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    Rocío García-Retamero, Granada ES

10:00-10:10  Helping Doctors and Patients Make Sense of Health Statistics
Speaker 1   Rocío García-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
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<th>Session Title</th>
<th>Chair</th>
<th>Speaker 1</th>
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<td>12:15-13:00</td>
<td>Introduction: Generating patient data, tissue and experiences</td>
<td>Peter Riegman, Rotterdam, NL</td>
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<td>Hans Gelderblom, NL</td>
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<td>12:15-12:25</td>
<td>Different types and purposes for cancer registries</td>
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<td>Hans Gelderblom, NL</td>
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<td>12:35-12:45</td>
<td>How patient groups can contribute to research?</td>
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<td>Jayne Bressington, Doynton, UK</td>
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<td>12:45-13:00</td>
<td>Q&amp;A and discussion</td>
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<td>13:00-14:00</td>
<td>lunch</td>
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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)

14:30-15:30 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
Speaker 1 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
Speaker 2 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 Lebrocquy, 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

PART 4: 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)