

2014 Patient Track Program

Saturday 27 September 2014

PART1: 10:00-13:00 Cancer Research

10:00-10:45 Clinical trials: making statistics a little bit easier to understand!

Chair Anastassia Negrouk, Brussels, BE

Co-Chair Rocio Garcia-Retamero, Granada ES

10:00-10:10 Helping Doctors and Patients Make Sense of Health Statistics

Speaker 1 Rocio Garcia-Retamero, Granada, ES

10:10-10:25 Pros and Cons of the new EU Clinical Trials Regulation

Speaker 2 Anastassia Negrouk, Brussels BE

10:25:10:45 Ask me what you still want to know about clinical trials (Audience Questions)

Speaker 3 Christian Dittrich, AU

10:45-11:30 Clinical Trials: endpoints

Chair "e-Patient Dave" deBronkart, Boston, USA

Co-Chair Anastassia Negrouk, Brussels, BE

10:45-10:55 Meaningful patient involvement in clinical trial endpoints

Speaker 1 "e-Patient Dave" deBronkart, Boston, USA

10:55-11:05 Regulatory process to involve patients in discussions on clinical trial endpoints

Speaker 2 Anastassia Negrouk, Brussels, BE

11:05-11:30 Q&A and discussion

11:30-12:15 Patient involvement in cancer clinical research

Chair Hein Jambroers, Roermond, The Netherlands

Co-Chair Hans Keulen, Sint-Oedenrode NL

11:30-11:40 Patients as co-researchers

Speaker 1 Hein Jambroers, Roermond, The Netherlands

11:40-11:50 Why is it so important to do research together with patients instead of doing it about or for patients?

Speaker 2 Hans Keulen, Sint-Oedenrode ,NL

11:50-12:00 How can patients be involved in protocol development

Speaker 3 Denis Lacombe, Brussels, BE

12:00-12:15 Q&A and discussion

12:15-13:00 Introduction: Generating patient data, tissue and experiences

Chair Peter Riegman, Rotterdam, NL

Co-Chair Hans Gelderblom, NL

12:15-12:25 Different types and purposes for cancer registries

Speaker 1 Hans Gelderblom, NL

12:25-12:35 How do Bio/Tissue banks operate?

Speaker 2 Peter Riegman, Rotterdam, NL

12:35-12:45 How patient groups can contribute to research?

Speaker 3 Jayne Bressington, Doynton, UK

12:45-13:00 Q&A and discussion

13:00-14:00 lunch

PART2: 14:00-17:45 Treatment & Living & Capacity Building

- 14:00-14:30** **Nutritional status and outcome: the emerging truth**
Chair **Alessio Molfino, Rome IT**
Co-Chair **Francesco De Lorenzo, Rome, IT**
- 14:00-14:10 Weight loss and the risk of chemotherapy toxicity: how and why?
 Speaker Alessio Molfino, Rome,, IT
- 14:10-14:30 Everything You Always Wanted to Know About Nutrition (But Were Afraid to Ask)

14:30-1530 **Why is strategic planning important and valuable for patient groups?**

- Chair** **Markus Wartenberg, Bad Nauheim DE**
Co-Chair **(TBC)**
- 14:30-14:50 Strategic Planning as survival tool for small & medium non-profits
 Speaker1 Markus Wartenberg, Bad Nauheim, DE
- 14:50-15:10 Strategic Planning: real life experience
 Speaker 2 (TBC)
- 15:10-15:30 Q&A and discussion

15:30-16:00 coffee break

16:00-17:00 **Patient interaction with multidisciplinary teams (MTDs)**

- Chair** **Anita Marguiles, Zurich, CH**
Co-Chair **Wendy Yared, Brussels, BE**
- 16:00-16:10 Nurse's perspective
 Speaker 1 Anita Marguiles, Zurich, CH
- 16:10-16:20 Expert's perspective
 Speaker2 Winette Van der Graaf, Nijmegen, NL
- 16:20-16:30 What patients expect from their medical team
 Speaker 3 Jana Pelouchova, Prague, CZ
- 16:30-17:00 Q&A and discussion

