



12th Edition

International Childhood Cancer Awareness Day (ICCD2022)

2 February 2022
12:00 to 14:00 CET

Virtual
Event

SPEAKER PROFILES

International Childhood Cancer Awareness Day (ICCD 2022)

Wednesday 2 February 2022 (12:00 – 14:00 CET)

‘Four years of the General Data Protection Regulation (GDPR) implementation in European childhood cancer research: taking stock of the impact, re-defining the needs’

EVENT HOST AND CHAIRS

Host

Loucas Fourlas
MEP (EPP, CY)



Loucas Fourlas was born in 1969 Limassol, Cyprus. He undertook university studies between the period 1989 – 1994 at the Aristotle University of Thessaloniki, Greece in Economics and Political Sciences. In 2006, he attended a number of courses in Research Journalism and International Crisis at the Columbia and Washington Universities respectively in the USA.

Loucas Fourlas is known for his long-lasting career as a Journalist and TV presenter (1995-2016) as well as for being the Press Secretary of the Presidential candidate Mr. Ioannis Kasoulidis during the Cyprus elections in 2008. He has also served as the Press secretary of the Cypriot Parliament for 2 consecutive years (2017-2019). During the euro-elections in May 2019, he received the highest number of votes in Cyprus, and since then he is undertaking duties representing Cyprus as a Member of the European Parliament.

Loucas Fourlas is also the Ambassador of the Charity Foundation “Hope” and Founder of the philanthropic organisation “Little Heroes” – children who suffer from cancer. In 2020, he was a candidate for the Health Award in the context of the Parliament Magazine’s MEP Awards. He was a member of the European Parliament’s Beating Cancer Committee (BECA) and Co-Chair of the MEPs Against Cancer (MAC) Interest Group. An important contribution to the BECA Committee’s own-initiative report on ‘Strengthening Europe in the fight against cancer’ was Loucas Fourlas’ initiative for a number of amendments dedicated to childhood cancer, notably the integration of small countries to clinical trials.

Loucas Fourlas is the author of the book ‘A sea upon a time’ depicting a special childhood story that was selected for the campaign [‘Readers of Europe 2021 – recommendation by the Permanent Representation of Cyprus to the EU’](#). All the revenues associated with the book will be donated to the philanthropic organisation “Little Heroes”. In addition, he recently published his second book entitled ‘23 years on air’.

Carmelo Rizzari
SIOPE President
**(University of Milano-
Bicocca, IT)**



Prof. Carmelo Rizzari is a Professor of Paediatrics at the University of Milano-Bicocca, Italy and has been involved in the field of paediatric leukaemias with a special interest in both traditional and innovative chemotherapy agents. He is currently running the Paediatric Haematology-Oncology Unit in Monza (MBBM Foundation, ASST Monza, University of Milano-Bicocca, Italy), which is one of the largest centres for the diagnosis and treatment of haematological malignancies in Italy.

Since the start of his career, he has been involved in the field of paediatric leukaemias with a special interest in both traditional and innovative chemotherapy agents.

He is currently Chairman of the AIEOP (Associazione Italiana di Ematologia ed Oncologia Pediatrica) Acute Lymphoblastic Leukaemia (ALL) Committee which aims to improve the knowledge and treatment of childhood ALL in the country. He is also a member of the national AIEOP scientific committees for first-line and relapsed trials for ALL and AML and an active member of several scientific and steering international committees (e.g. AIEOP-BFM ALL trials, International BFM Study Group, ITCC, INTREALL). Within the ITCC Consortium (Innovative Therapies for Children with Cancer), he served as a member of the Quality and Accreditation Committee and is currently the Chair of the ITCC Centre of Monza, Italy.

For several years now, he is also serving as the representative of the International BFM Study Group at ENPREMA (European Network for Paediatric Research at EMA) which aims to foster and integrate at the European level the research and innovation in different paediatric areas.

He is also currently national PI or Co-PI or local site PI for several national or international phase I and II Pharma sponsored or Academia driven studies involving innovative drugs for resistant/relapsed leukaemias and lymphomas.

Author or co-author of over 150 peer-reviewed scientific publications, he has also actively participated as an invited speaker in several international scientific meetings and disease-specific working groups.

As of January 2022, he is the President of the European Society for Paediatric Oncology (SIOPE Europe, or SIOPE). He previously served as Co-Chair of the SIOPE Europe Clinical Research Council, which gathers the thirty-five National Paediatric Haematology-Oncology Societies and the nineteen European Clinical Trial Groups.

