



EMBLEM Newsletter

A monthly means to inform and inspire our TEAM

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Youth from Middletown Maryland Raise \$1200 US to Treat Burkitt Lymphoma at Kuluva Hospital

Kuluva Hospital, established in the 1920s, was the site of many seminal studies of Burkitt Lymphoma (BL) in the 1960s and 70s. These include studies that led to the discovery of the association of childhood Epstein Barr Virus (EBV) infection with the risk of developing BL and, most importantly, the curative treatment of BL (EBV is now linked to several cancers). Forty years later, Kuluva's capacity to treat children with BL has been eroded, mostly due to lack of funds. In the [October 2013 EMBLEM Newsletter](#) Maryland youth learned of BL for the first time when a local young man from their community was diagnosed with BL, galvanizing their community to respond and support the young man. Youth in the middle and high school affiliated with the Christ Reformed United Church of Christ (CRUCC) in Middletown, were moved when they learned that BL is much more common among children in East Africa and that children at Kuluva (see photo at right) lack necessary drugs for treatment.



The CRUCC youth responded to the dire need for BL drugs at Kuluva by conducting a two-month information campaign to raise funds to assist children with BL at Kuluva in getting treatment. The youth spoke to Ismail Legason, an EMBLEM laboratory scientist working at Kuluva Hospital, via Skype to better understand what was needed at Kuluva.

In May and June 2015, the youths raised \$600 from a community car wash and yard sale (see photo at right), which included, fittingly, a child's bench featuring an African landscape backrest. Impressed by the fundraising success of the youth, the CRUCC Discipleship Board offered matching funds to the youth, thereby doubling the total amount raised to support BL treatment at Kuluva. Although modest, the funds raised by youths in Middletown are sufficient to provide full treatment for 2-3 children with BL. The generous gesture by youth in Middletown is an amazing example of how people are touched when illness strikes one of their own can be moved to help people from far away who are touched in a similar manner, but have less resources to respond. EMBLEM hopes that this example will unleash innovative ways to help children with BL in Africa.



Contributed by Janet Lawler-Heavner, Guest editor

EMBLEM UGANDA

EMBLEM Uganda has spotted 663 potential cases, 383 of whom were eligible and 357 have been enrolled. The cases include 64 who have also provided fresh-frozen tumor tissues for BL tumor genome sequencing. With completion of control enrollment, the team continues to focus on data cleaning and shipping samples to the Uganda Virus Research Institute for long-term storage and to the NCI for genetic testing.

EMBLEM KENYA

EMBLEM Kenya has spotted 564 potential cases, 279 of whom were eligible and 223 have been enrolled.

Matched population control enrollment is ongoing and 196 (100 males, 96 females) controls have been enrolled.

EMBLEM TANZANIA

EMBLEM Tanzania has spotted 473 potential cases, 121 of whom were eligible and 115 have been enrolled.

The team is computerizing the household data in preparation for starting matched control enrollment.

EMBLEM GOALS

Although EMBLEM's work takes place in remote locations in Africa, the scientific goals require close collaboration between well-funded centers in the developed countries and resource-limited populations in Africa. Through close collaboration, the data and collected biological samples will be tested to answer the scientific questions and provide important new knowledge to improve early detection and treatment of patients with BL. However, the promise of better treatment resulting from research provides little comfort for those children who have BL now. They need treatment, which the research budget is unable to support. We are gratified that children living thousands of miles away from East Africa responded to the unexpected diagnosis of one of their own by thinking about kids in Africa. The funds raised, although modest, suggest a new way to help African children with BL. If children from just 200 communities in the US raised funds to treat 3 children with in BL Africa, those children would eliminate death from BL in Africa. EMBLEM hopes that its policy to share its experiences on the web will facilitate these connections and, in a small way, begin chipping away at the death toll from BL in Africa.

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

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