

TJ – A Real Life Story Showing the Unbounded Human Dimension of Burkitt Lymphoma



If Janet had not been working as the Westat study manager for EMBLEM, it is quite likely that EMBLEM would not have known about TJ. Likewise, to Janet, TJ's serious illness would have been an odd cancer striking most-unexpectedly. In May 2013, TJ was one of many seniors at his high school in Maryland looking forward to his graduation. Like all teenagers, he was eager to get on with his life. However, his life was about to change – profoundly. In May, he was diagnosed with an aggressive lymphoma –Burkitt lymphoma – and referred to *Johns Hopkins Pediatric Oncology Unit in Baltimore*. TJ lives in the same community as Janet and her family. He attended the same school as Janet's daughters and was set to graduate with one of them. When he missed his high school graduation, his struggle became the entire class's and community's struggle. They were upset and confused by this exotic cancer that threatened TJ. They were, however, reassured that the Johns Hopkins Hospital in Baltimore, Maryland, the best in its league, would take good care of TJ. TJ has been hospitalized for five months. He has received intensive chemotherapy to treat BL.

Aggressive treatment has stopped the BL in its tracks and alleviated TJ's pain, but not without great cost. It has also left him paralyzed below his chest and robbed him of his ability to hear and to breathe on his own. TJ is fighting now to regain strength and to learn to live within these new limitations. TJ's experience, thousands of miles from where EMBLEM is being conducted, highlights the human dimension of suffering from BL and why research on BL holds hope not only for the African BL cases, but also for those that occur elsewhere. The complex treatments that TJ underwent are not practical or available in Africa. Yet, even where such complex treatments are available, TJ's experience underscores the need for better, simpler, and less toxic BL treatment everywhere. EMBLEM continues to provide an important opportunity to build bridges between need and hope through new discoveries to improve early diagnosis, treatment, and prevention of BL both in Africa and worldwide. (Read more about TJ at: <http://www.hope4tjruffy.com/>)



Janet Lawler-Heavner

- Janet Lawler-Heavner, Guest Editor

EMBLEM UGANDA

As of September, 416 (263M, 153F) potential cases have been spotted in Uganda, with 231 eligible and 213 (122M, 83F) enrolled. Matched control enrollment has been completed in the Lango sub region with 223 (121M, 97F) controls enrolled. Thirty-six of the 40 required samples of frozen BL tumor tissues and matched normal tissue for the NCI sponsored study on tumor genome atlas have also been collected. These samples will be shipped to NCI in November. Mr. Francis Ssebiryoy (at right), the EMBLEM Data Manager, left EMBLEM to join Path Uganda. We wish him success in his new job.



Mr. Francis Ssebiryoy

EMBLEM KENYA

As of September, 241 (149M, 92F) potential cases have been spotted, with 90 cases eligible and 81 (57M, 24F) enrolled.

During the month, the Kenyan EMBLEM team hosted the EMBLEM Principal Investigator (Dr Sam Mbulaiteye), visitors from Duke University (Profs. Nelson Chao and Sandeep Dave and Dr. Joel Ross), EMBLEM Study Monitors (Prof. Moses Joloba and Mr. Samuel Kirimunda from Makerere University) and the Senior EMBLEM Study Manager from the African Field Epidemiology

Network (AFENET) (Mr. Erisa Sunday). The visitors held review and consultation meetings with the local team, collaborators and other stakeholders (i.e MTRH, AMPATH and JOOTRH). The Team and the visitors paid a courtesy call to the Office of the Governor, Homa Bay to meet a delegation led by the Minister for Health Services, Dr. Lawrence. In his remarks, on behalf of



Hon. Dr. Oteng

the Governor, Hon. Dr. Oteng (in photo at right) welcomed and acknowledged the groundbreaking research EMBLEM has introduced to the region. He expressed the commitment of the government to support and strengthen the cancer work in the region and partner with EMBLEM and other groups to work in a manner that will foster sustainability. He welcomed the visitors from Duke and encouraged them to consider working in the region, noting the mutual benefits to the university and to the people in Kenya.

After their visit in Kenya, the visitors continued to Tanzania.

EMBLEM TANZANIA

Eight potential cases have been spotted since the last report bringing the total of cases spotted and screened to 295 (163M, 132F). Of the 8 cases spotted, 4 were eligible and were enrolled in the study, bringing the total of cases enrolled to 59 (32M, 27F).

EMBLEM joined other departments at Bugando Medical Center (BMC) to celebrate the annual “Bugando Day”

on October 26th. The Chief Guest was the Hon. Dr. Gharib Bila, Vice President of The United Republic of Tanzania, who also officiated at the opening of the new Oncology Center at BMC, which is headed by Dr. Nestory Masalu, EMBLEM co-PI in Tanzania. The Hon. Gharib Bila was pleased by the work being done by BMC and by EMBLEM, which was described as inspiring by many visitors.

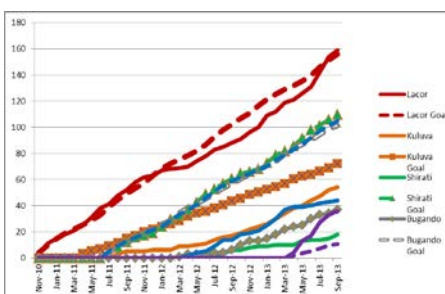


Hon Dr. Gharib Bila, Vice President of the United Republic of Tanzania (in a black suit), and Dr. Mwinyi, Minister of Health, receive an update about EMBLEM



Hon. Dr. Gharib Bila, Vice President of the United Republic of Tanzania, and Dr. Mwinyi, Minister of Health, receive a report from Dr. Masalu, EMBLEM Co-PI and Head of Oncology Department, and Dr. Charles Mazinge, Director General of BMC

EMBLEM GOALS



EMBLEM has been tracking cumulative case enrollment versus historical patterns (graph at right). Comparisons show that the Webuye site is accruing cases above the historical average. This suggests that cases were previously missed. Kuluva, Shirati, Bugando and Homa Bay sites are enrolling fewer cases than historically. This suggests that BL was historically over-diagnosed. Lacor enrollment mirrors historical numbers. This suggests stable BL diagnosis at this site. These comparisons highlight the changes in diagnosis and treatment of BL, in part, due to EMBLEM. The benefits are improved case identifications and decreased misclassification of cases, which saves drugs and unnecessary treatment of patients with toxic drugs.

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

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