The Need to Advocate for Children and Adolescents with Cancer: A Global Cooperative Demand

Gabriele Calaminus, Julia Challinor
SIOP Global Advocacy
No conflict of interest to disclose
THE FACTS

• Every child and young adult has the right to basic health care services (UNICEF statement of 2012)

• Children account for 50% of the world’s population in low- and middle-income countries (LMIC)

• They present the greatest leverage point for investments in human capital.

• Never before has the world seen such a large cohort enter the transition into adulthood as now
In LMIC, cases of childhood cancer will increase by 30% until the end of the decade.
THE FACTS

• Every year 250,000 children worldwide are diagnosed with cancer and 100,000 will die from the disease.

• Every day 500 children lose their lives to cancer.

• Childhood Cancer is the second cause of death already in children in resource-rich countries—resource-poor countries will catch up soon.
THE FACTS

• Every child whose life is saved is likely to contribute to the world economy with 60-75 years of productivity.

• While the number of children with cancer is still lower than that of adults, the potential for years of life saved is significant.

• This marks a public health and economic challenge.

• Therefore, the commitment and coordinated support of all organizations involved in care of children with cancer is needed, to achieve synergies and avoid redundancies.
THE NEEDS

• Children with cancer are susceptible to not only be a host of infections while on treatment, including nutrition deficiencies, there is also a need for a comprehensive public health approach to fighting childhood cancer.

• Childhood cancers have to be included as part of the WHO/UNICEF Integrated Management of Childhood Illnesses (IMCI).

• By integrating the diagnosis and treatment of childhood illnesses and health promotion into a single evaluation sequence, IMCI can increase opportunities for the early detection and treatment of childhood cancer.
STRIKING INEQUALITIES.....

5-year survival rates:
• 80% in highly resourced countries
• 10-40 % in less resourced countries

Incidence/mortality ratio
• 5 in highly resourced countries
• 1.6 in less resourced countries

No matter where they live, children and young people should have access to care and essential life-saving drugs.
WHY THESE INEQUALITIES?
LESS-RESOURCED COUNTRIES.....

• Tend to have many other competing priorities and childhood cancer is often neglected

• Usually lack social security and universal coverage

• Have scarce resources, and weak and poorly managed health systems

• Unavailable specialized services for diagnosis, treatment and even palliative care

• Lack of understanding of childhood cancer care needs and that it is a “best buy” in terms of investment and achievable results
MOST NEEDED ON A COUNTRY LEVEL...

- Improved awareness
- Early diagnosis in the community, and health facilities
- Improving specific diagnostic capacity, e.g. pathology
- Access to essential medicines
- Reduced treatment abandonment
- Effective supportive care
- Capacity building including satellite centres
- Increased role of stakeholders, working together
TO BRING Pediatric Oncology, MoH AND NGOs TOGETHER.....

- Event at World Cancer Leaders Summit in Cape-Town 2013
In 2012, SIOP reached out to WHO to collaborate on developing a cooperative action for childhood cancer globally.

In 2013, Childhood Cancer International joined the WHO collaboration.

For the first time ever a side event on childhood cancer was organized through WHO members states at WHA in 2015.
SIOP Advocacy Landmark Event
68th World Health Assembly, 18 May 2015

Childhood Cancer: The Importance of universal access to treatment, care and support
Supported by governments of Germany, Ghana, Philippines & Russian Federation

No child should die of cancer
WORKING ON THE GROUND LEVEL THROUGH OUR MEMBERS, SUPPORTED BY PARTNERS

Map of Childhood Cancer Twinning Programs Around the World
INITIATING DIALOG AND ACTIONS ......
WHO/SIOP/CCI WORKSHOPS IN WHO TARGET COUNTRIES WITH MoH PARTICIPATION......

ACCRA, Ghana, January 2016

Jimma, Ethiopia, May 2016

Myanmar, May 2016
STRONG PARTNERSHIPS ARE ESSENTIAL

Pediatric oncology can never be strong without the voices of parents, survivors and hand-in-hand work with nurses

Carmen Auste Chair
Childhood Cancer International
Parents and Survivors Organization

Ruth Hoffman Vice-Chair

Tina Baggott
SIOP Nursing Committee Chair

Rehana Punjwani
co-Chairs SIOP PODC Nursing Working Group

Linda Abramovitz

No child should die of cancer
Collaboration Plan for 2016-2018 between International Society of Paediatric Oncology and WHO for an application to official relations with WHO

This document outlines the plan for collaboration between the International Society of Paediatric Oncology and WHO as agreed by, respectively, their focal point(s) and the WHO Designated Technical Officers. They are responsible for the relations, including implementation of the agreed plan, on behalf of the non-State actor and WHO. Please note, participation in meetings of WHO’s governing bodies is not considered to be a joint activity, it is thus not necessary to include in the plan. Certain activities will be subject of a separate agreement between WHO and the non-State actor, for example a contract or Memorandum of Understanding, and a brief outline of the activities should be submitted in this plan.

The objectives of WHO’s collaboration with non-State actors is, inter alia, to promote, the policies and strategies derived from the decisions of the governing bodies of WHO. Unless otherwise indicated, the agreed activities are intended to contribute to the outcome targets in WHO General Programme of Work for 2014-19.

Non-State actor focal point: Dr. Gabriele Calaminus

WHO Designated Technical Officer: Dr. André Ilbawi

Please note that unless otherwise agreed the summary of the plan for collaboration will be published in the WHO Register on non-State Actors.

<table>
<thead>
<tr>
<th>Brief summary of the overall collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>In high-income countries (MIC), tremendous progress has been made in care for children with cancer resulting in more than 80% of children affected surviving five years or more after the diagnosis of cancer. The prognosis is much lower for children diagnosed with cancer in low- and middle-income countries (LMIC) where the disease burden is greatest. The survival divide between MIC and LMIC are due to diverse causes including (1) the late diagnosis of cancer leading to lower levels of effective treatment, (2) poorly equipped hospitals without appropriate or effective medicines and equipment, (3) inadequate human resource capacity, and (4) inaccessible treatment due to prohibitive costs.</td>
</tr>
</tbody>
</table>

At the 68th World Health Assembly (WHA) 2015, WHO Member States Ghana, Russian Federation, Germany and Philippines in close collaboration with the WHO secretariat as well as the International Society for Paediatric Oncology (ISOP) and Childhood Cancer International (CCI) sponsored a side event to raise awareness of childhood cancer. Ministers of Health of the co-sponsoring Member States called for concerted action with the WHO providing leadership in convening key stakeholders to strengthen national health plans to address childhood cancer.
WHO SIOP WORKPLAN OBJECTIVES........

Objective 1 –
Improve Early Diagnosis and Childhood Cancer Awareness

Objective 2 –
Human Workforce Strengthening

Objective 3 –
Essential Medicines and Technology
CURRENT STOCKOUTS OF ESSENTIAL CHILDHOOD CHEMOTHERAPIES

- Mercaptopurine
- L-Asparaginase
- Leunase
- Vincristine
  - Continual documented stockouts of these essential medications vital to childhood cancer treatment in multiple LMIC
- ADVOCACY efforts towards pharma, ministries, governments, WHO, UN, and cancer-focused organizations and NGOs needed now to address this critical situation
Around the world many, many people from various organisations are working to improve access to care and cure for children with cancer. SIOP, as the only and leading organisation of all caregivers for children and adolescents with cancer, will act as the platform to bring them together since

changes require a collaborative effort...
Advocating for Children with cancer is a global demand