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FIGHTING CANCER TOGETHER



CHILDHOOD CANCER

IMPROVING THE EARLY DETECTION, DIAGNOSIS AND TREATMENT OF CHILDHOOD CANCER IN LOW- AND MIDDLE-INCOME COUNTRIES



The following World Cancer Declaration targets reflect the full continuum of interventions required for the early detection, treatment and care of childhood cancer:

Target 01  STRENGTHEN HEALTH SYSTEMS FOR EFFECTIVE CANCER CONTROL	Target 02  MEASURE CANCER BURDEN AND IMPACT OF CANCER PLANS IN ALL COUNTRIES	Target 05  REDUCE STIGMA AND DISPEL MYTHS ABOUT CANCER	Target 06  UNIVERSAL ACCESS TO SCREENING AND EARLY DETECTION FOR CANCER
Target 07  IMPROVE ACCESS TO SERVICES ACROSS THE CANCER CARE CONTINUUM	Target 08  UNIVERSAL AVAILABILITY OF PAIN CONTROL AND DISTRESS MANAGEMENT	Target 09  IMPROVE EDUCATION AND TRAINING OF HEALTHCARE PROFESSIONALS	

THE FACTS



There are an estimated 250,000 new cases of cancer diagnosed each year in children aged less than 15 years old with more than 80% of these children living in low- and middle-income countries (LMICs).^{1,2} While the proportion of cancer in children is small compared with the burden of adult cancers globally, cancer is an important cause of child mortality. In high-income countries, cancer is the second cause of death among 5-14 year olds, after accidents and injuries.³

Despite remarkable treatment advances in childhood cancer over the past three decades that has resulted in a survival rate of more than 80% for children diagnosed with cancer in high-income settings, the survival rate for children with cancer in LMICs can be as little as 10% in some settings.⁴ In many LMICs, childhood cancer is often detected too late for treatment to be effective, with the additional issue of appropriate treatment and care often not being available or affordable. A lack of knowledge of signs and symptoms of childhood cancer among health workers and the general public, weak referral networks, stigma related to childhood cancer and high abandonment rates of cancer therapy are also important challenges contributing to low survival rates.

Since its adoption in 1989, the Convention on the Rights of the Child (CRC) has become the most ratified human rights treaty. The CRC addresses the civil, political, health, economic, social and cultural rights of children. With regard to the child's right to health, Article 24 of the Convention states:

"States parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States parties shall strive to ensure that no child is deprived of his or her right of access to such healthcare services."⁶

More than 90% of all deaths from cancer among children aged under 15 years of age occur in LMICs, home to the majority of the world's children.⁵ Inequitable access to treatment, care and support for childhood cancer and the unacceptable differences in survival rates around the world is a human rights and social justice issue for children.

MEETING THE CHALLENGE



IMPROVING PAEDIATRIC ONCOLOGY SURVEILLANCE

Few countries have paediatric cancer registries in place to conduct population-based surveillance of childhood cancer and fewer still have national childhood cancer control plans. Childhood cancer surveillance is critical to understand the disease burden, patterns of care and treatment and outcomes. Consequently, UICC is working with the Global Initiative for Cancer Registry Development (GICR) to build expertise in developing population-based paediatric oncology registries.

Please visit: <http://gicr.iarc.fr> for more information.

ADDRESSING MYTHS AND MISCONCEPTIONS ABOUT CHILDHOOD CANCER

Non-communicable diseases (NCDs) including cancer are frequently thought of as 'adult' diseases. Consequently, there are common prevalent myths and misconceptions about childhood cancer, including the notion that 'children don't get cancer' or that 'childhood cancer is a punishment for the child or family'. Another common misconception is that 'childhood cancer cannot be cured'. These misconceptions can result in delays in seeking diagnosis and treatment, or contribute to treatment abandonment.

Public awareness and information campaigns about childhood cancer are therefore important for increasing knowledge about childhood cancer and promoting early detection. Children who have been diagnosed with cancer and are undergoing treatment may feel socially isolated from their peers and not able to attend school or take part in everyday activities. Community and school-based activities are essential to educating classmates and enlisting understanding and support. Around the world, parent groups and childhood cancer survivors are active in developing and implementing advocacy and information campaigns to inform the general public about childhood cancer. For more information, please visit icccpo.org.

PROMOTING EARLY DETECTION AND REFERRALS

Early detection of childhood cancer is an important contributor to survival but is also important to improving the quality of life for children. When childhood cancer is detected late, there is a greater possibility of disability and disfigurement which is distressing for children and their parents, and may result in stigma in their communities.

Greater awareness of the signs and symptoms of childhood cancer among parents and health providers can help reduce 'patient delay' and 'provider delay' which frequently combine to influence the time it takes for cancer to be diagnosed and treatment initiated.

UICC is therefore working with partners such as the International Confederation of Childhood Cancer Parent Organizations (ICCCPO) and the International Society of Paediatric Oncology (SIOP) to develop educational tools to promote early detection. In addition, it is important that a strong referral system be set up so that children, particularly those in rural areas, are able to access life saving treatment. While most paediatric oncology units are concentrated in urban areas, some countries are piloting a decentralised approach to childhood cancer detection, treatment and care in order to improve survival rates and encourage adherence to treatment (see case study below). Twinning programmes around the world between hospitals are also being adopted to build expertise in treatment, as illustrated by the World Child Cancer Twinning Map, which is available at www.worldchildcancer.org/what-we-do.

