

In response to the release by the World Health Organization (WHO) of the second discussion paper on global targets and indicators for non-communicable diseases (version 22nd March 2012), we are writing on behalf of children with cancer, their families and organizations who are advocating on their behalf. We strongly urge WHO to include the fight against childhood cancer in the set of proposed targets and indicators at the upcoming meetings in this regard, especially as a significant percentage of the population in many countries is now below the age of 19. Should we not include children with cancer in these targets and indicators we will lose an opportunity to address a problem that will escalate in years to come.

This year 175,000 children worldwide will be newly diagnosed with cancer, of which an estimated 90,000 will die from the disease. At the end of today, some 250 children around the world will lose their lives to cancer. These numbers are staggering given the fact that 70% of all childhood cancers are curable.

Cancer is the second leading cause of death to accidental death among children in developed countries. While eighty percent (80%) of children with cancer survive in wealthier countries, the reality is vastly different for those who live in resource-challenged settings where 80% of all children with cancer live and where knowledge about childhood cancer remains limited, not to mention misunderstood. Childhood cancer is often detected too late for effective treatment and is often compounded by very limited access to appropriate treatment and care, resulting in approximately eighty percent (80%) of these children dying of cancer.

We ask that you join us in helping ensure that swift action is immediately undertaken to protect and promote the welfare of children with cancer. Although we realized there are many issues to be addressed, we would like WHO to focus on the following :

- Guarantee the availability, access and affordability of health services for the early detection and treatment of childhood cancer;
- Carry out high-impact and multi-sectoral information campaigns to create an awareness of the early warning signs of childhood cancer to ensure early detection, as well as to end the stigma and myths attached to the illness.
- Secure (through legislation, if necessary) availability and access to affordable essential drugs and technologies for children with cancer, irrespective of where they live;
- Support the establishment of effective population-based childhood cancer registries and ensure that childhood cancer is a notifiable disease in all countries in the world;
- Ensure quality training and education of health professionals in treating and caring for children with cancers;
- Support research to develop care (protocols, guidelines, SOPs) which is adapted to local resources and needs;

We thank you for your attention. In the meantime, should you have questions, comments or require further information, please do not hesitate to let us know.

About the International Confederation of Childhood Cancer Parent Organizations (ICCCPO)

ICCCPO is the largest organization of its kind representing families of children with cancer. ICCCPPO wants to see a world where the issues faced by children with cancer and their families, both in the short and long-term, are understood by families, healthcare professionals and the wider community to ensure that children receive the best possible care wherever they are in the world at the time of diagnosis and beyond. ICCCPPO's mission is to share information and experiences in order to improve access to the best possible treatment & care for children with cancer everywhere in the world. www.icccpo.org

About the International Society of Paediatric Oncology (SIOP)

Established in 1969, the International Society of Paediatric Oncology (SIOP), with over 1500 members, is the leading global organization concerned with the issues of children and young people who have cancer. The society envisions that "no child should die of cancer." To realize this vision, SIOP's mission are to: (1) ensure that each child and young adult with cancer has access to state-of-the-art treatment and care; (2) ensure that all involved in childhood cancer worldwide, have access to the latest progress through meetings, networking, and continuing professional development; (3) support those caring for children and young adults with cancer to provide the best curative and palliative therapies; and, (4) advocate for appropriate long-term follow-up for children and young adults after treatment for cancer. Dr. Gabrielle Calaminus is the president of SIOP. SIOP is governed by a board of directors and has its headquarters in Geneva, Switzerland. www.siop.nl

ICCCPO Secretariat Contact

Marianne Naafs-Wilstra
c/o VOKK
Schouwstede 2B, 3431 JB Nieuwegen
NETHERLANDS
tel: +31 30 242 2944
email: icccpo-secretariat@vokk.nl

SIOP Contact

JJ Divino, MPH
Communications and External Relations
International Society of Paediatric Oncology
Geneva, Switzerland
tel: +41 22 906 9123
email: jdivino@kenes.com