

EU collaborative models to tackle childhood cancer

STOA Workshop

Wednesday, 5 July 2023, 14:00 - 16:00 CET

Room SPAAK 7C50

Participants' booklet

Available at <https://www.europarl.europa.eu/stoa/en/events/details/eu-collaborative-models-to-tackle-childh/20230420WKS05221>

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1. Programme

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

Pernille WEISS, MEP and STOA Panel member (EPP, Denmark)

14:10–15:20 Panel discussion

Nichola LARKINS, 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 Q&A

15:50–16:00 Closing remarks

Pernille WEISS, MEP and STOA Panel member (EPP, Denmark)

The event is held in English.

2. Introduction

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 1 to 19. 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\(INI\)](#)).

3. Welcome and opening

3.1. Pernille WEISS, MEP and STOA Panel member



[Pernille Weiss](#) (EPP, Denmark) is a member of the European Parliament for the EPP Group and the Conservative People's Party (Denmark). She has a seat on the Committee on the Environment, Public Health and Food Safety ([ENVI](#)) and the Committee on Industry, Research and Energy ([ITRE](#)). She also has a substitute seat in the Committee on Women's Rights and Gender Equality ([FEMM](#)) and the Special Committee on the COVID-19 pandemic ([COVI](#)). Additionally, she is the chair of the MEP [Interest Group on Obesity and Health System Resilience](#) and a Member of the Panel for the Future of Science and Technology ([STOA](#)). MEP Weiss is a trained nurse, holds a cand.scient. in Health Sciences and a master in innovation and management (LAICS), and is a certified sexologist. Previously to entering the European Parliament, MEP Weiss ran her own company for 12 years.

4. Speakers

4.1. Nichola LARKINS, Deputy Head of Unit 'Health monitoring and cooperation, Health networks', DG SANTE, European Commission



Nichola is the deputy head of unit for DG SANTE's Health monitoring and cooperation, health networks unit. She joined the European Commission in 2019 within DG SANTE's Crisis management and preparedness in health unit. During this time in DG SANTE she worked on the EU's health security framework and was closely involved in the Commission's health response to the COVID-19 pandemic.

Following this, Nichola worked in the Health Emergency preparedness and Response Authority (DG HERA) and then returned to DG SANTE's health security unit to work on the implementation of the Regulation on serious cross border threats to health.

Nichola holds a B.A. in Arabic and Geography and an M.A. in Public Policy and International Affairs. Prior to joining the Commission, Nichola was working with Médecins Sans Frontières based in Amman, Jordan.

Take-home message

The Commission has put a particular spotlight on policy actions, research efforts and funding for childhood cancers in Europe's Beating Cancer Plan and in the Horizon Europe Mission on Cancer.

Paediatric cancers are also dealt with the European Reference Networks; virtual networks involving healthcare providers across Europe to tackle complex or rare diseases and conditions that require highly specialised treatment and concentrated knowledge and resources.

4.2. Kjeld SCHMIEGELOW, MD, Professor in Pediatrics, Head of Pediatric Oncology University Hospital Rigshospitalet, Copenhagen, Denmark



Professor [Kjeld Schmiegelow](#) is Head of Paediatric Oncology, Copenhagen University Hospital Rigshospitalet. He was Secretary General of The Nordic Society for Paediatric Haematology/Oncology 2000-2005 and the European Branch of the International Society for Pediatric Oncology 2002-2006. He is currently Chair of the European [I-BFM Committee](#) for Acute Lymphoblastic Leukemia (most common childhood cancer). His main research interests include the etiology of childhood cancer, including the role of cancer prone syndromes; cancer biology; pharmacology of anticancer agents and associated acute and chronic toxicities; psychosocial effects of childhood cancer; late effects, rehabilitation and quality of life. He has chaired multiple international research programs within all these areas. He has published 517 scientific papers.

Take-home message

In combination rare diseases affect 35 million Europeans. In general, the 7000 known rare diseases, including childhood cancers, lack behind in health care.

Childhood cancer constituted only 10% of all deaths in the age group 1-15 years during the 1960'ies, whereas it is responsible for 20% of all deaths in that age group, although with significant differences between member states. Although the death rates from childhood cancer have decreased markedly in recent decades and more than 80% of childhood cancer patients now survive, the improved survival is even more profound for more common diseases such as congenital malformations or infections. The initial therapy for childhood cancer fails in 25-30% of all cases and therapy needs to be adjusted or replaced by more experimental approaches. In addition, 20% of childhood cancer deaths (50% for leukemias) are caused by the treatment, and not by the cancer itself, and there is wide variation in how centers deal with treatment-related toxicities.