Pamela Kearns
SIOPE Past President
(University of
Birmingham, UK)



Prof. Pamela Kearns is Chair of Clinical Paediatric Oncology at the University of Birmingham and an Honorary Consultant Paediatric Oncologist at Birmingham Women and Children’s Hospital. She is Director of the University of Birmingham’s Institute of Cancer and Genomic Sciences and Director of the Cancer Research UK Clinical Trials Unit (CRCTU). As Director of CRCTU, she leads the research strategy for one of the UK's largest cancer trials units, delivering a trials portfolio of over 100 multi-centre & international cancer trials for a wide range of cancers, occurring in all children, young people and adults, notably leading the National Children’s Cancer Trials Team responsible the vast majority of UK’s clinical trial portfolio for children and young people with cancer. Her research is focussed on research in childhood acute leukaemias and lymphomas and drug development and innovation in the design and delivery of clinical trials for childhood cancers.

She served as President of the European Society for Paediatric Oncology (SIOPE Europe) from 2019 to 2021, having been a Board member since 2013 and now continues to sit on the Board of SIOPE Europe as Past President. She has several European roles including Executive Board Member of the academic consortium ‘Innovative Therapeutics in Childhood Cancer’ (ITCC), Chair of ITCC’s European Sponsor Institutions Committee and Steering Committee member of the International multi-stakeholder platform ‘ACCELERATE’. Her research interests are focussed of drug development and innovation of design and delivery of clinical trials for childhood cancers. She was also a Senior Clinical Advisor to Cancer Research UK from 2015 to 2020 and is now as Trustee for Cancer Research UK as well as continuing to be a Trustee of a Child of Mine, a charity dedicated to supporting bereaved parents. She is also Chair of the Research Assessment Panel for GOSH Charity, and Chair of The Independent Scientific Advisory Panel for Bone Cancer Research Trust.

Anita Kienesberger
CCI Europe Committee
Chair (AT)



Anita Kienesberger is the Chair of the CCI Europe Committee. Through her past role as Board Member of Childhood Cancer International (2003 – 2014), she put international collaboration high on the national as well as on the European agenda. Mrs. Kienesberger was also the CEO of the Austrian Childhood Cancer Organisation for 20 years. By training, Mrs. Kienesberger is a paediatric nurse with a specialisation in oncological diseases. She was Head of the Intensive Care Unit at the St. Anna Children’s Hospital in Vienna, Austria for over 10 years. Through her past experiences, she developed a multi-disciplinary approach to childhood cancer care.

Anita holds a master’s degree in international Gender Studies and Feministic Politics.

SPECIAL ADDRESSES

Stella Kyriakides European Commissioner for Health and Food Safety



During the COVID-19 crisis, **Stella Kyriakides** has been leading the Commission's work to coordinate the EU's health response and support Member States to tackle the pandemic. She is responsible for the EU's Vaccine Strategy in order to procure safe and effective vaccines for all EU Member States and Europe's broader neighbourhood. She is also responsible for the establishment of a strong European Health Union and supporting Member States to strengthen healthcare systems and deliver better patient outcomes for all EU citizens. She is leading the Commission's work on Europe's Beating Cancer Plan, to help improve cancer prevention and care and is in charge of developing a new Pharmaceutical Strategy to ensure that Europe has enough affordable medicines to meet its needs.

Previously, Stella Kyriakides was a clinical psychologist for the Cyprus Ministry of Health. In 2006-2019, she served in the Cyprus Parliament for the Democratic Rally party. She was appointed Head of the Cyprus Delegation to the Parliamentary Assembly of the Council of Europe (PACE). In 2017, she was elected President of the PACE.

Manfred Weber MEP and EPP Group Chairman (EPP, DE)



Manfred Weber is Chairman of the European People's Party (EPP) Group in the European Parliament. Born in Lower Bavaria in 1972, after a vocational baccalaureate and his military service, he became an engineer in physical technology working on environmental management and occupational safety. After two years as Member of the Bavarian State Parliament, he joined the European Parliament in 2004, where he became the EPP Group's Home Affairs Spokesman in 2006 and Vice-Chairman for Legal and Home Affairs in 2009. Since 2014, he is Chairman of the EPP Group. In 2019, he was the EPP lead candidate for the European elections. In the Christian Social Union (CSU) Party Manfred Weber has been Chairman of the Party Youth and District Chair for Lower Bavaria. Since 2015, he is Vice-President of the Party.

