

## 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

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 5<sup>th</sup> 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)*