17:00-17:45 **Highlighting some social challenges**

- Chair** **Francesco De Lorenzo, Rome, IT**
Co-Chair **Ward Rommel, Gent, BE**
- 17:00-17:10 Can cancer patients get insurance?
 Speaker 1 Ward Rommel, Gent, BE
- 17:10-17:20 Labour Participation after Cancer: Challenges and Social Impact
 Speaker 2 Isabelle Lebrocqy, Den Haag NL

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ESMO congress

Madrid, Spain 26-30 SEPTEMBER 2014

**39TH ESMO
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17:20-17:30 Long term survivorship issues
Speaker 3 Francesco De Lorenzo, Rome, IT

17:30-17:45 Q&A and discussion

Sunday 28 September 2014

PART4: 10:00-12:40 Patient Advocacy

09:45-10:10 Key Note Lecture

Moderator: Francesco De Lorenzo, Rome, Italy

09:50-10:10 Priorities of EU healthcare and cancer policies in the new mandate
(TBC)

10:10-10:45 An interesting journey through European healthcare politics

Chair Ingrid Kössler, Boras, Sweden

Co-Chair Francesco de Lorenzo, Rome, IT

10:10-10:20 Communication to patients and from patients: what should be included in a European quality assurance scheme?

Speaker 2 Donata Lerda, Ispra, IT

10:20-10:30 Social re-integration of cancer survivors

Speaker 3 Ingrid Kössler, Boras, Sweden

10:30-10:45 Q&A and discussion

10:45-12:00 European Cross Border Healthcare Directive

Chair (TBC)

Co-Chair Kathy Apostolidis, Brussels, BE

10:45-10:55 Nature of the directive

Speaker 1 (TBC)

10:55-11:05 Directive on Cross Border Health Care: An Opportunity or a Fallacy?

Speaker 2 Kathi Apostolidis, Brussels, BE

11:05-11:15 How long will the European patients wait for the European Reference Networks

Speaker 3 Dr Paolo G. Casali, Milan, IT

11:15-11:25 European patient who sought treatment in another member state

Speaker 4 Kenneth van Dessel, Dudzele, BE

11:25-11:35 Concerns and possible future scenarios

Speaker 5 Mariano Votta, Rome, IT

11:35-12:00 Q&A and discussion

12:00-13:00 Rare cancers in Europe: more common than you think!

Chair Jan Geissler, Riemerling, DE

Co-Chair Jayne Bressington, Doynton UK

12:00-12:10 Rarecarenet: Mapping rare cancers

Speaker 1 Annalisa Trama, Milan, IT

- 12:10-12:20 Challenges and solutions
Speaker 2 Jan Geissler, Riemerling DE
- 12:20-12:30 The Internet: The best companion of the rare cancer patient
Speaker 3 Hans Keulen, Sint-Oedenrode, NL
- 12:30-12:40 Q&A and discussion
- 12:40-14:00 *Lunch*

PART3: 14:00- 17:00 Tribute to Selma Schimmel / Advocacy in Action Forum

- 14:00-15:00 Palliative care: Living with cancer or dying of cancer?**
Chair Kathy Oliver, Tadworth, UK
Co-Chair Hans Joachim Schmoll, Halle DE
- 14:00-14:10 Palliative care: are we all speaking the same language?
Speaker 1 Kathy Oliver, Tadworth, UK
- 14:10-14:20 Results of the ESMO-EAPC European opioid policy initiative
Speaker 2 Augusto Caraceni, Milan, IT
- 14:20-14:30 Reducing national barriers to Palliative Care
Speaker 3 Nathan Cherny, Jerusalem, IL
- 14:30-14:40 How patients can influence regulatory policy to obtain adequate access to adequate pain relief
Speaker 4 James Cleary, Madison, USA
- 14:40-15:00 Q&A and discussion
- 15:00-17:00 5th European Advocacy In Action Forum**
- 15:00-15:30 Tribute to Selma Ruth Schimmel
- 15:30-16:00 European Reference Networks: Challenges and Solutions
- 16:00-16:30 How cancer patients deal with social challenges
- 16:30- 17:00 How patients and medical professionals can work together on tissue banks, cancer registries and clinical trials
- 17:00 *Close of the day*
17:30 *farewell cocktail (foyer Tenerife)*

