ENELEN High Quality, High Impact Research

# **EMBLEM PIs Who Champion BL Treatment at EMBLEM Sites**

Burkitt lymphoma is known for how it distorts the face, as this shows well in photographs. But the rapidly growing tumor can occur anywhere in the body, and it may affect function, such as eyesight, or ability to walk. This is normally of rapid onset, over a few days. If not recognized as BL, the child may be taken for various kinds of traditional treatment, which prove useless, and only delay appropriate treatment. Doctors working with EMBLEM confront these problems every day as they see their patients. In one case, a patient came when they are unable to walk well for a few days, but, once a correct diagnosis and chemotherapy is given, the patient recovered their ability to walk. In some unfortunate situations, patients come late, after receiving treatment from traditional healers which may cause abrasions from overly vigorous massage and irreversible paralysis. The longer the paraplegia has existed, the more unlikely it is to resolve fully.

However, hopeless or hopeful, doctors approach their patients with keen interest to help. Frequently, they are rewarded with great stories of success. Recently, one of our doctors, Dr. Esther Kawira, recalled a young man who finished chemotherapy four months ago and was still paraplegic and had to be carried home by his father. At a recent follow-up visit, he grinned broadly as he walked to the office door on his own, using only a stick for support. This month, we recognize the heroes in EMBLEM who bring hope to children with BL at EMBLEM sites.



Nestory Masalu, Tanzania



Esther Kawira, Tanzania



Constance Tenge, Kenya



Martin Ogwang, Uganda

Dr. Esther Kawira – Editor

## **EMBLEM UGANDA**

EMBLEM Uganda has spotted 656 potential cases, 376 of whom were eligible and 353 have been enrolled. The cases include 56 who have also provided fresh-frozen tumor tissues for BL tumor genome sequencing.

The EMBLEM Steering Committee for Uganda met at AFENET in April to review progress of the study.

### **EMBLEM KENYA**

In the month of May, 11 cases (8 males, 3 females) bringing the cumulative total to 549 (349 males, 200 females) spotted. Of the 11 spotted 6 (3 males, 3 females) were eligible and enrolled giving a total of 221 eligible and enrolled (156 males, 65 females).

Matched population control (MPC) enrollment has kicked off in Kenya. Nine villages have been visited. A total of 104 (54 males, 50 females) children have been enrolled.

Data entry of households is ongoing with selection of households by IMS. Verification and data entry of study and lab forms is ongoing. MPC for the next 10 wet villages is to kick off on June 14th in both Kisumu and Nyando Districts.

### **EMBLEM TANZANIA**

EMBLEM Tanzania spotted 6 new cases in May (2 females, 4 males), two of these (1 female, 1 male) were eligible and got enrolled in the study. The cumulative number of spotted cases now stands at 453 (252 males, 201 females). The total number of cases enrolled is now 111 (63 males, 48 females)

The team conducted the first CRA training in Mwanza. A total of 33 CRAs were trained on several topics that will give them skills required for them to facilitate the study activities in their villages. These included the importance and how to collect data, the symptoms of cancer in children and the general objectives of the EMBLEM study. The CRAs first task will be to collect household enumeration data from their villages and spotting potential cases.



Nelson, laboratory technologist, demonstrating sample collection during MPC in Nyaudho'A' village.



Dr. Beda addressing participants to officially open the CRA training on behalf of the Head of BMC –Oncology department.

#### **EMBLEM GOALS**

Although EMBLEM's goals are scientific, to enroll 1,500 cases and 3,000 controls, collect data about home and life experiences (including malaria exposures), and collect biological samples, the patients' goals are to be diagnosed, treated and get well. Thus, these goals often clash at the bedside. For research, meticulous attention to data and sample collection procedures prevail. For clinical care, relieving the patient's anxiety, pain and rapidly increasing symptoms or complications prevail. To enhance both patient care and research, EMBLEM works closely with the hospital clinicians to elevate the routine standard of care, and works with its research staff to increase their sensitivity to patient needs. The clinicians recognized this month play a central role in making this connection to both be meaningful for patients and to protect the high quality of data required for EMBLEM. They are our real champions.

**EMBLEM Newsletter** is a monthly on-line publication based on contributions of the EMBLEM Study staff. **Editor**- Dr. Esther Kawira<u>elkawira@gmail.com</u>

Reporters- EMBLEM Uganda – Esther Birungi; EMBLEM Kenya – Pam Akinyi Were, EMBLEM Tanzania – Herry Dhudha