'Little Heroes' /Μικροί Ήρωες/



The 'Little Heroes' Foundation is a charity organisation duly registered in Cyprus as a non-profit foundation. 'Little Heroes' started its activity as an initiative inspired by MEP Loucas Fourlas in 2017. It aims to assist the financial and psychological support of children and their families who are battling cancer and leukaemia in the Paediatric Oncology Department of the Makarios Hospital in Cyprus. The foundation is run by volunteers who receive no remuneration for their work and covers the expenses of the families who go abroad for treatment. This is possible through the various events and contributions made by the foundation. The activities of the foundation include a large annual event that takes place every December.

SPEAKERS

Gilles Vassal
SIOPE Board Member and
Policy Affairs Lead
(Gustave Roussy, FR)



Trained as a Paediatric Oncologist, **Prof. Gilles Vassal** received his PhD in Pharmacology. He is Professor of Oncology in University Paris-Saclay. Former head of Clinical Research, he is currently heading the Pediatric Research programme at Gustave Roussy Comprehensive Cancer Center in France, a large cancer centre with 12,000 new patients annually.

For the last 20 years, Gilles Vassal dedicated his research, clinical and training activity to the development of new drugs for children and adolescents with cancer. He co-founded three European networks, an EU academic Consortium for Innovative Therapies for Children with Cancer (ITCC), the European Network for Cancer research in Children and Adolescents (ENCCA) and the European Expert Paediatric Oncology Reference Network for Diagnostics and treatment (ExPO-r-Net).

Gilles Vassal is currently the Chair of ITCC, a network that conducts a comprehensive new drug development program from the biology and preclinical evaluation to the early drug trials in 16 EU member states and Israel. He is Past-President (2013-2015) and currently Board Member of the European Society of Paediatric Oncology (SIOP Europe) driving the EU Paediatric Oncology Policy agenda of several topics.

He is also Chair of ACCELERATE (www.accelerate-platform.org) – a multi-stakeholder international platform to accelerate innovation for children and adolescents with cancer. Created in 2015, ACCELERATE is a partnership between academia, industry, regulatory agencies (EMA and FDA) and patient advocate groups committed to improve and speed up the development of innovative therapies.

He has authored more than 250 publications, is an expert at the European Medicine Agency and member of several Scientific Councils.

Delphine Heenen
CCI Europe Committee
Member and European
Affairs Committee Lead
(KickCancer, BE)



Delphine Heenen is a mother, founder, director and day-to-day manager. Delphine was a successful lawyer (Linklaters), a strategy consultant (Bain & Company) and active in the investment world of renewable energy (TTR energy). She first supported her son in his fight by, among other things, decorating his hospital bedroom with hundreds of drawings made by his school friends. Since January 2017, she decided to change tactics and to move up another gear to fight childhood cancers by founding and working full-time for KickCancer, which has been active with other European paediatric cancer organisations with the aim of improving the cure rate and reduce the long-term side effects of the treatments for children with cancer, by advocating for more research and innovative treatments. She has participated in the review process of the Paediatric Medicines Regulation and the Orphan Medicines Regulation in 2016-2018. She became a member of the CCI Europe Regional Committee in 2020 and is carrying out her European activities in this capacity.

**Tomislav Sokol MEP
(EPP, HR)**



Dr. Tomislav Sokol was born in Zagreb in 1982. He obtained his first degree in law at the Faculty of Law, University of Zagreb, in 2006, magna cum laude. He then obtained a Master of Law (LL.M.) specialising in European Union Law at the Katholieke Universiteit Leuven (KUL), Belgium, in 2009, magna cum laude. He defended his PhD at KUL, dealing with the free movement of cross-border health care services in the EU and its impact on national health insurance systems in 2014.

He was an Assistant Minister in the Ministry of Science and Education in 2017, after which he became a Member of the Croatian Parliament. He was a Member of the Croatian Parliament until July 2019, when he became a Member of the European Parliament. He is a Member of the Committee on the Internal Market and Consumer Protection (IMCO) and a Substitute Member of the Committee on Regional Development (REGI). So far, he has published around 20 papers and 1 book on issues concerning EU law, including several articles in European journals, such as the European Law Review and the European Law Journal. He has presented papers at many international conferences and worked on different research projects. Previously, he worked in a legal practice and is currently a Senior Lecturer at the Zagreb School of Economics and Management where he has taught Introduction to European Union and Principles of Law courses since the academic year 2010/2011. He is also an assistant professor at the Catholic University of Croatia where he has taught since the academic year 2016/2017. His areas of professional interest include the law of the European common market, EU health law, competition law, International and European social law and International and European trade law.

**Cyrus Engerer MEP
(S&D, MT)**



Graduated in European Union Politics and Law, **Cyrus Engerer** became a Member of the European Parliament in 2020 where he sits as a full member on the Committee for Environment, Public Health and Food Safety (ENVI) and on the Special Committee Beating Cancer. He is also a substitute member on the Committee on Civil Liberties, Justice and Home Affairs (LIBE) and on the Committee on Industry, Research and Energy (ITRE). He is also the co-chair of the Mental Health Coalition.

