cancer advocacy during COVID-19

**16:05 – 16:15** ECPC Joint Letter on COVID-19 and Cancer: Best practice example on keeping cancer care in focus during the pandemic  
**Radu Ianovici, European Cancer Patient Coalition (ECPC)**

**16:15 – 16:35** Discussion

#### Topic 3: Perspectives from the rare cancer community

**16:35 – 16:45** The healthcare professional's perspective  
**Sergio Sandrucci, European Society of Surgical Oncology (ESSO)**

**16:45 – 16:55** The research community's perspective  
**Sandrine Marreaud, European Organisation for Research and Treatment of Cancer (EORTC)**

**16:55 – 17:05** The industry's perspective  
**Federica Castiglione, Novartis**

**17:05 – 17:45** Discussion & overall conclusions  
**Moderated by Wendy Yared & Radu Ianovici**

## PATIENT CAFÉ

### Cancer care: ensuring that digitalisation benefits rare cancer patients

Thursday 10 February, 16.00 - 17.30 CET

#### About the session:

Structured in a patient café format, the *Cancer care: ensuring that digitalisation benefits rare cancer patients* session will address the key developments in digital health due to COVID-19 as well as the continuing development of digital technologies in health. Thus, this session will focus on how digitalisation impacts the way in which patients receive treatment, the effect on diagnosis, as well as patient-physician communication. There are significant benefits to the increased digitalisation of the health field and there is a need for rare cancer patients to be fully aware of the changes and opportunities.

#### Agenda & Speakers

*Chairs:* **Fedro Peccatori & Markus Wartenberg**

- 16:00 – 16:05** Welcome and introduction to the session  
**Fedro Peccatori, European School of Oncology (ESO) & Markus Wartenberg, Sarcoma Patients EuroNet (SPAEN)**
- 16:05 – 16:15** Telepathology and telemedicine: what has changed during COVID-19 for rare cancer patients?  
**Giancarlo Pruneri, University of Milan**
- 16:15 – 17:00** Perspectives of key stakeholders on the opportunities and challenges of telepathology and telemedicine for rare cancer patients
- The hospital's perspective: **Jean-Yves Blay, ERN EURACAN, Rare Adult Solid Cancers**
  - The physician's perspective: **Virginia Ferraresi, Istituto Regina Elena**
  - The nurse's perspective: **Helena Ullgren, European Oncology Nursing Society (EONS)**
  - The patient's perspective: **Markus Wartenberg, Sarcoma Patients EuroNet (SPAEN)**
- 17:00 – 17:30** Discussion & conclusions  
**Moderated by Fedro Peccatori & Markus Wartenberg**