

NOTE FOR THE MEDIA

Children with cancer must have universal access to treatment and care

Geneva | 15 February 2014 Today is International Childhood Cancer Day – a day in which the strength, courage and resiliency of children with cancer and their families is celebrated. The International Society of Pediatric Oncology (SIOP) and the International Confederation of Childhood Cancer Parent Organizations (ICCCPO) represent some 2000 pediatric oncologists and 169 childhood cancer parents’ organizations from 88 countries representing children with cancer, survivors and their families. Members of ICCPO together with SIOP medical professionals will be hosting childhood cancer awareness activities around the world for the International Childhood Cancer Day from 15 February onward.

Each year, more than 250,000 children worldwide are diagnosed with cancer while an estimated 90,000 die from the disease. This number is staggering when one realizes that 70% of all childhood cancers are curable.

Cancer is the leading cause of disease-related deaths among children in industrialized countries where survival rates of childhood cancers has plateaued over the past two decades. Whereas adult cancers have benefited from the discovery of new types of targeted drug therapy, childhood cancer drug development has lagged behind and children continue to receive treatment with drugs that were discovered more than thirty years ago, some causing severe and often life-threatening long-term effects.

While eighty percent (80%) of children with cancer survive in wealthier countries, the reality is vastly different for those who live in poor countries where 80% of all children with cancer are located. Children with cancer in developing countries often do not survive due to the lack of access to essential medicines and to timely treatment and care. SIOP and ICCPO are calling on governments worldwide to ensure that children with cancer – no matter where they live – must have access to care.

SIOP President Prof. Giorgio Perilongo notes that the biggest challenge for children in resource poor-settings is having access to basic medicines and to timely treatment. “Most parents in these countries bring their children for consultation often at a very late stage and at this point, there are few treatment options available” explains Perilongo. According to Dr Lorna Renner, a pediatric oncologist based in Accra, Ghana, limited access to treatment centers, lack of awareness, drug costs and available ward space for children were among the most pressing challenges encountered by children with cancer in her country. “I see these children in the wards and I see the pain in the faces of their parents. My fellow doctors in Ghana are doing their absolute best to try to help these children, but more often than not, many of them are already very sick or even in a palliative stage by the time they receive a diagnosis ” she adds.

Access to treatment in many developing countries is often difficult for families with limited financial means as medical facilities are most often located in capital cities, far away from rural areas. It is imperative that health systems in these countries address these challenges by developing the necessary health infrastructure that would include satellite facilities in other areas where routine maintenance and medication can be offered patients closer to home.

Kenneth Dollman, ICCCPPO Chairman from South Africa, is the father of a child who survived cancer, states “after the initial intensive treatment phase, patients and their families need to travel long distances for routine or maintenance treatment - treatment that often takes only a couple of hours and which adds to the cost and time burden of travel and the possibility of interruption. With support from government, health departments can and should be offered in centers away from the main health facilities.” To prevent interruption, ICCCPPO members not only provide assistance with transport costs to families coming from remote regions, but also offer so-called *parent homes* where those from out-of-town can stay at no-cost to themselves for the duration of treatment. The reality is that such homes are not yet available to many families from low-income countries.

SIOP and ICCCPPO recently entered into a formal partnership by signing a Memorandum of Understanding to work closely together in all matters related to the fight against childhood cancer, thereby becoming the leading united global voice for tens-of-thousands of pediatric oncologists, nurses, patients, survivors and parents of children diagnosed with cancer. These include joint advocacy initiatives and raising funds to support childhood cancer initiatives worldwide, but especially in low and middle-income countries.

Childhood cancer does not have borders. Unlike other childhood diseases, it equally affects children and young people in both developed and low and middle-income countries. The 46th International Congress of SIOP, taking place in Toronto, Canada this year from 22-25 October, presents the ideal forum for the exchange of top scientific knowledge on pediatric oncology and the venue for sharing the coordinated childhood cancer response by people coming from all over the world. The conference constitutes the largest gathering of pediatric oncologists, allied health professionals, childhood cancer parents’ organizations, public health specialists and advocates. ICCCPPO will hold its annual meeting during the SIOP Congress.

About SIOP

Established in 1969, the International Society of Pediatric Oncology (SIOP), with over 1500 members, is the lead 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. Prof. Giorgio Perilongo is the president of SIOP. The society is governed by a board of directors and has its headquarters in Geneva, Switzerland. www.siop-online.org

About ICCPO

The International Childhood Cancer Confederation of Parents Organizations (ICCPO) is the largest organization of its kind representing patients, survivors and families of children with cancer. ICCPO wants to see a world where the issues faced by children with cancer, survivors and their families, both in the short and long-term, are understood by families, healthcare professionals and the wider community to ensure that children with cancer and those who survive this disease receive the best possible care wherever they are in the world at the time of diagnosis and beyond. ICCPO's mission is to share resources, 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

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