Among the notable successes in his work as an MEP in the last 11 months are becoming the lead negotiator for the Socialists and Democrats (S&D) regarding the historic declaration of the EU as an LGBTI Freedom Zone and being appointed drafter and negotiator on the Parliamentary resolution concerning the rights of LGBTIQ citizens in Hungary. Also, following his appointment to the Committee on Environment and Health (ENVI Committee), he became one of the most vocal MEPs on healthcare issues relating to the Covid-19 Pandemic and the need for further action on health policy at EU level. On behalf of the S&D group, he has also negotiated the Opinion of the ENVI Committee on a report concerning the protection of workers from asbestos. Most recently, he has also been appointed rapporteur on the proposed revision to the Market Stability Reserve mechanism which is linked to the proposed revisions of the Emissions Trading System within the Fit for 55 package. Engerer has also made a name for himself vis-a-vis European Migration policy and has been appointed as the S&D spokesperson on the recast of the EU's Reception Facilities Directive and the Home Affairs Committee's

legislative initiative on Legal Migration- Law and Policy. In September 2021, Engerer was also appointed S&D Shadow Rapporteur for the LIBE Committee's annual report on the Situation of Fundamental Rights in the EU.

Engerer's career in politics includes posts such as the Personal Representative of the Maltese Prime Minister to the European Institutions. During the Maltese Presidency of the Council of the European Union, Engerer was the President of the General Affairs Group and took care of the Council's relations with the European Parliament. Most recently before he got elected to the European Parliament he worked as an advisor to the Maltese Minister for the Environment, Climate Change and Planning. Earlier in his career, Engerer worked in numerous Ministries, political entities and in EU funding and served as Deputy Mayor of the town of Tas-Sliema in Malta.

Cyrus is a leading activist for Civil Liberties in Malta. He was the spokesperson for the Stand UP! Campaign which led to the introduction of divorce legislation in Malta and he chaired LGBTIQ Labour. After 2013, the Government appointed Engerer as the first Chairperson of the LGBTIQ Consultative Council which was tasked with the introduction of a number of equality laws in Malta which put Malta at first place in Europe on the ILGA-Europe Rainbow Map.

He is 40 years old and is the partner of Randolph De Battista.

Owe Langfeldt
Legal and Policy Officer –
Data Protection,
European Commission,
DG JUST



Owe Langfeldt is a legal and policy officer in the data protection unit of the European Commission's Directorate-General for Justice and Consumers. Before joining the Commission, Owe worked as a legal officer in the supervision and enforcement unit of the European Data Protection Supervisor.

Jerome de Barros
**Policy Officer – Digital
Health and European
Reference Networks,
European Commission,
DG SANTE**



Jerome de Barros is a Policy Officer in the Directorate-General for Health and Food Safety (DG SANTE) at the European Commission and is responsible for the development of Digital Health policies and initiatives, including the European Health Data Space. Prior to joining the European Commission, he worked on digital health programmes in academia and government agencies in Belgium and the UK.

Eva Steliarova-Foucher
**Scientist, Cancer
Surveillance
International Agency for
Research on Cancer**



Dr. Eva Steliarova-Foucher is a senior scientist at the International Agency for Research on Cancer (IARC) of the World Health Organization (WHO). She graduated in 1985 from the Comenius University, Bratislava, Slovakia and obtained an MSc degree in 1989 at the London School of Hygiene and Tropical Medicine, UK. She worked at the National Cancer Registry of Slovakia, then affiliated with the National Cancer Institute of the Slovak Academy of Sciences in Bratislava, where she defended in 1994 her PhD thesis on childhood cancer epidemiology in Slovakia. Since 1994 she was involved in epidemiology research, primarily related to childhood cancer and she had also coordinated international consortia of cancer registries. At the Cancer Surveillance Branch of IARC, she leads the Childhood Cancer Team and coordinates international studies on cancer burden and data standards, including International Incidence of Childhood Cancer (IICC, <https://iicc.iarc.fr>), Automated Childhood Cancer Information System (ACCIS, <https://accis.iarc.fr>), Cancer risk in childhood cancer survivors (CRICCS): understanding the causes to target prevention (<https://iarc.fr/criccs>) and Targeting Childhood Cancer through the Global Initiative for Cancer Registry Development (ChildGICR, <https://gicr.iarc.fr/child-gicr>). She also led the development of three editions of the International Classification of Childhood Cancer (<https://iicc.iarc.fr/classification>). In 2015 she joined the International Society of Paediatric Oncology (SIOP). She participated in projects affiliated with the European Society for Paediatric Oncology (SIOPE), the European Network for Cancer Research in Children and Adolescents (ENCCA) and PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies (PanCareSurFup).

