

PAEDIATRIC ONCOLOGY IN ETHIOPIA: AN INCTR-USA AND GEORGETOWN UNIVERSITY HOSPITAL TWINNING INITIATIVE WITH TIKUR ANBESSA SPECIALIZED HOSPITAL

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In January 2012, the International Network for Cancer Treatment and Research, USA (INCTR-USA) in collaboration with the Division of Pediatric Hematology Oncology, Blood and Marrow Transplantation Program, Lombardi Comprehensive Cancer Center, Georgetown University Hospital (GUH), Washington DC, signed an agreement with the Federal Ministry of Health, Ethiopia, Addis Ababa University Medical Faculty and the Tikur Anbessa Specialized Hospital (TASH), Addis Ababa, to demonstrate that a significant number of paediatric cancer patients in Ethiopia can be cured when they are treated by physicians trained to recognize cancer early, diagnose it correctly, and treat it according to standard chemotherapy protocols and supportive care regimens specifically designed for developing countries.

The Paediatric Oncology Initiative in Ethiopia was initiated to honour the memory of Temesgen Gamacho, an extraordinary 16-year-old young man from Ethiopia, who fought a valiant battle against metastatic osteosarcoma. After initial treatment in Addis Ababa, Temesgen came to Washington, DC and was treated at Georgetown University Hospital by Dr Aziza Shad. After Temesgen died in September 2008, his American “mom”, Mary Louise Cohen, joined Dr Shad, President of the International Network for Cancer Treatment and Research’s USA branch (INCTR-USA) and Director of Georgetown University Hospital’s Division of Paediatric Hematology/Oncology, to spearhead an effort to make a difference in the lives of children with cancer in Ethiopia.

Background

Ethiopia has long been known to the outside world as “Abyssinia”. One of the world’s oldest nations, it is referred to in the second chapter of Genesis. Never colonized, Ethiopia

has a long and rich tradition of formal medical care and education, beginning in 1896¹. It is located in the north-eastern part of Africa, also called the “Horn of Africa” and is bordered by Eritrea (N), Kenya (S), Djibouti and Somalia (E) and Sudan (W). Ethiopia occupies 686,180 square miles and approximately 80% of the population lives in remote and rural areas making access to health care, and in particular cancer care², a distant and expensive proposition.

Ethiopia is one of the world’s poorest nations. It has a population of 83 million people speaking more than 80 languages³; more than half the population is under the age of 18 years and most people live on less than US\$2 a day⁴. It rates as the 174th out of 187 countries on the United Nations Development Program’s Human Development Index⁵.

Health care in Ethiopia

The Ethiopian Government is the country’s main health care provider with 138 hospitals and 635 health centres⁶.

Treatment is provided free to patients with limited incomes. However, with the per capita expenditure of US\$16 on health (as compared to US\$54 in India and US\$649 in South Africa)⁷, resources are few and care sub-optimal. The doctor/nurse to population ratio is approximately 0.0272/1000 and 0.2576/1000 respectively⁸. The neonatal mortality rate is 35 deaths/1,000 live births and the under-five mortality rate is high at 106 deaths/1,000 live births with a tenth of the children dying before their fifth birthday⁹. Pneumonia, malaria, diarrhoea and newborn conditions are the major causes of child death¹⁰. Recently, with the institution of immunization programmes all over the country, there is a trend towards decreased mortality from communicable diseases¹⁰.

Pattern of cancer in Ethiopia

There is no cancer registry in Ethiopia yet; one is currently being established for the city of Addis Ababa. Extrapolation from clinical records from the TASH Radiotherapy Centre estimates that there are 120,500 new cancer cases/year, although Globocan estimates are much lower (51,000 per year). Most patients present with advanced disease and there is a high rate of abandonment of treatment. Morphine is not readily available for cancer patients.

Paediatric oncology in Ethiopia

Based on extrapolating estimates from another East African nation, Tanzania, with an incidence of paediatric cancer of 134 cancer cases per million¹¹, Ethiopia probably has close to 6,000 new cases of paediatric cancer each year. The commonest cancers seen at TASH include leukaemia, lymphoma, retinoblastoma, Wilm's tumour and bone and soft tissue sarcomas. Most children present late, with advanced disease, and in pain.

