



EMBLEM vehicle delivering the remains of a BL patient

## THE UNMET NEEDS OF EMBLEM

The EMBLEM study protocol has clearly stated benefits to the participants. Among these are free diagnostic evaluation and treatment for cases, and mosquito bed nets. However, other needs have arisen during the course of the study. Some of these needs have been addressed through a “Distress Fund”, which was established on the advice of the Uganda EMBLEM Community Advisory Board. This fund was initially meant to assist needy patients with refunds for transportation, particularly those patients coming for treatment from far away. This fund, however, has proved flexible enough to respond when other urgent needs have arisen, as explained below.

Treatment of BL involves chemotherapy drugs that induce immune suppression and leave the patient vulnerable to many other infections, such as measles and pneumonia. When the first-line drugs do not cure the patient, other, second-line drugs, which cause even more severe immunosuppression, are tried. Sadly, they are not always successful. In the event of a patient’s death, families, who are often already impoverished, are usually desperate for funds to hire a private vehicle to transport the body back home. The public bus transit system does not allow transport of bodies on the bus.

In the last three months, EMBLEM Lacor has been involved in transportation of bodies of five BL patients whose families faced such a situation. The nurse of the BL ward and the hospital chaplain, Rev. Father John Peter Olum, along with endorsement from the BL Study Coordinator and the hospital’s Director, provided the assessment of need for this service. This is surely an example of the EMBLEM study supporting BL patients, their families, and the community to fulfill an unmet need amidst profound grief.

Another example is in Kuluva, where case enrollment is yet to start and cases will, for the time being, be referred to Lacor. This positive gesture from EMBLEM, is expensive in terms of fuel and EMBLEM staff time, but earns appreciation from the community and is likely to have a positive impact on the study.

Appreciation of this help was manifested by one parent from Kuluva, who stated *“I am very grateful to EMBLEM for transporting the body of my son back to his roots. I do not know what I would have done without this help”*. He added, “Awaidifo saruu” in his local language, to emphasize the point.

*Dr. Tobias Kinyera, Study Coordinator EMBLEM Uganda, Guest Editor*

## EMBLEM Tanzania

Case accrual is underway at Bugando Medical Center in Mwanza Region, including several new cases sent from Mara Region. At the time of this writing, a total of five cases had been enrolled.

Planning for control enrollment has now resumed, with a target of about 500 controls to be enrolled from each of the two study regions. The newly purchased EMBLEM Tanzania study vehicle, a Toyota Landcruiser, to be primarily used for community mobilization and control enrollment activities, finished clearing procedures and was brought from Dar es Salaam to Mwanza.

## EMBLEM Uganda

Case enrollment continues, with enrollment figures hitting the 80 case mark. Of these, 55 are males and 25 are females. Control enrollment in Amolatar Acon B Village in Amolatar District is complete, with 21 health centre II controls enrolled and 60 Pilot Population Controls enrolled from the village. Of these, 29 were male and 31 were female.

The Air Conditioner for the EMBLEM Laboratory in the Lacor Hospital study site has been fixed and is now fully functional again.



A.C. unit fixed outside the EMBLEM Lab

Interviews for hiring a new data manager for EMBLEM - Uganda have been completed. Three candidates have been identified and in a period of two weeks, we will have new data manager. Orientation continues for the administrative assistant who is currently the latest addition to the EMBLEM team.



L to R: William Aketch, Dr. Peter Odada and Mediatrix Mumia discussing sample storage in the EMBLEM Lab.

## EMBLEM Kenya

Emblem Kenya has spotted 37 cases, of which 6 were BL, 5 were eligible and 2 have been enrolled in the study.

The saying goes that when a tree is uprooted, it comes out with all its roots including the soil. This has been the case with the EMBLEM study where, not only BL cases are being identified, but several other childhood malignancies have also been diagnosed.

The first Community Advisory board meeting took place on April 27, 2012. The well-equipped EMBLEM laboratory is now in operation and, most importantly, EMBLEM Kenya is now having collaboration with the OGRA Foundation.

OGRA Foundation is providing medication and social support as EMBLEM ensures that diagnostic procedures are carried out effectively.

EMBLEM Newsletter is a monthly on-line publication based on contributions of the EMBLEM Study staff.

Editor- Dr. Esther Kawira, Email address: [elkawira@gmail.com](mailto:elkawira@gmail.com)

Reporters: EMBLEM Uganda – Isaac Otim; EMBLEM Kenya – Pam Akinyi Were; EMBLEM Tanzania – Josiah Magatti