MEETING THE CHALLENGE (CONTINUED)



PROVIDING PALLIATIVE CARE FOR CHILDREN

Palliative care, including pain control, remains an important challenge for childhood cancer. A recent report developed by the International Children's Palliative Care Network (ICPCN) and UNICEF that assessed the need for palliative care for children found that there are critical gaps in the current palliative care response across a range of health conditions such as HIV/AIDS and NCDs including cancer.⁷ There are inadequacies in pain management, with pain relief medications unavailable, as well as a lack of training in children's palliative care among health professionals. Among its recommendations, the report highlights the importance of an integrated approach to palliative care for children with the broader health system and an expansion of children's palliative care education to different health service settings (e.g. primary health care, hospital and hospice). UICC, through its Global Access to Pain Relief Initiative (GAPRI), is conducting an advocacy campaign on pushing for universal access to specialised palliative care services and joins partners such as the ICPCN, UNICEF, NCD Child and others to call for particular attention to children's palliative care needs.

ADOPTING A HEALTH SYSTEMS APPROACH TO CHILDHOOD CANCER

The promotion of early detection, treatment and palliative care for children should not occur as unlinked 'stand alone' services but as part of a health systems approach where childhood cancer programmes are integrated into primary health services with strong referral mechanisms to higher levels of the health system for specialised care. NCDs such as cancer are an important part of adopting a comprehensive approach to children's health. As such, they need to be integrated into child health programmes, including in routine child health examinations and assessments, with appropriate information, training and tools provided to health workers to be able to recognise

signs and symptoms of cancer and refer children for appropriate treatment and care. An important step towards creating a health systems approach to childhood cancer is to develop a strategy for early detection, diagnosis, treatment and care for childhood cancer as part of a country's national cancer control plan.

Through the My Child Matters programme, a partnership between Sanofi Espoir Foundation and UICC, emphasis is placed on developing projects that can strengthen the health sector response to childhood cancer through, for example, building capacity of health personnel, providing strong public information about childhood cancer and involving local governments as the key drivers of improving childhood cancer survival. In addition, UICC is working with its members and partners to collect and share guidance and examples from different settings on developing childhood cancer control plans and strategies to include in the recently launched International Cancer Control Planning Partnership (ICCP) Portal. For more information: www.iccp-portal.org/



GLOBAL ADVOCACY MESSAGE

Survival and a high quality of life for children with cancer is possible in all income settings and various actions can be taken to promote early detection of childhood cancer and improve the access of children to treatment, care and support.

CASE STUDY

PARAGUAY: BRINGING CHILDHOOD CANCER CARE CLOSER TO HOME

In Paraguay, childhood cancer is the second leading cause of death amongst children, with almost 400 children being diagnosed with cancer each year. The Paediatric Cancer Center at the School of Medicine in Asuncion is the national referral centre for children with cancer and deals with more than half of the country's total number of children with cancer. Common challenges encountered included children being referred very late for effective treatment, as well as a high rate of treatment abandonment due to difficulties faced by families who have to travel vast distances to reach the hospital for therapies that need to be continued over months and, often, years. In 2009, a project put forward by the Paediatric Cancer Center was supported by the My Child Matters (MCM) initiative. The project aimed to create a network of satellite clinics spread across the main regions of Paraguay from where patients were referred to the cancer centre. The network was named the Childhood Cancer Care Network - Red Nacional para la Atencion al Cancer Infanti or ReNACI. It provided a local facility in each region, which patients could easily access without having to travel long distances. The project also included educating the public about early warning signs of childhood cancer, as well as training local doctors and nurses in early detection and delivering cancer chemotherapy and on-going patient care. These interventions allowed patients to continue their therapy closer to home after initial diagnosis and therefore reduced the possibility of treatment abandonment.

The project came to the attention of the Paraguayan government who declared it a 'project of national interest' through a decree issued in 2009. In 2011, the government began implementing a National Cancer Control Programme, and in 2012 announced financial aid for childhood cancer treatment in the national budget. The Paediatric Cancer Center in Asuncion has become a regional centre of excellence with state of the art diagnostic capability for acute leukaemia, one of the most common childhood cancers.⁸

References

1. My Child Matters: Together we create a sustainable impact. 2013. Sanofi Espoir Foundation and UICC. Paris: Fondation Sanofi Espoir.
2. Magrath I, Steliarova-Foucher E, Epelman S et al. 2013. Paediatric cancer in low-income and middle-income countries. *Lancet Oncology*. Available online at [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(13\)70008-1/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70008-1/fulltext)
3. Cancer Facts and Figures, 2012. American Cancer Society. Available at <http://www.acco.org/LinkClick.aspx?fileticket=EcECXIUZyeA%3d&tabid=670>
4. Ribeiro R, Steliarova-Foucher E, Magrath I et al. 2008. Baseline status of paediatric oncology care in ten low-income or mid-income countries receiving My Child Matters support: a descriptive study. *Lancet Oncology*. 2008 Aug;9(8):721-9.
5. Pritchard-Jones K, Pieters R, Reaman G et al. 2013. Sustaining innovation and improvement in the treatment of childhood cancer: lessons from high-income countries. *Lancet Oncology*. Available online at <http://press.thelancet.com/childhoodcancer1.pdf>
6. Convention on the Rights of the Child. 1990. Accessed online at <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>
7. ICPCN and UNICEF. 2013. Assessment of the need for palliative care for children. Three Country Report: South Africa, Kenya and Zimbabwe.
8. My Child Matters: together we create a sustainable impact. 2013. Sanofi Espoir Foundation and UICC. Paris: Fondation Sanofi Espoir)