

WORLD CHILD CANCER: THE FIRST FIVE YEARS AND BEYOND



LIZ BURNS, OPERATIONS MANAGER, WORLD CHILD CANCER AND
TIM EDEN, EMERITUS PROFESSOR OF PAEDIATRIC AND ADOLESCENT
ONCOLOGY, UNIVERSITY OF MANCHESTER, UK AND FOUNDING
MEDICAL TRUSTEE, WORLD CHILD CANCER

World Child Cancer is a charity which works to improve the lives of children with cancer in low- and middle-income countries. Around 80% of the world's children live in these countries where survival can remain below 10%. Through the development of twinning partnerships (currently in eight countries) between hospitals the charity is trying to redress the inequality in care these children receive. A major challenge for the future is extending the work of the charity and reaching a larger fraction of the 100,000 children who die unnecessarily each year without any care at all, not even palliation.

The problem of child cancer

Since the 1960s childhood cancer survival has progressively increased to 75% – 80% in high-income countries (HICs). However 80% of children live in low- and middle-income countries (LMIC) where survival can remain below 10%.

In these countries tens of thousands of children die needlessly every year, most without any effective pain relief. A lack of awareness, poor diagnosis and too few trained doctors and nurses, along with the mistaken belief that childhood cancer is too difficult to cure, all combine to result in very low survival rates.

At least 50% of child cancers can be cured even in resource-poor environments with relatively simple and inexpensive drugs and procedures which have been known to doctors for decades.

There is a great need to raise awareness, improve cancer registration to define the cancer burden and record outcomes, concentrate expertise in paediatric cancer units and develop twinning between high-income countries and low- and middle-income countries.

Who we are – vision and mission

World Child Cancer was established in 2007. Our vision is to see a world where every child has access to the best possible treatment and care. Our mission is to improve cancer diagnosis, treatment and palliative care for children across the developing world, redressing the global inequality in the treatment of child cancer.

The charity facilitates and funds international twinning partnerships linking hospitals in high-income countries and low- and middle-income countries to create a two-way

transfer of medical expertise and skills to save lives and reduce suffering. Through these partnerships vital medical expertise and skills are transferred between medics in developed and developing countries.

Twinning partnerships provide important opportunities for training through mentoring programmes between senior doctors, visits by health care professionals to the hospital in the developing country to hold training workshops and regular internet tutorials or teleconference calls.

The funding required to support each of our projects for five years is approximately £30,000 – £45,000 every year, including in the project application an in-built strategy to develop long term sustainability with increasing internal support. This funding broadly covers the areas of capital costs (computer equipment, ward refurbishments), staff costs, provision of training workshops and drug costs.

The projects are chosen very carefully and are required to meet several vital criteria before being considered by the charity for funding. Ideally the hospital in the low- and middle-income country should be situated in a major city which is easily accessible for the population. There must be a strong and competent local leader who is capable of gathering together a team of other doctors and nurses and gain the support of parents and the community. Support from the hospital and hopefully the local health service or Ministry of Health is also required for long-term success.

Twinning

World Child Cancer currently has eight active projects; in Bangladesh, Malawi, Mozambique, Cameroon, Ghana, The

Philippines, Colombia and the Pacific Islands. There are further projects in development including Namibia and Zambia.

Each project has at least one twinning partner hospital and these are situated in countries including the UK, USA, Canada, Brazil, The Netherlands, Singapore, New Zealand and South Africa. Cancer has emerged as a threat to life as traditional killers like infectious diseases are brought under better control in all of our project countries and the local staff have recognized the challenges facing them and sought our help.

Key objectives in all of the projects are raising professional and public awareness of childhood cancer, reduction in refusal and abandonment of treatment, improvements to the clinical facilities, the creation of family support groups and improving overall survival.

The hospitals and health care professionals who dedicate their time to these twinning partnerships provide their expertise and knowledge free of charge and the contribution of their voluntary medical aid is valued at two or three times the actual financial contribution of World Child Cancer.

To fund these twinning initiatives World Child Cancer raises money from charitable trusts and foundations, companies, individuals and child cancer parent support groups. In 2011 over 1,400 doctors and nurses attended training workshops in our project countries and we have estimated that since 2007 over 4,400 children have been treated within the supported projects. The training workshop topics are driven by the needs of the doctors and nurses in the country and cover topics including supportive and palliative care, improvement in earlier diagnosis/recognition of signs and symptoms of malignancy, management of specific common tumours, emotional support for children and families, communicating good and bad news, nursing skills, safe preparation and delivery of drugs and the development of satellite centres. Monitoring and evaluation is done where possible including pre- and post-evaluation questionnaires and interviews with delegates. This allows us to learn from each training workshop and amend the methods where necessary to suit the needs of the doctors and nurses attending future workshops.

A key part of the twinning work is to develop long-term sustainability within the projects where we work so that after the five years of funding from World Child Cancer, the project and twinning partnership will continue to work effectively with decreasing external aid and increasing internal self-reliance.

We work on long-term sustainability in several ways:

- ▶ By demonstrating successful outcomes we hope to lever more funding from governments, companies and charitable organizations in each country.
- ▶ Parent support groups which form an integral part of every

project are encouraged to develop local fundraising initiatives.

- ▶ Including training as a priority activity at each of the projects ensures that many more health care professionals are appropriately trained in caring for children with cancer. These professionals can in turn train other staff and can extend the training from the project centre to satellite units and at district levels for supportive and palliative care especially.

