



## International Childhood Cancer Awareness Day 2015

### **‘Balancing Personal Data Protection and Research Progress: The Case of Childhood Cancer’**

**Tuesday 3 February 2015**

**10:30 – 12:30**

*followed by a networking lunch*

**European Parliament**

**Hosted by MEP Glenis Willmott (S&D, UK)**

## Programme

- 10.30 – 10.35**    **MEP Glenis Willmott (UK): Welcoming Speech**
- 10.35 – 10.40**    **Prof. Gilles Vassal, SIOPE President (FR): Opening remarks**
- 10.40 – 11.30**    **PART I: Setting the Scene - Data Protection and Childhood Cancer**
- 10.40 – 11.20**        **Practical examples of impact on paediatric cancer research**
- 10.40 – 10:48     *Enhanced population-based Cancer Registry Data to serve Outcome Research - Past Benefits and Future Complexities*  
**Speaker: Prof. Kathy Pritchard-Jones (UK)**
- 10:48 – 10:56     *Survivor's perspective: Quality of Life and Long Term Follow Up*  
**Speaker: Mr. Jaap den Hartogh (NL)**
- 10:56 – 11:04     *Data Linkage of Clinical Trial Data to Research Biomaterial Suppositories*  
**Speaker: Prof. Ruth Ladenstein (AT)**
- 11:04 – 11:20     *Use of Tumour Materials for Research: Researcher and Parents' perspective*  
**Speakers:**  
- **Prof. Angelika Eggert (DE)**  
- **Ms Sabine Karner (AT)**
- 11:20 – 11:35**     **Legal perspective on the implications for paediatric haematology oncology**
- Speakers:**  
- **Prof. Nikolaus Forgo (DE)**  
- **Dr. Marc Stauch (DE)**



## 11.35 – 12.20 **PART II: Stakeholder Statements and Roundtable discussion**

Chairs: **MEP Glenis Willmott** (UK) and **Prof. Gilles Vassal** (FR)

- **European Parliament:**
  - o **MEP Jan Philipp Albrecht** (DE)
  - o **MEP Nessa Childers** (IE)
- **European Commission:**
  - o Directorate-General for Health and Food Safety: **Dr. Tapani Piha** (EU)
- **EU Council Presidency - Latvia**
  - o **Ms Baiba Jugane-Lintere** (LV)
- **Academic Representative:**
  - o **Prof. Martin Schrappe** (DE)
- **Parent/Patient Associations:**
  - o **Ms Sabine Karner** (AT)

**12.20 – 12.25 Prof. Gilles Vassal (FR): Summary of discussions**

**12.25 – 12.30 MEP Glenis Willmott (UK): Conclusions**

**12.30 – 13.30 Networking lunch (PHS 5 B 001, 5<sup>th</sup> floor)**