With a per capita income of approximately US\$2 a day, resources devoted to health and health care in Ethiopia are limited. Ethiopia has no paediatric oncologists. Mortality rates for most paediatric cancers are close to 100%. In contrast, the survival rate for children and adolescents diagnosed with the most treatable cancers, including leukaemia, lymphoma, retinoblastoma and Wilm's tumour is rapidly approaching 90% in developed countries and close to 50% in South Africa.

The situation in Ethiopia is similar to that of other countries with severely limited resources; children with cancer often receive incomplete, inadequate or no care and those with incurable disease are frequently sent home to die without palliative care. Ethiopia lacks trained medical personnel, adequate facilities, a sufficient supply of essential chemotherapy drugs and simple pain medications necessary to treat cancer patients. As a result, there is little public

awareness that cancer can be cured, little public demand that health systems address cancer, and consequently, few government medical resources devoted to cancer treatment.

Ethiopian paediatric oncology twinning project

The mission and vision

The mission of the project is to achieve substantial survival rates for children with cancer in Ethiopia. By doing so, we intend to demonstrate that just as in other countries with limited resources (e.g. Tanzania, Nicaragua, Davao Philippines), given the right training and resources, many childhood cancers can be cured using low-cost generic drugs and proven treatment protocols. By training local specialists in paediatric oncology/haematology, haematopathology, nursing, pharmacy and palliative care, and by working with parents and advocates to provide vital family and psychosocial support, the Ethiopian paediatric oncology initiative seeks to nurture local champions for paediatric cancer care. Drawing on local resources for teaching, cultural insight and advice, we include local stakeholders (including parents of children with cancer) in every aspect of the project.

Goals

- Increase capacity to recognize and treat children and adolescents with cancer in Ethiopia through the training of doctors, nurses, pharmacists and social workers.
- Increase survival rates for children with curable cancers by training a core group of paediatricians to treat patients using cost-effective protocols designed for developing nations.
- Establish a dedicated Paediatric Oncology Unit (POU).
- Improve diagnostic capacity through INCTR's i-Path programme.
- Improve supportive care and infection control practices through training.
- Introduce palliative care for all patients, particularly those with incurable disease.
- Help establish a sufficient supply of essential chemotherapy drugs to prevent interruption of treatment.
- Provide a mechanism for family support to decrease rate of abandonment of treatment.

Mechanism to achieve these goals

- Twinning programme between Georgetown University/INCTR and TASH for training.
- Curriculum for a fellowship training programme in paediatric oncology and palliative care.
- Curriculum for paediatric oncology nursing training.
- Telecommunications: i-Path for training and consultative

services in pathology.

- ▶ Training workshops targeted to specific cancers and their management.
- ▶ Data management programme to capture data on demographics, presentation, patterns of disease and outcomes of treatment.
- ▶ Visiting faculty programme for hands-on and distance learning.
- ▶ Family support programme in collaboration with the Tesfa Addis Parents Childhood Cancer Organization (TAPCCO) and other agencies in Addis with the aim of providing housing, nutrition and financial support to families in order to reduce abandonment during treatment.
- ▶ Fundraising efforts by The Aslan Project to support all areas of the project.

Progress to date

The INCTR Programme for Ethiopia was inaugurated in January 2011 with a Paediatric and Adolescent Oncology Symposium held in Addis Ababa. Physicians, nurses and other allied health care professionals from TASH and other academic institutions around the country attended the meeting. The conference faculty, who came from the United States, Europe, Israel, Asia and Africa, volunteered their time to participate in the symposium. The presenters brought clinical and research expertise in paediatric oncology, palliative care, oncology nursing, infection control and patient/family support.

Since then, steering committees have been established, comprising of key personnel from TASH and INCTR involved in the project. The Steering Committee at TASH is headed by CEO of TASH and Dean of Addis Ababa University School of Medicine Dr. Mahlet Yigeremu, and includes representatives from hospital administration, paediatrics, pharmacy, nursing and the coordinator of the twinning project in Ethiopia, Dr Alemnesh Wolde. Members of the INCTR and GUH Steering Committee include paediatric oncologists: Aziza Shad (Georgetown University Hospital, Washington DC), Sheila Weitzman (Hospital for Sick Children, Toronto, Canada), David Korones (University of Rochester, New York, USA), Wond Bekele (Barnabas Health, West Orange, New Jersey, USA), Carlos Rodriguez-Galindo (Harvard University, Boston, USA), oncology nursing: Julia Challinor (University of California, San Francisco, CA, USA), pathology: Nina Horowitz (INCTR and University of Basel, Switzerland). The committee is assisted in this effort by other internationally recognized experts in paediatric oncology, pathology, nursing, data management and transfusion medicine. Dr Ian Magrath, President, INCTR, serves as an adviser to the project.

