EVERY AFRICAN CHILD WITH CANCER DESERVES A CHANCE:

Care for all, cure for more

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Message from the African Paediatric oncology community

Created by the Société Internationale d’Oncologie Pédiatrique (SIOP), Africa branch, in partnership with Childhood Cancer International Africa (CCI Africa)
Childhood cancer is

DIFFERENT to cancer in adults

NOT currently preventable

CURABLE when diagnosed promptly and treated effectively

Our Children are the Future of our Continent

We would like to invite the African union governments and stakeholders to sustain and reinforce its support of the paediatric cancer cause.
In recent years, 5-year survival rates for children with cancer have risen to over 80% in most high-income countries (HICs). This has largely been achieved through optimised use of generic drugs and better organisation of specialist care. The prospects are much worse for children with cancer in low and middle-income countries (LMICs), where survival rates are, on average, only 30%.

Currently, about 89% of the world’s children (aged 0 to 19 years) live in LMICs, and they account for 95% of the mortality from cancer in this age group worldwide. In addition, the incidence rates of many childhood cancers are increasing by 1% each year in many countries with population-based cancer registration that allows this to be measured.

In 2018, the World Health Organization (WHO) set a global survival target of 60% for all children with cancer, wherever they may live, with the goal of saving a million more lives by the year 2030. This target is feasible with current knowledge. The causes of poor survival in children with cancer in Africa, which include late presentation and abandonment of treatment, are well understood and solutions are tried and tested in the African setting.

It was estimated that there were 397,000 new cases of childhood cancer worldwide in 2015, with 146,000 cases in Africa. However, only 224,000 were diagnosed, suggesting that 43% (172,000 of 397,000) of childhood cancer cases were undiagnosed globally, with substantial variation by region, ranging from 3% in western Europe (120 of 4300) and North America (300 of 10,900) up to 57% in sub-Saharan Africa (43,000 of 76,000 in western Africa).

Many types of paediatric cancer can be treated with generic medicines and regimens that are readily adapted to resource-limited settings. These include Burkitt lymphoma, Wilms tumor, acute lymphoblastic leukemia, Hodgkin lymphoma and retinoblastoma. About 50% of all cancers in the 0 to 19-year age group would be in this “favourable prognosis” category if diagnosed early and treated appropriately.
Unfortunately, treatment failure is common in LMICs, including all African countries, because of many factors, including

- Failure to diagnose or misdiagnosis,
- Delayed presentation or diagnosis,
- Unaffordable or abandoned treatment,
- Treatment-related death,
- Drug shortages and use of poor quality medicines
- Lack of consistent adherence to treatment,
- Use of reduced intensity treatment regimens to facilitate tolerability may also contribute to treatment failure and excess relapse.

Many causes of treatment failure are preventable. In order to overcome this global challenge, it is essential that African countries adopt a comprehensive paediatric cancer control strategy through continental and international collaboration.

The international Society of Paediatric Oncology (SIOP), as the global professional body uniting all types of health care professionals involved in childhood cancer care, training and research, has committed expertise and resources to improving care and survival for children and adolescents with cancer in Africa for many years.

We support several projects directly, such as the Pan-African Wilms tumour collaborative, and our society’s members are leading many initiatives to improve access and quality of care, to increase capacity through training and educational programmes based in Africa, and to facilitate research that is directly relevant to the Continent’s needs. We are available to work with WHO and governmental health services to accelerate their efforts in childhood cancers and to ensure learning is shared.
## Your Commitment and Support

