

WORLD CHILD CANCER: SUPPORTING PARTNERSHIP MODELS IN PAEDIATRIC ONCOLOGY



LIZ BURNS (TOP LEFT), **TIM EDEN** (TOP RIGHT) AND **JON ROSSER** (BOTTOM LEFT),

WORLD CHILD CANCER



World Child Cancer funds international twinning programmes, aiming to develop paediatric oncology services in low- and middle-income countries. The organization is currently planning a new programme strategy which would enable expansion of its work in Africa and Asia. This article sets out to describe the most recent programme developed and funded by the charity, in Myanmar, where a twinning partnership between centres in the United Kingdom and the United States is building the capacity of paediatric oncology services in Yangon.

World Child Cancer (WCC) is a charity with a mission to help children who develop cancer in low-middle-income countries (LMICs) and to develop cancer services for children when cancer emerges as a major threat to life, while also supporting families through a hugely difficult time. Together with our partners, we are trying to improve public and professional awareness of the signs and symptoms of cancer, the speed and accuracy of diagnosis, development of locally appropriate treatment and overall care of children with cancer, and support for families of these children. The organization works with local and international partners including health-care professionals who are passionate about improving paediatric oncology care. These teams have the knowledge and experience to help with the development of locally appropriate, affordable and sustainable solutions in an effort to bridge the inequality in access to quality cancer care across the globe.

Support for paediatric oncology

World Child Cancer was established in 2007 by a team of international experts in paediatric oncology partnerships, family support and medical care (1). The charity aims to ensure that children in LMICs can access cancer care. It is estimated that currently between 160,000–200,000 children develop cancer each year with evidence of a real increase as deaths from communicable diseases have decreased over the last two decades (2, 3, 4, 5). Eighty

percent of these children live in LMICs where survival rates are 10% in low-income countries (LICs) and only at 30% in most middle-income countries (MICs) compared with 80% in high-income countries (HICs) (1, 6). The factors contributing to this unacceptable disparity include: poor awareness of cancer, beliefs of incurability, high rates of treatment refusal and subsequent discontinuation of treatment, delayed or missed diagnoses, limited diagnostic resources/facilities, lack of trained staff, inability to access appropriate treatment, unaffordability of medicines especially for parents who, in most LMICs, carry the full financial burden of therapy and an excess of toxic deaths from infections and comorbidities like malaria, TB and HIV.

In order to try to help developing teams in LMICs, World Child Cancer works with hospitals and university centres of excellence in HICs and creates twinning partnerships with health-care centres in resource-poor countries. This partnership model, connecting centres and professionals together, establishes a sustainable linkage which improves access to care for patients who would otherwise not receive any treatment (1, 7, 8).

In some cases, WCC actively recruits twinning partners in HICs by giving presentations about twinning work at hospitals which have an interested staff. In other cases WCC is financing partnerships which have been in place for many years and are seeking support. The team involved in the twinning are multidisciplinary: doctors, nurses, pharmacists, play therapists, psychologists and others. The team is linked

Figure 1: A patient at Queen Elizabeth Central Hospital in Malawi, which the charity has been supporting since 2009



with the LMIC centre through a Memorandum of Understanding (MOU) developed by WCC and signed by all parties. The MOU details the roles of each partner, financial procedures and expectations. Detailed programme plans and budgets are developed with the LMIC hospital team, and activities are overseen by the WCC programmes team. The MOU is signed by a representative of the hospital administration, with the understanding that the staff involved will mainly be from the paediatric oncology and wider paediatric department. All of the staff from the twinning centres are volunteers and so they are not paid a salary by the charity but their costs for travel are reimbursed. Volunteers give up their own time to mentor staff in the LMIC centre; exchanging emails and taking part in online case discussions.

WCC currently supports programmes based in Malawi, Ghana, Cameroon, The Philippines, Bangladesh, Myanmar and Central America. Each hospital is linked with one or preferably two established centres in HICs including in the United Kingdom: London, Edinburgh/Dundee, Newcastle, Birmingham, Southampton, Oxford; in Canada: Vancouver; in the United States: Boston and Memphis, as well as South Africa and Singapore. In addition, it is jointly funded with the International Society of Paediatric Oncology a regional collaboration in sub-Saharan Africa for Wilms tumour management (9).

Each programme is based around a five-year framework of outputs and planned outcomes. Impact targets are designed with LMIC teams and are used as standards against which to monitor the progress of the programme. Reports and statistical information pertaining to the WCC-funded programme are submitted on a quarterly basis and overseen by the programmes team at the charity. This enables the organization to understand impact and share learning from programmes to other country teams.