The role of the local team cannot be understated. The TASH Steering Committee is actively involved in the approval of all proposed treatment protocols and procurement of necessary chemotherapeutic and supportive medications in concert with the pharmacy. Addis Ababa University has approved the fellowship training programme that will start in March 2013. Key members of the School of Medicine have agreed to participate in the teaching. An oncology nursing curriculum is currently in development and will be presented to the Addis Ababa University School of Nursing for approval.

Renovation of a separate unit for children with cancer has begun and will be completed in March 2013. Dr Yasar Celiker, a US-based paediatric oncologist with 17 years of experience who is board-certified in both paediatric oncology and palliative care, will serve as the full-time Clinical Director for the programme. Dr Celiker will be responsible for the day-to-day clinical care on the unit and supervise the fellowship training programme.

INCTR's i-Path programme (including the donation of a microscope equipped with a digital camera), an internet-based pathology and diagnostics support system was initiated in January 2011 and is making good progress. A TASH pathologist was trained for four months in Basel, Switzerland with Dr Nina Horowitz. Online tumour board and diagnostic case consults are being organized.

Dr David Korones and Dr Barbro Norrstrom Mittag-Leffler (adult palliative care expert, Sweden) have initiated a paediatric and adult palliative care initiative. A TASH paediatric faculty member with an interest in palliative care has attended two palliative care courses (one in India with Dr Gayatri Palat from the INCTR Palliative Care Programme, (PAX), and one at the University of Minnesota). A pain clinic to treat all paediatric patients is currently being established at TASH.

An officially government-licensed parents' group, Tesfa Addis Parents Childhood Cancer Organization (TAPCCO), has been established to provide support to parents of children with cancer. A nursing-led "coffee ceremony", initiated in August 2011 to serve in lieu of psychosocial support until such support could be put in place, is being held weekly. Efforts are underway to address family financial and logistical support (e.g. housing, food, etc.); however, these still remain challenges that must be addressed to decrease the rate of abandonment of treatment and provide psychosocial care during hospitalizations.

Efforts to improve safe administration of chemotherapy are underway. A chemotherapy training class designed and taught by Ato Ephrem, Lecturer and Head of Experiential Teaching, School of Pharmacy at Addis Ababa University was held in

November 2011. A strong partnership with both the TASH pharmacy and the School of Pharmacy is a major component of our programme. Plans are now in place to install biosafety cabinets for chemotherapy preparation in the paediatric haematology/oncology as well as adult haematology/oncology units and to support pharmacist training in chemotherapy preparation. In September 2012, two TASH pharmacists attended a one-month training in chemotherapy preparation and handling in the pharmacy of the Children's Cancer Hospital Egypt, under the guidance of Sherif Kamal, Director Department of Pharmaceutical Services

The project has also established a collaboration with Dr Ken Miller, a medical oncologist, and Annette Galassi, an oncology nurse, both of whom are working under the aegis of the American Society of Clinical Oncologists and Health Volunteers Overseas. This group is directing its attention to adult haematology and medical oncology at TASH, pursuing a model similar to ours. This collaborative effort is helping further strengthen our ties with Dr Amha, in Adolescent and Adult haematology, and the medical oncology team.

Since January 2011, INCTR-USA and GUH Steering Committee members as well as the ancillary faculty have made multiple visits to TASH for on-going assessment, dialogue on implementation and clinical teaching. In this way, we hope to strengthen our relationship with our partners in Ethiopia and empower all local stakeholders to take the lead in advocating for children and adolescents with cancer and supporting their optimal care.

In September 2012, a licensed 501(c)(3) public charity called The Aslan Project was founded in Washington, DC in order to raise funds to support the project.