Across Europe, a recent EURO-CARE study showed that survival from childhood cancer was higher when treatment was given in higher-volume hospitals compared to lower-volume hospitals (Gatta, European Journal of Cancer, 2019). Thus, there is an unmet need for establishment of deep networking between a limited number of childhood cancer centers. Although such networks can address multiple aspects of pediatric oncology, the most important aim is well-defined prospective sharing of clinical data based on clear legal contracts between the involved institution and based on families' informed consent in order to promote clinical expertise, complementary research and test innovative therapeutic strategies. Such prospective data sharing is not feasible within current legal frameworks, in spite of its support by clinicians, researchers and families.

4.3. Ruth LADENSTEIN, Professor in Paediatrics, ERN PaedCan coordinator, St. Anna Children's Hospital, Vienna, Austria



Ruth Ladenstein is Professor in Paediatrics and Senior Consultant for Paediatric Haematology and Oncology at the St. Anna Children's Hospital. She is Head of the Clinical Trials Unit S²IRP (Studies & Statistics for Integrated Research and Projects) at the Children's Cancer Research Institute ([CCRI](#)), St. Anna Kinderkrebsforschung GmbH. Her recent project activities are the coordination of the European Reference Network in Paediatric Cancer [ERN PaedCan](#), and the Austrian Medicine for Children Research Network [OKIDS](#). Among other involvements, she is a member of the Oncology Advisory Board of the Ministry of Health Austria, an advisory board member of the [SIOPEN](#) Europe Neuroblastoma Group, as well as Co-Chair of the Transatlantic Working Group bridging the US Moonshot initiative with the EU's European Beating Cancer Plan and Cancer Mission.

During her presidency from May 2007 – May 2011 she founded the SIOPEN Association in Vienna giving SIOPEN a legal structure and governance. Since 2002 she is principle Coordinating Investigator of the High Risk Neuroblastoma 1/SIOPEN trial and associated ch14.18/CHO development tasks. By now, the "*SIOPEN Association to foster neuroblastoma research*" has 495 active members in 34 countries, 29 countries are involved in SIOPEN studies.

Furthermore, Prof. Ladenstein is Chair of the Austrian Group for Paediatric Haematology-Oncology ([AGPHO](#)) and Chair of the Specialisation Commission in Paediatric Haematology and Oncology of the Austrian Medical Association 2022-2027.

4.4. Lucie ŠRÁMKOVÁ, MD, PhD, Head of Department of Paediatric Hematology and Oncology, Motol University Hospital, Prague, Czechia



Dr. Lucie Šrámková is an Associate Professor of Pediatrics at the Department of Pediatric Hematology and Oncology, [University Hospital Motol](#), Prague, Czechia. She received her Ph.D. in biological sciences from the Second Medical Faculty at [Charles University](#), Prague. Dr. Šramková's primary interest includes the biology and the treatment of hematological malignancies in children, mainly resistant acute leukemias. She is involved in many academic and commercial clinical studies in pediatric malignancies, her research activities are supported by national and EU grants.

Take-home message

Childhood cancer is a rare disease and for obtaining experiences in this field it's necessary to cooperate not only at the national but also at the international level. This cooperation is essential to better the quality of care and the scientific advancement in the treatment of childhood cancer which is the second most common cause of death in children. New drug development in pediatrics often falls behind the drug development for adults. This is caused by the rarity of pediatric cancer. Therefore many drugs used in pediatrics are approved only for adults. The Eastern part of the European Union has in general unequal access to new drugs and their development. As access is dependent not only on the high quality of diagnostics and treatment but also on the education of highly specialized staff such as study coordinators, data managers, and other members of research teams and their funding. In the last years, the gap between Western and Eastern access to new drugs has begun shrinking especially thanks to various European activities and the NGO sector. But as always there is still some room for improvements.

4.5. Uta DIRKSEN, PhD, President-Elect of the European Society of Pediatric Oncology (SIOPE)



University Professor Uta Dirksen PhD is a Professor for Paediatrics and a Paediatric Haematologist and Oncologist. She is the vice director of the [Paediatric III](#) Haematology, Oncology, Cardiology, Rheumatology, Immunology and Pulmonology of the University Hospital Essen. Furthermore, she is a full Professor at the University Duisburg- Essen, where she is leading the Paediatrics Sarcoma Unit and is the core team for the Paediatric Phase I/II unit. At the West German Cancer Centre (WTZ) she is [Vice Director](#) and Head of the AYA Unit at the same institution.

On the national level, she is the elected vice chair of the German Society for Paediatric Oncology and Haematology ([GPOH](#)) and leader of the Adolescents young adults and transition “AJET” group of the GPOH and part of the German Consortium for Translational Cancer Research (DKTK), NCT Cologne-Essen.

