

# **EMBLEM Newsletter**

A monthly means to inform and inspire our TEAM December 2012 Vol. 3, No. 12

## **Families**



BL families normally come from rural environments such as this one, that shows a mother with four of her children, multiple thatched houses in a group, and livestock kept in bush-fenced enclosures adjacent to the dwellings. Note Lake Victoria on the horizon

"Has any other child in your family or clan ever been affected by BL?"

This is a standard question asked at intake for new BL patients in the EMBLEM Study. In some families in Rorya District of Tanzania, there appears to be a genetic predisposition to BL. In the past 30 years, we have found pairs of siblings, half-siblings, or cousins, and aunts and uncles paired with nieces or nephews in which both are affected with BL, usually many years apart. The largest "BL Family" we have found is one in which a man with multiple wives had four children affected by BL, two each from two of his wives. In another family, since clan histories are so well known, and one's "extended family" consists of one's 500 to 1000 closest relatives, we have found two BL patients from the same clan, linked by a common ancestor about 5 generations back.

Since detailed questionnaires are administered to each new BL patient, the EMBLEM Study will be in a position to answer the question as to whether these familial cases occur elsewhere in our study area or seem isolated to this one district. Also, with genome-wide analysis now available on stored blood samples from these families, we can begin to examine which genetic factors might contribute to the higher incidence of BL in Rorya District compared with other study districts.

#### Dr. Esther Kawira -Editor

### **EMBLEM KENYA**

EMBLEM Kenya has spotted 27 cases of BL and enrolled 19 cases (14 Males, 5 Females). Five cases were not eligible and 3 died before they could be enrolled.

EMBLEM Staff continued community mobilization activities in Turbo, Uasin –Gishu County during a primary health care free Medical Camp, where the co-Principal Investigator gave a talk about EMBLEM. Staff also continues to make outreach phone calls to primary health care givers to encourage referral of cases. EMBLEM Kenya staff met with the Red Cross Kenya staff to plan joint community mobilization activities where their activities overlap. Plans are underway to hold a joint meeting with other stakeholders to strategize on joint community mobilization activities.

The long awaited laboratory equipment for Webuye District Hospital arrived. This is the 6<sup>th</sup> and final EMBLEM site to be set up. We are grateful to the Ministries of Finance and Medical Services of the Government of Kenya for granting tax exoneration for the research equipment.

Finally, EMBLEM staff gave a talk at the Kenya Progressive Nurses' Association annual scientific conference in Eldoret. The conference was attended by over 600 nurses from all over Kenya.

## **EMBLEM TANZANIA**

EMBLEM Tanzania has spotted 192 cases of BL and enrolled 20 cases (11 Males, 9 Females). A regional medical meeting for Mara Region, one of the two EMBLEM Study regions in Tanzania, gave an opportunity for the PI to present the EMBLEM Study to attendees. The meeting was called by the Regional Medical Officer to brainstorm on ways to address the high rate of HIV in the region. Interestingly, BL is an HIV-related tumor in the West, however, the same linkage has not yet been found in African BL.

## **EMBLEM UGANDA**

EMBLEM Uganda has spotted 263 cases (175 Males, 88 Females) and has currently enrolled 118 (79 Males, 39 Females). The team is working in Kangudde Yumbe in northwest Uganda. They have attained their target of 75 pilot population controls and have enrolled 11 of the 15 health center controls needed to complete control enrollment for this village.

In preparation for the holiday season, 2,200 vials of blood and saliva research samples were shipped from the two field study laboratories at Lacor Hospital and Kuluva Hospital to the central laboratory at the Uganda Virus Research Institute in Entebbe, where electricity supply is more stable.

Emblem Uganda held its last Quarterly Review meeting on December 4, 2012. Participants, representing all departments at Lacor hospital and those hospitals in Gulu district involved with the BL study, discussed the successes and limitations of case spotting strategies in 2012 and the ways to improve in 2013.

A joint Community Advisory Board meeting for North Central and North West Uganda was held on December 7, 2012. The Board received a report on the challenges of BL awareness in the community and reviewed concerns about children with BL not getting standard treatment. They advised that a solution to this issue would improve uptake of mobilization messages.



EMBLEM Staff loading samples into a liquid Nitrogen shipper



Liquid Nitrogen Shipper ready to be loaded

## **EMBLEM Study Goals**

<u>Accrual Goals</u>: 157 BL cases; 670 controls; 8800 sample vials. <u>Implementation Goals</u>: A major part of making medical research sustainable in new places is to invest in improving infrastructure. For the EMBLEM Study, laboratory capability is critical in order to make study findings valid and verifiable. Microscopes with camera capabilities are now available and working in EMBLEM labs in each of the three countries. Photographs taken through the microscope and stored in the computer include histologic and pathologic views of tumor cells, blood slides viewed for malaria, and stool specimens examined for pathogens. Since microscope photos can be viewed and verified independently, and don't depend on variable skills of the microscopist at each site, reported results will be of extremely high and reliable quality.

EMBLEM Newsletter is a monthly on-line publication based on contributions of the EMBLEM Study staff.
Editor- Dr. Esther Kawira, Email address: <u>elkawira@gmail.com</u>
Reporters: EMBLEM Uganda – Esther Birungi; EMBLEM Kenya – Pam Akinyi Were; EMBLEM Tanzania – Josiah Magatti