

## Training Course for Rare Cancer Patient Advocates 2-4 December 2017 in Milan (Pilot Course)

### Draft PROGRAMME

#### SATURDAY, 2 DECEMBER 2017

**09:00** Registration and coffee entry (all)

#### INTRODUCTION (Plenary Session)

*Moderators:* JY Blay, PG Casali, R Stahel

09:45	Welcome from ESO and ESMO	F Peccatori, R Stahel
10:00	The problem of rare cancers	PG Casali
10:15	The epidemiology of rare cancers	A Trama
10:30	The pathologic diagnosis in rare cancers	AP Dei Tos
10:45	The European Reference Networks	JY Blay
11:00	Discussion	

#### PATIENT EMPOWERMENT IN RARE CANCERS (Plenary Session)

*Moderators:* F De Lorenzo, K Oliver

11:30	Patient empowerment in rare cancers: a consensus	G Pravettoni
11:50	The EU scenario	F De Lorenzo
12:10	Patients & Experts: The power of working together	K Oliver
12:30	Discussion	

**13:00** Lunch Break (all) = 60 Min.

#### PA's parallel session -----

#### UNDERSTANDING IMPORTANT RARE CANCERS INITIATIVES IN EUROPE

##### (PA's parallel session)

*Moderators:* K. Oliver

14:00	Rare Cancers Europe (RCE)	PG Casali
14:20	EURACAN - what it means to rare cancer patients?	K Oliver
14:40	The Joint Action on Rare Cancers (JARC)	A Trama
15:00	Discussion	

#### CLINICAL, REGULATORY AND COMMERCIAL CHALLENGES IN RARE CANCERS DRUGS DEVELOPMENT (PA's parallel session)

*Moderators:* R Wilson

15:30	Clinical perspective	S Stacchiotti
15:45	Regulatory perspective	K Tzogani
16:00	Commercial perspective	J Tuischer
16:15	Discussion	

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

## PATIENT ORGANISATIONS TACKLING RARE CANCERS CHALLENGES (PAs parallel session)

*Moderators: E Lecoite*

17:00	The Power of Rare Disease Patient Advocacy	A Weinman
17:15	Patient Power: GIST Support UK	V Bassett
17:30	Patient Power: INCA The European NETWORK	T Kolarova
18:00	Discussion	

**19:30** *Dinner*

## SUNDAY, 3 DECEMBER 2017

### DIAGNOSIS, TREATMENT & RARE CANCERS CARE (PAs parallel session)

*Moderators: R Giles*

08:30	Cancer: some definitions	A Frezza
08:50	Pathologic diagnosis in rare cancers	AP Dei Tos
09:10	Molecular diagnostics in rare cancers	AP Dei Tos
09:30	Targeted therapies & Precision oncology	N Fazio
09:45	Discussion	

**10:00** *Coffee Break (all) = 30 Min.*

### RARE CANCERS TREATMENT: THE CHALLENGES (PAs parallel session)

*Moderators: T Kolarova*

10:30	The surgical oncologist's perspective	S Sandrucci
11:00	The radiation oncologist's perspective	V Grégoire
11:30	The medical oncologist's perspective	I Ray-Coquart
12:00	Beyond the treatment: the needs of RC patients	I Galloway
12:30	Discussion	

**13:00** *Lunch Break (all) = 60 Min.*

### CLINICAL RESEARCH IN RARE CANCERS (PAs parallel session)

*Moderators: I Manneh-Vangramberen*

14:00	How are we doing clinical trials for the last decades?	S Litiere
14:30	Understanding endpoints & patient reported outcomes	S Stacchiotti
15:00	Statistical facts for non-statisticians	P Bruzzi
15:30	Discussion	

**16:00** *Coffee Break (all) = 30 Min.*

### CLINICAL RESEARCH IN RARE CANCERS – CAN IT BE IMPROVED? (PAs parallel session)

*Moderators: R Wilson*

16:30	Innovative approaches for rare cancers clinical research	P Casali
17:00	Real World Evidence: How patient groups can contribute	E Low
17:30	How to engage patient groups in clinical research	E Low
18:00	Discussion	

## MONDAY, 4 DECEMBER 2017

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

Moderators: TBC

08:30	Trying to achieve changes: advocating & lobbying for RC	R. Wilson
09:00	Speaking up for rare cancers/sharing best practices	
	Case Report 1 – Position Papers in Sarcomas	E Lecointe
	Case Report 2 – World Kidney Cancer Day	R Giles
	Case Report 3 – ECPC	I Manneh-Vangramberen
10:30	Discussion	

11:00 *Coffee Break (all) = 30 Min.*

### THE EUROPEAN RARE CANCER PATIENT CAFÉ (PAs parallel & brainstorming session)

11:30 - 12:45 (75 Min.)

Short introduction of the format. Changing tables - three sessions – 20 min. each

Important: Topics of the 5 different tables should bring value to the participants - but also gain insights/ideas/input for RCE and WeCan

**TABLE 1: How can we successfully overcome misdiagnosis and late diagnosis of rare cancers?**

Table Host: T. Kolarova

**TABLE 2: Is Quality of Life different for rare cancer patients?**

Table Host: R. Wilson

**TABLE 3: Clinical Trials in Rare Cancers:**

**What is the reality – what are challenges, hurdles for rc patients?**

Table Host: I Galloway

**TABLE 4: How do we reach RC patients & minority populations in our healthcare systems?**

Table Host: K Oliver

12:45 (Plenary) Closing remarks with a view to networking PG Casali