



ICCD2022 DRAFT PROGRAMME

Four years of GDPR implementation in European childhood cancer research:

Taking stock of the impact, re-defining the needs

2 February 2022 (12:00 – 14:00 CET)

Format: Online, link available upon registration

Hosted by Loucas Furlas MEP (EPP, Cyprus)

In collaboration with:



ABOUT ICCD

Currently in its 12th edition, the **ICCD is an annual flagship conference to mark the International Childhood Cancer Awareness Day (15 February)**. The event regularly gathers a large multi-stakeholder audience with interest in childhood cancer and related issues on the health and research agenda.

All individually rare, paediatric cancers jointly represent the first cause of death by disease in children older than 1 year in Europe: more than 6,000 young patients die, and 35,000 cases are diagnosed annually. The rarity of individual paediatric cancer types and their leading collective health burden in Europe make coordinated EU level approaches crucial. The ICCD event is thus dedicated to finding novel solutions to foster more and better cures for childhood cancer through EU policy, programmes, and collaboration with all stakeholders.

The EU General Data Protection Regulation (GDPR) has been a key milestone in childhood cancer due to the importance of cross-border health research data sharing in this rare disease field. Four years after the implementation of the GDPR, ICCD 2022 will focus on its implications for childhood cancer professionals and parents, patients, and survivors and engage key stakeholders to elucidate the current framework and ways to achieve further progress.



Programme ICCD 2022

12:00 – 12:05	WELCOME REMARKS
	<ul style="list-style-type: none"> - Loucas Furlas MEP (EPP, CY) - Carmelo Rizzari, SIOPE President (University of Milano-Bicocca, IT) - Anita Kienesberger, CCI Europe Committee Chair (AT)
12:05 – 12:15	SPECIAL ADDRESSES
	<ul style="list-style-type: none"> - Stella Kyriakides, European Commissioner for Health and Food Safety (<i>video address</i>) - Manfred Weber, MEP and EPP Group Chairman (EPP, DE) (<i>video address</i>) - Little Heroes: a message of hope from Cypriot non-profit childhood cancer organisation (<i>video address</i>)
12:15 – 12:30	<u>PART I: Presentation of the State of Play – GDPR Survey Results</u>
	CHAIR: Carmelo Rizzari, SIOPE President (University of Milano-Bicocca, IT)
	<u>The Impact of the GDPR on Childhood Cancer Research – Key Survey Findings</u> <ul style="list-style-type: none"> - Gilles Vassal, SIOPE Board Member and Policy Lead (Gustave Roussy, FR) - Delphine Heenen, CCI Europe Committee Member and European Affairs Committee Lead (KickCancer, BE)
12:30 – 13:50	<u>PART II: Panel Discussion and Q&A: How to optimise the GDPR to facilitate childhood cancer research</u>
	<u>CHAIR:</u> <ul style="list-style-type: none"> - Pamela Kearns, SIOPE Past President (University of Birmingham, UK) <u>PANELISTS:</u> <u>European Parliament:</u> <ul style="list-style-type: none"> - Tomislav Sokol MEP (EPP, HR) - Cyrus Engerer MEP (S&D, MT) <u>European Commission:</u> <ul style="list-style-type: none"> - Owe Langfeldt, Legal and Policy Officer – Data Protection, DG JUST - Jerome de Barros, Policy Officer – Digital Health, DG SANTE <u>International Agency for Research on Cancer (IARC):</u> <ul style="list-style-type: none"> - Eva Steliarova-Foucher, Scientist, Cancer Surveillance <u>Academia:</u> <ul style="list-style-type: none"> - Ruth Ladenstein, SIOPE Board Member & ERN PaedCan Coordinator (CCRI, AT) - George Astras, Director of Medical Oncology (American Medical Center/Platonas Medical Center, CY) <u>Survivors:</u> <ul style="list-style-type: none"> - Zuzana Tomášiková, CCI Europe Committee Member and Survivorship Lead (CH) Q&A WITH THE AUDIENCE
13:50 – 14:00	CONCLUDING REMARKS
	<ul style="list-style-type: none"> - Carmelo Rizzari, SIOPE President (University of Milano-Bicocca, IT) - Anita Kienesberger, CCI Europe Committee Chair (AT) - Loucas Furlas MEP (EPP, CY)

ABOUT THE ORGANISERS



The European Society for Paediatric Oncology (SIOP Europe or SIOPE) is the only pan-European organisation representing all professionals working in the field of childhood cancers. With more than 2,300 members across 35 countries, SIOP Europe is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe. www.siope.eu

Representing childhood cancer professionals, SIOP Europe is working in Memorandum-based partnership with European organisations of parents, patients and survivorship community:



Childhood Cancer International – Europe (CCI Europe, or CCI-E) represents childhood cancer parents' and survivors' groups as well as other childhood cancer organisations in Europe: 67 organisations in 34 European countries are members of CCI. CCI Europe works together with all relevant stakeholders for the same aim, namely to help children and adolescents with cancer to be cured, with no – or as few as possible – long term health problems/late effects. www.ccieurope.eu



The Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare) is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side effects of the treatment of children and adolescents with cancer. Together with the paediatric oncology community PanCare is working to achieve equity of access to care for childhood cancer survivors across Europe, to perform collaborative research, to develop evidence-based surveillance guidelines together with the International Guideline Harmonisation Group and to act as a resource of research-based information concerning all late side-effects of cancer treatment. www.pancare.eu