



EVENT LAUNCHING THE EUROPEAN PAEDIATRIC CANCER COMMUNITY MANIFESTO:

“CURE MORE AND CURE BETTER – TOWARDS ZERO DEATHS & ZERO LATE EFFECTS”

Hosted by MEP Elena Gentile (S&D, IT)



Wednesday 6 March 2019 (15:00 – 17:00)
European Parliament (ASP 3G-2), Brussels, Belgium

EVENT CONCEPT NOTE

This edition of the annual ICCD meeting will officially launch the European Elections 2019 Manifesto of the paediatric haematology-oncology community and foster multi-stakeholder discussion on how to achieve the vision of a Europe free from childhood cancer.

Despite progress made over the last 50 years, paediatric cancer remains a major public health and societal issue in Europe: it is still the leading cause of children's death by disease over the age of one and an important contributor to long-term morbidity in survivors.

The rarity of individual paediatric cancer types and their high collective burden across Europe make coordinated EU level approaches crucial to address this life-threatening disease. Ahead of the next terms of the European Parliament and the European Commission as well as the new EU programming period, the SIOPE Europe and CCI Europe Manifesto will highlight priority areas for childhood cancer and other severe and rare paediatric diseases, such as:

- Enabling legislative environment for faster and more efficient development of affordable innovative paediatric medicines
- Sufficient resource allocation to childhood cancer research with focus on big data and deep learning tools
- Sustainability of the European Reference Networks to combat inequalities in access to the best available treatment and expertise for children across Europe
- Sustained and appropriately resourced collaborative efforts on the development and implementation of surveillance guidelines and long-term care models for survivors
- Interoperability, harmonisation and security of eHealth platforms to foster cross-border research and knowledge transfer for the benefit of patients and survivors
- Active patient advocacy and empowerment in research, healthcare, and socio-economic areas

These and other relevant focus areas will be addressed by expert speakers including academia, parents and patients, policy makers and industry to trace the steps towards achieving a cure for paediatric cancer in Europe through joint efforts.

PROGRAMME

15:00 – 15:10	WELCOME ADDRESS
	<ul style="list-style-type: none"> ▪ Elena Gentile, MEP (S&D, IT) ▪ Pamela Kearns, SIOPE President (University of Birmingham, UK)
15:10 – 15:15	<p><u>Address from the MEPs Against Cancer Group (MAC)</u></p> <ul style="list-style-type: none"> - Alojz Peterle MEP (EPP, SL) and MAC President
15:15 – 15:45	<u>PART I: Paediatric cancer in Europe – perspectives from parents and academia</u>
15:15 – 15:25	<p><u>The SIOPE-CCI-E Manifesto: Joint vision for a Europe with more and better cures for childhood cancers</u></p> <ul style="list-style-type: none"> - Gilles Vassal, SIOPE Board Member (Gustave Roussy, FR) - Nicole Scobie, Member, Childhood Cancer Intentional - Europe (CH)
15:25 – 15:35	<p><u>New horizons for research and innovation in life-threatening paediatric diseases</u></p> <ul style="list-style-type: none"> - Pamela Kearns, SIOPE President (University of Birmingham, UK)
15:35 – 15:45	<p><u>Furthering the potential of the European Reference Network model across the care continuum</u></p> <ul style="list-style-type: none"> - Ruth Ladenstein, SIOPE Board Member (Children's Cancer Research Institute, AT)
15:45 – 16:50	<u>PART II: Panel discussion on future policy and programme orientations</u>
	<p style="text-align: center;"><u>Chairs:</u> MEP Elena Gentile (IT) and Pamela Kearns (UK)</p> <p><u>EUROPEAN PARLIAMENT:</u></p> <ul style="list-style-type: none"> - Lieve Wierinck, MEP (ALDE, BE) <p><u>EUROPEAN COMMISSION:</u></p> <ul style="list-style-type: none"> - Barbara Kerstiens, Head of Unit, Non-communicable diseases and the challenge of healthy ageing, Directorate-General for Research and Innovation (DG RTD) - John Ryan, Director - Public health, country knowledge, crisis management, Directorate-General for Health and Food Safety (DG SANTE) - Olga Solomon, Head of Unit, Medicines: policy, authorisation and monitoring, Directorate-General for Health and Food Safety (DG SANTE) <p><u>INDUSTRY:</u></p> <ul style="list-style-type: none"> - Nathalie Moll, Director General, European Federation of Pharmaceutical Industries (EFPIA) <p><u>PARENT/PATIENT/SURVIVOR ASSOCIATION:</u></p> <ul style="list-style-type: none"> - Frederic Arnold, Member, Childhood Cancer International - Europe (FR) <p><u>ACADEMIA:</u></p> <ul style="list-style-type: none"> - Gilles Vassal, SIOPE Board Member (Gustave Roussy, FR)
16:50 – 17:00	CONCLUDING REMARKS
	<ul style="list-style-type: none"> ▪ Pamela Kearns, SIOPE President (University of Birmingham, UK) ▪ Elena Gentile, MEP (S&D, IT)
17:00	SIGNING OF THE MANIFESTO