On an international level she is the Head of the International Cooperative Ewing Sarcoma Study Group, upcoming president of European Society for Paediatric Oncology ([SIOPE](#)), member of the International Society of Paediatric Oncology (SIOP), member of the Clinical Trials, Solid Tumor and Biology Committee of Innovative Therapies for Children with Cancer (ITCC) and leader of the Ewing Sarcoma ERN-group. She is furthermore active member of the EORTC Soft Tissue and Bone Sarcoma Group and our national and the international late effect guidance harmonization group. She was also an active member in the ENCCA project that led to the implementation of the SIOPE CRC 10 years ago.

Her main clinical and research interest is in sarcoma of children and young people. She published a multitude of publications on sarcoma especially Ewing Sarcoma in children and young people in various journals and furthermore received various Grants for research projects.

Take-home message

In rare diseases, such as Childhood Cancer, we have a great chance and opportunity to work together for a better cure for all patients. This also includes a close connection and partnership with so called “widening countries” as even in Europe we still have a geographical gap in outcome of survival and late effects of childhood cancer patients. It is of the utmost importance to develop novel treatment strategies for paediatric cancers that are still incurable, wherever the child is diagnosed with cancer. International cooperation will be of the utmost importance to develop and launch clinical trials in children and adolescents with cancer in Europe.

4.6. Patricia BLANC, parent representative and CCI-E European Affairs Committee Member



Patricia Blanc founded Imagine for Margo - Children without Cancer in 2011 to accelerate research against childhood cancer, the leading cause of death by disease in children in France and Europe. She collaborates closely with the pediatric oncology scientific community and other parents' associations in France and Europe, and is a member of ACCELERATE, CCI-E, and ITCC. Blanc has received the French National Order of Merit for her service as president of Imagine for Margo.

Take-home message

Childhood cancer remains the primary cause of disease-related death for children above one year old in Europe, with 35,000 new diagnoses and 6,000 deaths annually. Pediatric cancers encompass over 60 types and present numerous challenges. Parent representatives emphasize issues such as the lack of progress in survival rates for certain tumor types, including brain tumors, and the scarcity of approved medications for children compared to adults.

This presentation highlights collaborative initiatives within the pediatric oncology community aimed at increasing the number of children participating in clinical trials and improving access to innovative drugs that could benefit rare diseases. ACCELERATE brings together stakeholders to accelerate drug development for childhood cancers. The creation of Paediatric Strategic Forums, where industry and academia share scientific knowledge on specific molecular targets and seek input from regulators and parents, proves valuable in setting drug development priorities.

The FAIR Trials initiative incentivizes and rewards the inclusion of children in adult clinical trials, thereby increasing the number of children participating in clinical trials. Additionally, the academic community of SIOPE and the parents' organization of CCI-E have collaborated to adapt pediatric medicine regulations, which were previously ineffective for children with cancer. The proposed review of the regulation as part of the EU pharma strategy includes the development of drugs based on molecular targets, the introduction of prioritization, recognition of data for drug repositioning, and the progressive Pediatric Investigation Plan, changes which are beneficial for rare diseases.

Challenges remain in ensuring access to innovative treatments. It is crucial to develop incentives for drugs specifically designed for children and for implementation and harmonisation across all Member States.

5. About STOA

5.1. Mission

The Panel for the Future of Science and Technology ([STOA](#)) forms an integral part of the structure of the European Parliament. Launched in 1987, STOA is tasked with identifying and independently assessing the impact of new and emerging science and technologies.

The goal of its work is to assist, with independent information, the Members of the European Parliament (MEPs) in developing options for long-term, strategic policy-making.

The STOA Panel

The STOA Panel consists of 27 MEPs nominated from eleven permanent parliamentary committees: Agriculture & Rural Development ([AGRI](#)), Culture & Education ([CULT](#)), Employment & Social Affairs ([EMPL](#)), Environment, Public Health & Food Safety ([ENVI](#)), Internal Market & Consumer Protection ([IMCO](#)), International Trade ([INTA](#)), Industry, Research & Energy ([ITRE](#)), Legal Affairs ([JURI](#)), Civil Liberties, Justice and Home Affairs ([LIBE](#)), Regional Development ([REGI](#)) and Transport & Tourism ([TRAN](#)).

[Marc ANGEL](#) is the European Parliament Vice-President responsible for STOA for the second half of the 9th parliamentary term. The STOA Chair for the second half of the 9th parliamentary term is [Christian EHLEER](#), with [Ivo HRISTOV](#) and [Ivars IJABS](#) elected as 1st and 2nd Vice-Chairs, respectively.

The STOA approach

STOA fulfils its mission primarily by carrying out science-based projects. Whilst undertaking these projects, STOA assesses the widest possible range of options to support evidence-based policy decisions. A typical project investigates the impacts of both existing and emerging technology options and presents these in the form of studies and options briefs. These are publicly available for download via the [STOA website](#).

Some of STOA's projects explore the long-term impacts of future techno-scientific trends, with the aim to support MEPs in anticipating the consequences of developments in science. STOA communicates its findings to the European Parliament by organising public events throughout the year.

