



# EMBLEM Newsletter

A monthly means to inform and inspire our TEAM

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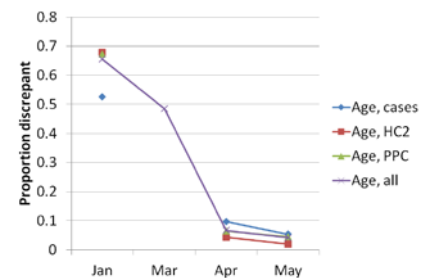
## Data Quality Control



Dr. James J. Goedert, M.D., NIH/NCI

EMBLEM has been spotting, screening, and enrolling Burkitt Lymphoma (BL) cases and controls for 28 months - since November 2010. Over that period, 243 BL cases and 953 controls, mostly from Uganda where the study was first launched, have been enrolled. Close to 20,000 forms have been completed which document responses to a 52 item questionnaire along with 200 laboratory result variables across 29 form types. This whole process is captured in a study registry database, compartmentalized for research and local-use. In the field, quality assurance is implemented through use of standardized procedures and regular visits by study monitors (<http://www.emblem.cancer.gov/newsletters/2011.june.html>).

Recently, EMBLEM has instituted a rigorous data quality control regimen. Led by Dr. James J. Goedert, senior investigator on the EMBLEM Study at NCI, data quality control focuses on 11 variables (age, gender, family home from water source, child use of mosquito net, tumor anatomic site, white blood cells, malaria-thin and thick microscopy and malaria-rapid test, ultrasound, and stool parasitology). Rigorous inspection of data will allow corrections against systematic or random variation. Early results are encouraging. For example, for age, which is collected on multiple forms, it seemed in January 2013 that 60-70% of records had discrepant age (+/-1 year). By April, the proportion is less than 5% (see graph at left 1). Other areas require more work. For example, results have not been computerized for about 20% of records, whose data record still indicates a missing stool form.



## EMBLEM UGANDA



Members of the EMBLEM Northwest Community Advisory Board and EMBLEM PIs at a meeting in Nebbi

By end of April, 330 potential cases (117 females and 213 males) were spotted and screened and 159 were enrolled (59 females and 100 males). Control enrollment was completed in Kirombe Village - the 10<sup>th</sup> of 12 pilot villages.

The 3rd Northwest Community Advisory Board (CAB) meeting was held in Nebbi on the 13<sup>th</sup> of April 2013. The meeting was an opportunity for EMBLEM to report to the community and receive feedback.

The protocol for collection of fresh frozen BL tumor tissues for the BL Genome Sequencing Project was finalized, tested, and approved after successful pilot experiments were performed on two patients with suspected cancer. Eligible patients are being enrolled.

## EMBLEM KENYA

By the end of April, 163 potential cases have been spotted and screened. Of these 54 were BL and 43 (10 females and 33 males) have been enrolled in the study.

EMBLEM staff was retrained in Tanzania. Mr. Genga and Ms. Were have initiated a retraining plan for local staff. They have renewed BL Health Communication messages to public health students in Homa Bay and Uasin Gishu Districts. Ms. Mediatrix Mumia, an EMBLEM technician, received training in stock management and procurement. These changes bring Kenya close to starting community control enrollment later in the year.



EMBLEM Staff complete testing SOPs for collecting fresh-frozen tumor samples

## EMBLEM TANZANIA

Case spotting stands at 236, of which 35 have been enrolled (16 females and 19 males).

The retraining workshop facilitated by Dr. Tobias ended in early May. It was attended by EMBLEM Tanzania staff, senior staff from EMBLEM Kenya and staff from Shirati and Bugando Hospitals where the study is taking place in Tanzania. The second Tanzania EMBLEM Community Advisory Board meeting is planned to take place at the end of May, in Mwanza. It will focus on updates since the first meeting and description of plans for control enrollment.

Poster distribution to health facilities in the districts has continued. A talk on Burkitt Lymphoma, its diagnosis and treatment, and the EMBLEM Study, was given to student nurses at Shirati Hospital, who will soon graduate and be working widely in the districts of our study regions.



L to R Pamela Were, Isaiah Genga, Dr. Tobias and Hillary reviewing equipment documents (SOPs and Manuals) in the EMBLEM lab in Bugando Medical



Dr. Nestory Masalu, Capt. Josiah Magatti, Kheri Vincent, Nick Hu and Mr. Senya during a retraining session in Bugando.

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

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