Figure 2: Dr Robert Carr, Guy's Hospital London and Dr Carlos Rodriguez-Galindo, St Jude Children's Research Hospital Memphis, with Dr Aye Aye Khaing at Yangon Children's Hospital



Programme expansion and impact measurement

After seven years of supporting programmes in specific hub centres (teaching hospitals in country capitals), the charity has begun to expand its work in each region to provide more countrywide support and further investment with the aim that each child receives holistic care, all the essential supporting services and a greater chance of cure.

To ensure that comprehensive health-care programmes are planned and implemented to meet beneficiary needs, programme coordinators have been identified and appointed in some of the countries where we work, following the award of three-year funding in 2014 through UK Aid from the United Kingdom Government (both through the UK Aid Match and Global Poverty Action Fund streams). Their aim is to provide programme support to partners, identify areas of expansion within established partnerships and measure the impact of our interventions. Previously we have relied on already very busy clinicians to plan and implement our programmes, but we are now moving to a model which provides health-care teams with increased organizational support. The appointed programme coordinators are all experienced in designing such projects, planning budgets, monitoring and evaluating development work. They are able to work on the expansion of clinical programmes from our initial single hospital unit support, to exploring more holistic developments and the appropriate partners with whom to engage in order to extend the focus to areas such as advocacy, awareness, income generation for families, outreach services and training for community health workers. Such moves are essential for long-term sustainability of the LMIC paediatric oncology service and ultimately the progress towards universal health coverage in each country (10, 11). In all the

Figure 3: There is no accommodation outside Yangon Children's Hospital available to families so wards become very crowded



Figure 4: Twinning partnerships enable the sharing of expertise to build capacity within local teams



programmes WCC supports the ultimate goal must be self-sufficiency, albeit with a variable timeframe for each country.

The focus for 2016–2019 will be on enabling more support for children, including better palliative care services, psychological support for families, development of hostels to provide parental accommodation, education for children undergoing long hospital stays, community health-care training, outreach and follow-up services, support for wider paediatric systems and focused advocacy with policy-makers and planners to work towards the inclusion of paediatric oncology services in national health-care budgets.

In line with the Sustainable Development Goals (12), we aim to draw attention to the rising importance of tackling the challenges faced by children with cancer in the developing world, and by their families, as communicable disease mortality and morbidity progressively decrease and cancer rises up the list of major threats to young life as it has done in high-income countries. One very pressing issue requiring action by all involved in treating children with cancer is to ensure that all children have access to the Essential Medicines they need and that those drugs are of good quality and affordable for whoever pays the bill for their costs (13, 14, 15). The partners involved in the WCC programmes address these issues by advocating for children with cancer with governments and funding bodies, raising

awareness both in LMIC and HIC professional and community spheres and raising funds to support the ongoing activities within the WCC programmes.

Myanmar programme

In July 2014, World Child Cancer began supporting a new programme in Myanmar. Based in Yangon Children's Hospital (YCH), the programme links this centre with partner units at Guy's and St Thomas' NHS Foundation Trust UK (GSTT) and Dana Farber/Children's Hospital Boston, USA (DF/CHB).

The programme is funded and led by WCC and the responsibility of the programme activities, reporting to donors and maintaining financial control lies with the charity. The various elements that make up this programme are led by the partners within Myanmar and the twinning hospitals. Clinical mentoring is provided to the team in Yangon by Dr Robert Carr (GSTT) and Dr Carlos Rodriguez-Galindo (previously DF/CHB and now at St Jude Children's Research Hospital), nursing training is led by Lisa Morrissey (DF/CHB) and the psychosocial aspects of the programme are guided by the psychology team at Evelina Children's Hospital in London (part of GSTT).

Prior to commencing this programme, the YCH team diagnosed around 180 new patients every year. This figure has already risen to 260 new patients in 2015. This is one of two centres in the country (the other being in Mandalay) which are able to treat children with cancer, and is only able to reach a fraction of the estimated 1,600 – 3,000 children in Myanmar expected to develop cancer every year.

The challenges faced by children with cancer in Myanmar are similar to those faced in other low-income countries (1); a lack of specialist training for staff, late diagnosis with children presenting with advanced-stage disease, lack of access to and funding for drugs, minimal palliative care, high rates of treatment refusal and abandonment, no hostel facilities for families and a lack of social support.

The aim of the partnership, led by Dr Aye Aye Khaing (Myanmar), Dr Robert Carr (United Kingdom), Dr Carlos Rodriguez-Galindo and Lisa Morrissey (United States) is to start to address these challenges.

