

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, M Wartenberg

11:30	Patient empowerment in rare cancers: a consensus	G Pravettoni
11:45	The EU scenario	F De Lorenzo
12:00	Patients & Experts: The power of working together	M Wartenberg
12:15	Patient involvement in clinical research	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 Lecoïnte*

17:00	The Power of Rare Disease Patient Advocacy	A Weinman
17:15	Patient Power: Cancer 52	K Oliver
17:30	Patient Power: TBC	TBC
17:45	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	Understanding cancer risks and cancer development	TBC
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	TBC
09:45	Discussion	

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

RARE CANCERS TREATMENT: THE CHALLENGES (PAs parallel session)

Moderators: *T Kolarova*

10:30	The surgeon's perspective	S Sandrucci
11:00	The radio-therapist's perspective	V Grégoire
11:30	The 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	M. Wartenberg
17:30	How to engage patient groups in clinical research	E Low

19:30 Dinner

MONDAY, 4 DECEMBER 2017

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

Moderators: M. Wartenberg

08:30	Trying to achieve changes: advocating & lobbying for RC	R. Wilson
09:00	Working with the media and social media in RC	TBC
09:30	Speaking up for rare cancers/sharing best practices (4-5 case reports – 10' min each)	
	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
	Case Report 4 – TBC	J Grey
	Case Report 5 – TBC	TBC
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: Do elderly patients in your rare cancer community get a bad deal because of their age?

Table Host: F de Lorenzo

**TABLE 4: Clinical Trials in Rare Cancers:
What is the reality – what are challenges, hurdles for rc patients?**

Table Host: I Galloway

TABLE 5: 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