Focus areas

STOA activities and products are varied and are designed to cover as wide a range of scientific and technological topics as possible, such as genetic engineering, antimicrobial resistance, energy, pollution, sustainable agriculture and fishing, artificial intelligence & digital technologies such as blockchain, 5G, satellite communications, IoT and Internet, Covid-19 and health in general.

These activities are clustered within three main thematic areas: Artificial intelligence & other disruptive technologies, The new Green Deal, and Quality of life. In addition, STOA's work addresses four cross-cutting policy areas: Science, technology and innovation; Societal and ethical challenges; Economic challenges; and Legal challenges.

ESMH

The European Science-Media Hub ([ESMH](#)), operating under the political responsibility of the STOA Panel, is a platform to promote networking, training and knowledge sharing between the European Parliament, the scientific community and the media. The ESMH creates a network among policy-makers, scientists and media involving science, academia, educational and research entities, and professional associations of journalists and scientists.

For journalists and media representatives, the ESMH organises training sessions and workshops on current technological developments, both as subjects of their reporting and as means of facilitating their work. Via media monitoring and media intelligence tools, the ESMH follows the most popular topics in the field of science and technology on different platforms including journals, newspapers and social media.







The ESMH makes information available to journalists, other media and citizens about new scientific developments, as well as about scientific topics that attract media attention, and promotes information based on evidence.














Centre for AI (C4AI)

To intensify its activities in the field of artificial intelligence (AI), STOA has launched its Centre for AI ([C4AI](#)). C4AI was established by decision of the STOA Panel on 19 December 2019 and was announced at the high-level STOA workshop '[The Future of Artificial Intelligence for Europe](#)', which took place on 29 January 2020 at the European Parliament in Brussels.

Within the context of STOA and based on decisions of the STOA Panel, C4AI produces studies, organises public events and acts as a platform for dialogue and information exchange on AI-relevant topics within the Parliament and beyond. In particular, it provides expertise on the possibilities and limitations of AI and its implications from an ethical, legal, economic and societal perspective. Through these activities, C4AI aims to contribute to the quality and coherence of discussion and policy-making as the EU seeks to coordinate its efforts and influence global AI standard-setting.

5.2. STOA Panel members

	Panel Member	Committee		Panel Member	Committee
	Marc ANGEL (S&D, LU) EP Vice-President STOA Bureau member			Rosa D'AMATO (Greens/EFA, IT)	REGI
	Christian EHLER (EPP, DE) STOA Chair STOA Bureau member	ITRE		Jakop DALUNDE (Greens/EFA, SE)	TRAN
	Ivo HRISTOV (S&D, BG) 1st STOA Vice- Chair - STOA Bureau member	ITRE		Pietro FIOCCHI (ECR, IT)	ENVI
	Ivars IJABS (Renew Europe, LV) 2nd STOA Vice- Chair - STOA Bureau member	ITRE		Emmanouil FRAGKOS (ECR, EL)	AGRI
	Atidzhe ALIEVA- VELI (Renew Europe, BG)	EMPL		Lina GALVEZ MUÑOZ (S&D, ES)	EMPL
	Adam BIELAN (ECR, PL)	IMCO		Maria GRAPINI (S&D, RO)	TRAN
	David CORMAND (Greens/EFA, FR)	IMCO		Martin HLAVÁČEK (Renew Europe, CZ)	AGRI

	Panel Member	Committee		Panel Member	Committee
	Marina KALJURAND (S&D, EE)	LIBE		Susana SOLÍS PÉREZ (Renew Europe, ES)	ENVI
	Radan KANEV (EPP, BG)	EMPL		Barbara THALER (EPP, AT)	TRAN
	Maria-Manuel LEITÃO-MARQUES (S&D, PT)	IMCO		Patrizia TOIA (S&D, IT)	ITRE
	Victor NEGRESCU (S&D, RO)	CULT		Marion WALSMANN (EPP, DE)	JURI
	Michèle RIVASI (Greens/EFA, FR)	ENVI		Pernille WEISS (EPP, DA)	ITRE
	Bronis ROPĖ (Greens/EFA, LT)	AGRI		Juan Ignacio ZOIDO ALVAREZ (EPP, Spain)	INTA
	Jordi SOLÉ (Greens/EFA, ES)	ITRE	AGRI: Agriculture and Rural Development CULT: Culture and Education EMPL: Employment and Social Affairs ENVI: Environment, Public Health and Food Safety IMCO: Internal Market and Consumer Protection INTA: International Trade ITRE: Industry, Research and Energy JURI: Legal Affairs LIBE: Civil Liberties, Justice and Home Affairs REGI: Regional Development TRAN: Transport and Tourism		

5.3. STOA administration

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Luisa ANTUNES

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Vasco Nuno GUEDES FERREIRA

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