

STOA Workshop

EU collaborative models to tackle childhood cancer

5 July 2023, 14:00 - 16:00 CET
Room SPAAK 7C50



Rare diseases affect less than 5 out of 10 000 people in the EU, with childhood cancer being a leading cause of death among children aged [5 to 14](#). Although there has been significant progress in the diagnosis and treatment of childhood cancer, there remains a lack of organisational and legal coordination among EU Member States.

This workshop aims to address the legal, societal, and technical challenges of developing multi-country collaboration models for childhood cancer as a model for rare diseases. Experts from various sectors will discuss ways to improve EU coordination in the research and innovation (R&I) for new medicines, vaccines, medical devices and equipment, knowledge and data sharing, resources and infrastructure, and education and training.

The STOA event is crucial for Members of the European Parliament in discussing the upcoming revision of the EU legislation on rare diseases. It is also relevant in the context of the European Health Data Space ([2022/0140\(COD\)](#)), the General Data Protection Regulation ([2016/679](#)) and the EP resolution on cancer ([2020/2267\(INI\)](#)).

Programme

14:00-14:10 Welcome remarks and introductory statement

Pernille WEISS, MEP and STOA Panel member

14:10 - 15:20 Panel discussion

- **Nicholas LARLING**, Deputy Head of unit 'Health monitoring and cooperation, Health networks', DG SANTE, European Commission
- **Kjeld SCHMIEGELOW**, Professor of pediatrics and pediatric oncology, Copenhagen University Hospital (DK)
- **Ruth LADENSTEIN**, PaedCan coordinator (AT)
- **Lucie SRAMKOVA**, Head of Department of Paediatric Hematology and Oncology, Motol University Hospital, Prague (CZ)
- **Uta DIRKSEN**, President-Elect of the European Society of Pediatric Oncology (SIOPE)
- **Patricia BLANC**, parent representative and CCI-E European Affairs Committee Member

15:20 - 15:50 Questions & Answers

15:50 - 16:00 Closing remarks

Pernille WEISS, MEP and STOA Panel member

The event will be held in English.

The event will be webstreamed. The link will be published on the event page.