The main objectives of the partners are to increase survival rates of children with cancer in Myanmar through sharing knowledge between the twinning institutions and YCH, developing locally appropriate treatment protocols, twinning partners and specialists at YCH providing training for health workers across Myanmar in recognizing early warning signs of cancer in children, increasing the capacity of pathologists and laboratory staff to accurately diagnose

malignancies, and providing mentoring, training and support for over-stretched doctors and nurses. World Child Cancer is providing funding for specialist staff from the HIC partnership centres to carry out training visits to Yangon, and also for Burmese staff to undertake further professional development for short periods in specialist centres outside of the country. The pathologist working at YCH has recently completed a training period in London, linking with the pathology team at Guy's hospital. The charity is also supporting staff costs on the ward at YCH, including salary enhancement for doctors and nurses to recognize their increased responsibilities, a data manager and a social worker. In addition, some treatment costs are funded through the programme, alleviating the burden which families face in bearing the cost of their child's treatment. At the same time, WCC was involved in a joint advocacy workshop in the Spring of 2016 highlighting the needs of children with cancer in Myanmar in conjunction with the International Society of Paediatric Oncology (SIOP)/Childhood Cancer International childhood (CCI)/World Health Organization and representatives from the Burmese Health Service and Government.

There is currently a lack of data on the actual incidence of childhood cancer in Myanmar. An important aspect of this programme, therefore is, to initiate a reliable and accurate electronic data registry called ERICC, created by WCC, initially at YCH and with planned extension subsequently to Mandalay. WCC is assisting the data collection, by funding a full-time data management post and through the provision of this free and locally adaptable data collection system.

In addition to focusing on hospital support, World Child Cancer is reaching out to partner organizations in Myanmar to try to increase community awareness of childhood cancer, and its potential curability. This will tie in with the advocacy work which is starting in the country, with the aim of gaining government support for paediatric oncology and sustaining this service in the long-run.

The core activities of this programme are vital to improving and maintaining the access for children to paediatric oncology services. In the next stage of this project, in order to provide a more holistic service to children in Myanmar, local support has been leveraged to already start providing nutritional supplements for patients and their families; both to reduce patient malnourishment and ease the financial burden for families of buying food during long hospital stays. This is managed by a WCC-funded social worker to ensure that data is captured on the families being supported by this programme, enabling better future planning and advocacy.

Figure 5: Patients and families on the paediatric oncology ward at Yangon Children's Hospital



Funding has also been identified to initiate an education and play therapy provision for children on the oncology ward, as well as their siblings. This is a service which could in the future also benefit other long-stay patients in the paediatric department. The development of this facility is also supported through the partnership model, with expertise being provided by the Evelina Children's Hospital (London) school faculty. With their help, the new hospital school opened in the summer of 2016.

Despite these developments, a huge challenge facing children with cancer in Myanmar is the difficulty in accessing treatment. In this large country travel is expensive and limited, so reaching Yangon or Mandalay will remain a barrier to care for most patients. In addition, facing a long and expensive journey back to the hospital for follow-up appointments means many families will be unable to complete treatment. The future of this programme will seek to address the constraints of patients in accessing treatment, by supporting transport costs in the short-term and developing satellite services across the country to ensure access to care for as many children as possible in the long-term. Financial support has been provided for this work

through the Global Poverty Action Fund of the UK Government's Department for International Development.

The health-care team at YCH are extremely dedicated and passionate about improving the services available for children with cancer and increasing survival rates. To ensure the continuing development of this programme, the support from the partners in the United Kingdom and the United States for the Myanmar team is essential. World Child Cancer will continue to seek ongoing support for this programme, with the long-term aim of developing a sustainable and government-supported service, to which all children in the country will have equal access.

Summary

World Child Cancer has now identified over 50 different international twinning programmes, created an open access online map and in collaboration with international partnership organizations has promoted the development of others. Short- to medium-term support is helpful, but what is now required is a universal effort to move towards each country's self-sufficiency and universal health coverage which includes children with cancer and other noncommunicable diseases. The United Nations Convention on the Rights of the Child states that "every child has the right to life, survival and development" (Article 6) and in Article 24 "the right to the best possible health" and this

must surely include childhood cancer. So the goal of all interested parties is to make this a reality within the next decade (6). ■

Liz Burns joined World Child Cancer UK in 2011 and is now the Head of Programmes for the charity. She has expertise in developing and managing childhood cancer projects in low- and middle-income countries and is currently developing the programme strategy for World Child Cancer.

Professor Tim Eden has held senior academic and clinical positions in Bristol, Edinburgh, London and Manchester where he was initially the CRUK Professor of Paediatric Oncology then the Teenage Cancer Trust Professor of Adolescent and Young Adult Oncology. He was President of SIOP 2004–2007. Professor Eden retired in 2009 but is Emeritus Professor of Paediatric and Adolescent Oncology at the University of Manchester, and remains active in a number of organizations working in the field of childhood and teenage cancer in the United Kingdom and in developing countries.

Jon Rosser joined World Child Cancer in September 2015. He is an experienced Chief Executive and consultant in the not-for-profit sector with considerable experience in health programmes in Africa and Asia.

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