

Téa E. Collins, MD, MPH, MPA, DrPH
Executive Director
The NCD Alliance
62 route de Frontenex
1207 Geneva
Switzerland

Geneva, 16 August 2011

Dear Dr Collins,

We are writing to you on behalf of children with cancer, their families and organizations who are advocating on their behalf. We strongly urge the NCD Alliance to include the fight against childhood cancer in key discussions at the upcoming United Nations General Assembly Special Session on Non-Communicable Diseases (NCDs) taking place in New York on 19-20 September.

With some 30 days remaining prior to the aforementioned landmark event taking place, we would like to ensure that the message of hope for children with cancer and their families is brought to the attention of world leaders, politicians and key policy makers present at the meeting. We are asking for political commitment and swift action from these leaders to address the challenges and struggles that children with cancer and their families are confronted with each and every day.

We are grateful to you for reiterating the message that cancer claims the lives of more people each year than AIDS, tuberculosis and malaria combined and the fact that more than 70 percent of all deaths are occurring in low- and middle-income countries. Cancer in children is a fraction of the global cancer burden, but for children with cancer and their families, it is the difference between life and death.

Each year 175,000 children worldwide are 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 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 them 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. We are also requesting that you include specific wording related to childhood cancer in the final Summit Outcomes Document. In particular, we seek your support in implementing the following actions by 2020:

- ✓ Guarantee the availability, access and affordability of health services for the early detection and treatment of childhood cancer;
- ✓ Develop a comprehensive, adequately-resourced national strategy or national action plan for children with cancer and ensure that civil society organizations are involved in its formulation, implementation, monitoring, and assessment;

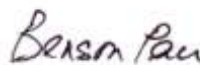
- ✓ Secure (through legislation, if necessary) availability and access to affordable essential drugs and technologies for children with cancer, irrespective of where they live;
- ✓ Support research to develop care (protocols, guidelines, SOPs) which is adapted to local resources and needs;
- ✓ Provide education for general medical practitioners and related clinicians in the identification of co-morbidities associated with childhood cancers;
- ✓ Provide separate, child-centered, childhood cancer wards or units;
- ✓ Ensure quality training and education of health professionals in treating and caring for children with cancers;
- ✓ Avoid the “Brain-drain” phenomenon by helping to support national health systems to retain qualified and highly-skilled childhood cancer professionals in their countries of origin;
- ✓ Ensure education for volunteers in the care and support of children with cancer;
- ✓ Support formation and growth of parents groups, provide assistance and engage them for awareness projects;
- ✓ Promote community-based actions and initiatives that assist and support children with cancer and their families to ensure the highest possible quality of life;
- ✓ And, carry out high-impact and multi-sectoral information campaigns to create an awareness of the signs and symptoms of childhood cancer while ending the stigma and myths attached to the illness.

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

Yours sincerely,



Gabriele Calaminus, MD
President
International Society of Paediatric Oncology



Benson Pau
Chairman
The International Confederation of Childhood Cancer
Parent Organizations

cc: C. Adams, CEO, UICC
J. Torode, Deputy CEO, UICC
G. Paton, Manager, Policy and Projects, The NCD Alliance