Conclusion

All these collective efforts have prepared the way at TASH and Addis Ababa University to begin the two-year paediatric oncology fellowship and the oncology nurse clinician training that are the mainstay of this project. By conducting the intensive training of local doctors and nurses, expected to start in March 2013, the project is taking the first step towards the development of effective, sustainable systems for paediatric and adolescent cancer treatment in Ethiopia. This is also in keeping with the mandate of the Ethiopian government, that the project, once established in Addis Ababa, be expanded to include other medical schools and university hospitals in Ethiopia, e.g. Jimma, Mekele, and Gondor.

This programme has been the collective effort of numerous Ethiopian, international and INCTR faculty, administrative staff in Ethiopia, Washington DC and Brussels without whom this wide-reaching endeavour would not be possible. ●

Dr Aziza Shad is the Amey Distinguished Professor of Neuro-Oncology and Childhood Cancer and Director of the Division of Pediatric Hematology Oncology, Blood and Marrow Transplantation at the Lombardi Comprehensive Cancer Center, Georgetown University Hospital in Washington DC, USA. She is also the Director of the Leukemia Lymphoma Program and Director of the Cancer Survivorship Program.

Dr Shad graduated with honors from Dow Medical College, Karachi, Pakistan in 1977. After completing a residency in paediatrics, she obtained a Post-Graduate Diploma in Child Health (DCH) from the University of Karachi, Pakistan in 1980. After additional training in paediatrics and oncology in London, UK, she completed another paediatrics residency at the Children's Hospital, Pennsylvania State University, Hershey, PA, (1986-89), followed by a Fellowship in paediatric Hematology/Oncology at the National Cancer Institute, NIH, Bethesda, MD, (1989-92). She then continued her research on Pediatric Lymphomas at the Lymphoma Biology Section at the NCI through 1995. Dr Shad joined the Division of Pediatric Hematology Oncology, Georgetown University in November 1995. She is Board certified in paediatrics and paediatric hematology oncology.

Dr Shad is actively involved in the development of paediatric oncology programmes in developing countries, particularly in Asia, the Middle East, Africa and Latin America.

She is the President of the US branch of INCTR (International Network for Cancer Treatment and Research), Chair of the Pediatric Oncology Education Committee and Member of the Governing Council of INCTR. She is also Chair of the Palliative Care Committee for MECC (Middle East Cancer Consortium) and PODC, SIOP. She has spoken at numerous scientific meetings, both nationally and internationally, and is widely published in the field of paediatric lymphomas, paediatric oncology in developing countries and late effects in cancer survivors, a major area of her research. She is the author of two books.

Julia Challinor RN, PhD, MS in Education and MS in Med Anthropology, is a graduate of Wheelock College, San Francisco State University, the University of California, San Francisco and the University of Amsterdam, Netherlands.

A former teacher, Julia was the Educational Liaison for children with cancer and those who had survived their disease at the University of California, San Francisco from 1993-2003. During 1994-2006, she also headed A Tomorrow for Children Foundation and worked in partnership with pediatric oncology centres in Latin America.

Julia's current professional focus is mentorship of pediatric oncology nurses in Ethiopia and other developing countries. In

Addis Ababa, the team considers the needs of the children, adolescents and parents at the Tikur Anbessa Specialized Hospital as they work to develop an interconnected multidisciplinary approach to cancer care that includes nurses and parents as key partners.

As an international nursing consultant for oncology with an anthropological perspective, Julia seeks to strengthen nursing resources and opportunities in countries with limited resources.

Mary Louise Cohen is a founding partner of the law firm of Phillips & Cohen LLP, and has represented whistleblowers for more than 20 years in lawsuits to recover fraud damages for the United States Treasury. Before founding the law firm, Ms Cohen spent many years in public service positions, serving as counsel

and chief counsel to the Subcommittee on Juvenile Justice of the US Senate Judiciary Committee; legislative director for a national public interest organization working with law enforcement on gun safety issues; and counsel to the Senate Judiciary Committee's Subcommittee on Antitrust, Monopolies and Business Rights focusing on drug safety and business ethics.

In 2007, Mary Louise joined with Beninese singer and songwriter, Angeliqe Kidjo to form the Batonga Foundation to support secondary education for girls in five African nations. She also serves as Chairman of the Opportunity Fund which supports health and education efforts abroad and on the Board of Directors for INCTR. Mary Louise graduated cum laude from Harvard Law School where she was a member of the Harvard Legal Aid Bureau.

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