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<td>• Many of the causes of preventable treatment failure in LMICs noted above are rooted in fragile or insufficient health care infrastructures (including facilities) and workforces.</td>
<td>• An additional challenge affecting the care of children with cancer in LMICs is access to essential medicines.</td>
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<td>• Management of childhood cancer in LMICs is ideally facilitated by being part of a national cancer control programme that coordinates the identification of priorities and resource allocation and supports the delivery of goods and services.</td>
<td>• WHO has provided global guidance recommendations in the form of Model Lists of Essential Medicines (EMLs) across health conditions; these have included common cancers for adolescents and adults since 1977 and those for children (up to age 12) since 2007.</td>
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<td>• The design of strategies to improve care should integrate the input of partners across the health system - not only clinicians, but also policy-makers responsible for budget allocations, legal and regulatory bodies overseeing the approval of medicines, academic bodies overseeing the training and accreditation of providers, and civil society organisations providing support for patients and families.</td>
<td>• Recent shortages in anti-cancer and supportive care medicines’ availability and variation in access have impacted the care of children with cancer. This highlights the importance of developing initiatives to ensure the availability of safe and affordable medicines for all children. A further complexity is to ensure the quality of these medicines.</td>
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<td>• Successful sustained partnerships have stimulated the engagement of other local governmental and nongovernmental actors to invest in services benefiting children.</td>
<td>• Important ethical issues arise whenever the supply of an effective drug is insufficient to meet demand. Using the ethical principles of beneficence, non-maleficence, and justice, institutions can guide prioritisation of drug distribution before a shortage occurs to avoid unfair and unethical distribution of resources.</td>
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<td>• National policies should support the ongoing collection and analysis of local data for monitoring and evaluation.</td>
<td>• SIOP aims to support the WHO’s 2018 global initiative to engage additional partners to increase economies of scale and uphold accountability mechanisms for product availability and quality consistency worldwide.</td>
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<td>• Beyond increasing survival alone, coordinated policy efforts for children with cancer can improve patients’ quality of life and reduce suffering by ensuring access to morphine for pain, as well as palliative medicine and psychosocial support.</td>
<td>• Lessons learned from addressing social and financial barriers to increase access to medicines can also be leveraged for other critical technologies.</td>
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<td>• As more children survive cancer, policies can also include resources to support the distinct needs of children and families while strengthening the local capacity to prevent, monitor, and manage late effects of treatment among survivors.</td>
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## YOUR COMMITMENT AND SUPPORT

### 3. Reducing treatment abandonment

- Treatment abandonment, defined as 4 weeks or more of missed appointments during therapy, is a major contributor to treatment failure for children with cancer in most cancer centres in LMICs but is rare in HICs.
- In some settings, such as rural Zambia, abandonment rates approach 50%; after war or during civil unrest or natural disasters, abandonment rates increase sharply.
- Risk factors for abandonment include poverty, the local cost of treatment, low educational attainment of parents, distance from the cancer centre, cancer type, and in some cases, patient gender.
- Government support matters: in a study from Kenya where more than 70% of children with cancer lacked health insurance at diagnosis, these children had a risk of treatment failure (most commonly treatment abandonment) three times as high as those with insurance.
- To address treatment abandonment, various strategies have been deployed successfully.
- To support local creative strategies to reduce treatment abandonment and related topics, the global SIOP community has organised active working groups and online educational podcasts.

### 4. Early detection campaigns

- Early diagnosis of cancer is a fundamental goal in oncology because it allows an opportunity for timely treatment while disease burden is still in its earliest stages. Consequently, prognosis improves and cure can be attained with minimal side effects or longer term sequelae.
- Lack of education, limited access to healthcare, and complex and deficient socioeconomic environment result in delayed and under-diagnosis in LMICs. The magnitude of the problem is difficult to ascertain given the paucity of population-based cancer registries.
- Delayed diagnosis is associated with more refractory disease and excess relapse, increasing costs, morbidity of treatment and likelihood of treatment abandonment.
- As demonstrated in HICs, community-based public and professional awareness-raising campaigns can be effectively coupled with diagnosis-specific referral guidelines.
- Inclusion of materials to raise awareness of signs and symptoms of retinoblastoma, the most common eye cancer in young children, into national immunisation platforms in health centres reduced the proportion of patients presenting with advanced tumours.
- Similar resources to increase timely diagnosis of childhood cancer have been developed for various settings, with ongoing work to demonstrate effectiveness, especially in LMICs.
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<td><strong>5. Development of dedicated paediatric oncology units</strong></td>
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<td>• Paediatric oncology programmes can be located in cancer centres or hospitals with paediatric departments.</td>
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<td>• If in general hospitals, physical separation of oncology patients from general hospital patients is important since other patients might have transmissible infectious diseases. Cancer patients have reduced immunity during treatment, making infection potentially fatal.</td>
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<td>• Attention to basic hygienic facilities, including avoiding overcrowding, adhering to standard procedures for disposal of contaminated materials and avoiding reuse of needles, is essential.</td>
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<td>• Training and protocols for prompt recognition and treatment of the common reversible side-effects of chemotherapy will reduce avoidable deaths.</td>
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<td>• Many LMICs have heterogeneous levels of care at various centres combined with complex health systems that may mandate treatment at a specific centre based on insurance coverage and other factors unrelated to expertise. Many centres lack sufficient trained oncology staff and appropriate infrastructure.</td>
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<td>• While there is general agreement that patients should be treated at the paediatric oncology centre that offers the highest chance of cure, it is recommended that financial support should be focused on centres accredited on the basis of appropriate trained expertise, available infrastructure, patient volumes and access, and the ability to report outcomes.</td>
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<td>• Treatment regimens adapted to local conditions provide an opportunity to cure as many children as possible with the available resources, while working to improve services and supportive care.</td>
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<td><strong>6. Capacity building</strong></td>
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<td>• Similar to adult cancer, paediatric cancer diagnosis, treatment, and support require a sophisticated integration of multiple specialties, including (but not limited to) nursing, paediatric and radiation oncology, surgery, pathology, infection control, laboratory and imaging medicine, psychosocial, and palliative medicine.</td>
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<td>• Education and training of all involved professional are cornerstones to improve childhood cancer outcomes in a sustainable way.</td>
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<td>• Adequate training for all those healthcare professionals is difficult in HICs, and often nonexistent in LMICs.</td>
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<td>• The development of successful paediatric oncology programmes in LMICs should progressively incorporate clinical research into their practices. In this context of limited resources, clinical research is not only possible, but also necessary. The design and conduct of clinical research should focus on the epidemiologic, biologic, clinical, and psychosocial questions relevant to the advancement of local care, the development of treatment guidelines and interventions, and to guiding public health priorities.</td>
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<td>• Capacity building is crucial to improve care and treatment of children with cancer in LMICs. Locally relevant research and clinical trials build capacity and improve care, while answering important local research questions.</td>
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<td>• The importance of incorporating solid data management programmes early in the process of programme building should be emphasised.</td>
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WE CALL ON AFRICAN FIRST LADIES AND MINISTRIES OF HEALTH TO:

1. Commit to ensuring the WHO Global Initiative for Childhood Cancer aim of reaching at least a 60% survival rate for children in Africa is realised.
2. Establish or support national childhood cancer registries to ensure accurate data collection to facilitate planning of childhood cancer services.
3. Train primary healthcare workers to recognise signs of childhood cancer and refer timeously and appropriately.
4. Establish centers where children and adolescents with cancer can be treated with dignity to the best possible medical standard.
5. Ensure that appropriate and affordable medicines and devices are made available to treat young patients with cancer.
6. Facilitate access to oral Morphine Sulphate solution which is safe, effective, affordable and essential for providing comfort to children with incurable cancer.
7. Train healthcare workers in the tenets of palliative medicine to ensure that all forms of suffering are alleviated for patients with cancer and their families.
8. Establish research programs to ensure that standards of care for young people with cancer are improved and are documented.
9. Improve the quality of survivorship.
10. Facilitate collaborations with communities, industry and relevant stakeholders to achieve comprehensive and affordable cancer care.

THE AFRICAN PAEDIATRICONCOLOGY COMMUNITY CALLS ON AFRICAN REPRESENTATIVES TO SUPPORT THE FIGHT AGAINST CHILDHOOD CANCER
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About SIOP
Established in 1969, the International Society of Paediatric Oncology (SIOP), is the only global multidisciplinary society entirely devoted to paediatric and adolescent cancer. The society has over 1,800 members worldwide including doctors, nurses, other health-care professionals, scientists and researchers. Our members are dedicated to increasing knowledge about all aspects of childhood cancer.
SIOP’s vision is that no child should die of cancer and that cure can be achieved with no or minimal late effects.
www.siop-online.org

About CCI
Childhood Cancer International (CCI) is the largest organization of its kind representing families of children with cancer. CCI 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. CCI's vision is to advance cure, transform care and instill hope for children and families who are affected by childhood cancer regardless where they live in the world. Ruth Hoffman, CEO of the American Childhood Cancer Organization is the president of the CCI Board of Trustees.
www.childhoodcancerinternational.org

Supported by

About Sanofi Espoir Foundation
The Sanofi Espoir Foundation was created in October 2010 to consolidate more than 20 years of commitment to national and international solidarity. Its mission is to contribute to reducing health inequalities among populations that need it most by applying a socially responsible approach.
Its action lines are focused on three key targets: fighting childhood cancers in low-income countries, improving maternal and newborn health and improving access to care for the most vulnerable population in France.
The Foundation naturally responds to humanitarian emergencies but focuses primarily on long-term partnerships to act on such recurrent issues as education and prevention, training and access to care.

Other resources, partners and stakeholders:

- SIOP Paediatric Oncology in Developing Countries (PODC)
- Paediatric Oncology International Network for Training and Education (CancerPointe)
- Groupe Franco Africain d'Oncologie Pédiatrique (GFAOP)
- World Child Cancer (WCC)
- Collaborative Wilms' Tumour Africa Project