Ruth Ladenstein
SIOPE Board Member and
ERN PaedCan Coordinator
(St. Anna Children's
Hospital, AT)



Prof. Ruth Ladenstein is a 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 (<http://science.ccri.at/>)).

Prof. Ladenstein's recent project activities include the coordination of the European Reference Network on Paediatric Cancer – ERN PaedCan (<http://paedcan.ern-net.eu/>), and the Austrian Medicine for Children Research Network OKIDS (<http://www.okids-net.at/>).

Prof. Ladenstein holds the following memberships:

- Member of Oncology Advisory Board of the Ministry of Health of Austria since 2013
- Advisory board member of the SIOPE Europe Neuroblastoma Group since May 2011 (<http://www.siope.wildapricot.org/>; <https://www.siope.net>).

During her presidency from May 2007 – May 2011, she founded the SIOPE Association in Vienna giving SIOPE a legal structure and governance. Since 2002 she is principle Coordinating Investigator of the High Risk Neuroblastoma 1/SIOPE trial and associated ch14.18/CHO development tasks. By now, the "SIOPE Association to foster neuroblastoma research" has 440 active members in 34 countries, 29 countries are involved in SIOPE studies.

- Board member of SIOPE Europe (<http://www.siope.eu>), SIOPE Europe President in the period September 2009 – October 2012
- Member of the EU Mission Board for Cancer (Horizon Europe) in the period July 2019 – December 2021

Prof. Ladenstein is furthermore Chair of the Austrian Group for Paediatric Haematology-Oncology (AGPHO member – Arbeitsgruppe für Pädiatrische Hämatologie-Onkologie; www.paediatrie.at)

George Astras
Director of Medical
Oncology
(American Medical
Center/Platonas Medical
Center, CY)



Prof. George Astras is a Medical Oncologist and a Professor of Oncology at the European University.

He is currently Director of Medical Oncology at the American Medical Center, Platonas Medical Center and St George /Blue Cross Clinics.

He contributed to the development of two Oncology Centers and three Satellite Oncology Units and in the development of 24-hour Acute Oncology Services and he is currently Director of the Haemato-Oncology Department at the American Medical center (AMC) and Platonas Medical Center (PMC).

He set up and created e-learning modules for doctors and contributed to the development of I-QEMO the first online electronic chemotherapy prescribing system. He is the Vice President of the Cyprus Brain Tumor Association (CTBA), the RMHC and a member of the scientific board of the Cyprus Anti-Cancer Society and he contributed widely to the development of the Movember Foundation in Cyprus.

He presented multiple motivational speeches relating to Cancer through the years with the aim of raising awareness and limiting the stigma related to cancer.

He tackled projects dedicated to soft tissue sarcomas, pediatric rare tumors and adults tumors and is heavily involved in Cancer Charity currently leading multiple Initiatives to improve regional cancer care. In the last few years, he devoted himself to improving the National Healthcare System focusing on reforms that will improve Cancer Prevention, Cancer Care and supportive measures, Treatment Access and improvement of the quality of care.

Zuzana Tomášiková
CCI Europe Committee
Member and Survivorship
Lead (CH)



Zuzana Tomášiková is CCI Europe Committee member and responsible for Survivorship Issues (lead of the strategic pillar on Survivorship). She is furthermore actively involved in the survivors' community since 2007. She is a former osteosarcoma patient. Zuzana is Manager of the Competence centre for Survivorship issues by Childhood Cancer Switzerland and an active patient advocate. She holds a MSc. Degree in Chemistry/Material Sciences from University of Technology Vienna.

Between 2007-2015 she takes up different roles and with different responsibilities: peer mentor, organiser, regional and national co-leader and patient advocate in Austria.

Since 2012, she is also involved at the international level within Childhood Cancer International (CCI) and Childhood Cancer International – Europe (CCI Europe).

Meanwhile, she is responsible for the long-term follow-up and survivorship topics in the national umbrella organisation in Switzerland. She is involved in collaboration with health care professionals, responsible for the development of the survivors' community on the national level as well as for raising awareness about survivorship issues within the community and beyond.

Zuzana is actively involved in international projects with different stakeholders such as PanCare and SIOP Europe, a regularly invited speaker in national and international meetings across Europe and co-organiser of the programmes of international conferences.