

## Working Group on Rare Cancers (WGRC) Meeting

**Date:** 8 June 2018

**Time:** 12:00 – 16:00

**Location:** [Renaissance Hotel, Brussels](#)

**Theme:** Medical Education

### Agenda

**12:00 - 12:15 Registration**

Registration table, [Madrid room](#)

**12:15 - 12:25 Opening Message**

Francesco De Lorenzo, ECPC President

**12:25 – 12:50 Welcome Speech and Introductions**

Jana Pelouchova, ECPC General Secretary and WGRC Chair

Mary Skehan, WGRC Co-Chair

Isabelle Manneh-Vangramberen, ECPC Head of Health and Research Programmes  
WGRC Members

**12:50 - 13:05 Update on ECPC 2107/2018 activities in Rare Cancers**

Jana Pelouchova, ECPC General Secretary and WGRC Chair

**13:05 - 13:20 Joint Action on Rare Cancer: JARC 2018/2019 Priorities**

Dr. Annalisa Trama, Insituto Italiano Dei Tumouri JARC Coordination team

**13:20 - 13:30 European Reference Network: boosting cooperation through ERNs**

ERNs' role in Promoting Patients' Rights: Isabelle Manneh-Vangramberen, ECPC Head of Health and Research Programmes

**13:30 - 13:40 Patient Educational Material in Europe: What's out there and what is needed**

Isabelle Manneh-Vangramberen, ECPC Head of Health and Research Programmes

**13:40 - 14:00 WGRC Members feedback: Identifying gaps in Rare Cancer patient Educational Material while sharing success stories and challenges at the local level**

Facilitated by:

Jana Pelouchova, ECPC General Secretary and WGRC Chair

Mary Skehan, WGRC Co-Chair

Isabelle Manneh-Vangramberen, ECPC Head of Health and Research Programmes

**14:00 – 14:30 Stretch / Lunch break**

**14:30 - 15:00 Best Practices in Rare Cancer Patient Information:**

- Merkel Cell Carcinoma: Lindsey Devlin, NET Foundation
- Radiotherapy in Head and Neck Cancer: Pr. Vincent Gregoire, Université Catholique de Louvain in Belgium

**15:00 - 15:20 WGRC Members brain storming session: with a specific focus on Patient Educational Material**

Facilitated by:

Jana Pelouchova, ECPC General Secretary and WGRC Chair  
Mary Skehan, WGRC Co-Chair  
Isabelle Manneh-Vangramberen, ECPC Head of Health and Research Programmes

**15:20 – 15:50 WGRC Members feedback: JARC with a specific focus on 2018/2019 priorities**

Facilitated by:

Jana Pelouchova, ECPC General Secretary and WGRC Chair  
Mary Skehan, WGRC Co-Chair  
Isabelle Manneh-Vangramberen, ECPC Head of Health and Research Programmes

**15:50 - 16:00 Wrap up**

Jana Pelouchova, ECPC Secretary and WGRC Chair