Training is a major focus for the work of World Child Cancer and the charity believes in the need to maximise the training in-country and not bring doctors and nurses out of the project country. In the past this has led to considerable loss of trained staff failing to return home. However we do promote the concept of training on a loco-regional basis if that is available, for example the paediatric oncologist in training at our project in Malawi will be completing his training in South Africa in 2013 for a year within the designated scheme there. Contractual arrangements are in place to ensure that training benefits the home country.

In addition to workshops and long-term training the funding which World Child Cancer provides each project covers the cost of online training which has a minimal cost expenditure for purchasing a computer and paying for internet access and is then driven by volunteers. Doctors and nurses at the twinned hospital can conduct formal online seminars on a regular basis which have very good feedback from the staff at the project hospitals.

We hope that as the cancer care system for children develops in the project countries that courses and specialist training will become more available in the local universities. During the term of our project in Ghana a specialist training programme for paediatric nurses has been developed in the university in Accra which is a most welcome development.

Case study: Bangladesh

Most recently World Child Cancer has started an operational project in Bangladesh at the Bangabandhu Sheikh Mujib Medical University (BSMMU) in Dhaka for which funding will be provided for the next five years. This project has been started with the full support of two twinning partners; University College Hospital in London, UK, and British Columbia Children's Hospital in Vancouver, Canada.

Bangladesh is a low-income country with an average per capita annual income of US\$690. Government health priorities focus on child and maternal health, disease prevention and noncommunicable diseases including cancer and there has been a significant reduction in child mortality

since 1990. Cancer is the sixth leading cause of death in Bangladesh and it is rising up the priority ranking as infectious and parasitic diseases are brought under control. The precise childhood cancer incidence is unclear because there is no national register (in common with most LMIC). However, 6,000 to 10,000 cases are estimated to occur annually based on a population of 143 million of whom 47% are aged 16 and under.

The BSMMU is the largest specialist cancer treatment centre in Bangladesh. It receives government funding and saw 400 new cases of childhood cancer in 2011 of whom approximately 20% survive at one year. There are eight regional medical colleges which provide a basic level of care and are keen to develop further.

Following a thorough needs assessment visit and project application process, World Child Cancer has identified the following key problems being faced in Bangladesh:

- ▶ Lack of reliable data on the real size of the child cancer workload in Bangladesh.
- ▶ Very low diagnosis – at best less than 25% of children are diagnosed but the figure is likely to be much lower.
- ▶ Late diagnosis with children presenting with very advanced symptoms.
- ▶ Lack of access and funding for drugs leading to high rates of abandonment of treatment.

Doctors from the BSMMU and the twinning hospitals have worked together to formulate a five year strategy which aims:

- ▶ To increase survival rates of child cancer at BSMMU and eight government funded regional child cancer centres across Bangladesh by improving the quality of care.
- ▶ To share knowledge, technology and organizational skills with the twinning hospitals in Canada and the UK to develop locally appropriate treatment protocols.
- ▶ To reduce abandonment of treatment due to unaffordability of drugs and lack of knowledge about the nature of treatment amongst parents by 50%.
- ▶ To raise awareness of child cancer, its symptoms and curability amongst health care professionals in Bangladesh leading to improved diagnosis.
- ▶ To improve access to care with more children receiving curative and palliative treatment.

These objectives will be achieved through three key activities:

- ▶ The development of an online child cancer database at BSMMU and the eight regional child cancer centres.
- ▶ Development of on-site and online training programme for around 570 health care professionals in Bangladesh with

focus on diagnostic techniques, supportive care, palliative care, curative affordable treatment and clinical management. Workshops will be led by experts from both of the twinning hospitals in the UK and Canada and also internally led by Bangladeshi experts.

- ▶ Provision of a reliable supply of drugs, both curative and palliative, for children with cancer and to provide drugs free of charge for poor children. During the course of the project an aim will be to increase and leverage local funding sources and donors, and also facilitate the fundraising activities of a parent support group to enable long-term sustainability for the provision of drugs.

Funding for the project began in June 2012 and will continue for five years.

Future

The project in Bangladesh forms part of an ambitious vision for World Child Cancer to be able to reach 10,000 children with cancer in low- and middle-income countries each year within the next five years. This is still a fraction of the 100,000 children who are estimated to die unnecessarily each year, often undiagnosed or misdiagnosed, without curative therapy and frequently in pain.

Our strategy will be to develop new projects and extend existing ones – working in partnership with other like-minded organizations. In Bangladesh alone we may be able to help several thousand children if the project is working efficiently.

A key problem remains the lack of awareness about cancer – both for adults and children – in low- and middle-income countries. The perception remains that it is too difficult and too expensive to cure. By focusing on child cancer, World Child Cancer is attempting to alter these perceptions by showing that it is possible to cure children at reasonable cost even within relatively basic health infrastructures. ●

Liz Burns joined World Child Cancer in 2011 and became the Operations Manager in January 2012. She has expertise in developing and managing child cancer projects in low- and middle-income countries.

Professor Tim Eden has held senior academic and clinical positions in Bristol, Edinburgh, London and Manchester where he was the Teenage Cancer Trust Professor of Teenage Oncology. He was formerly President of SIOP (International Society of Paediatric Oncologists). He retired in 2008 but remains active in a number of organizations working in the field of childhood and teenage cancer in the UK and in developing countries.