



# “I Want to be President of Liberia”: Reflections on Pediatric Cancer Management in West Africa

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Liberia is a country in West Africa with a stormy history. In the last 30 years, Liberia has survived two civil wars and was the epicenter of the Ebola outbreak, leaving a fragile healthcare system. Despite strides in the reduction of childhood mortality in recent years, nearly 1 in 10 children will die before their fifth birthday in this small, coastal country.<sup>1</sup>

Just 10 years ago, there were only two pediatricians in Liberia where >2 million children reside. Through a partnership between the Department of Pediatrics at Liberia's national referral hospital, John F. Kennedy Medical Center (JFKMC), and Boston Children's Hospital (BCH) in the United States, Liberia's first pediatrics residency program was established in 2017. As a result of this program, there are now 20 pediatricians in Liberia and more in training. However, there are no pediatric oncologists in Liberia. Here, we illustrate how pediatric cancer management in Liberia has progressed through the description of the country's first child to survive a central nervous system malignancy.

A 4-year-old boy named LJ experienced weakness and vomiting for months. At nearby clinics his parents were told he did not have malaria, he did not have typhoid, and so on, but they were never told what he *did* have. One day things suddenly changed. He lost balance, developed severe headaches, and fell over screaming. His parents called two family friends, newly-trained pediatricians at JFKMC, to describe what happened. They instructed LJ's family to go to the hospital immediately. There, a team of residents examined LJ as he fumbled over himself. The team recommended an urgent magnetic resonance imaging (MRI) of his brain to evaluate the cause of his ataxia. LJ's father recounted,

“Driving on the dusty roads across town to Liberia's only MRI machine, we were afraid, but hopeful we were getting closer to knowing what LJ did have.” As preparations were being made for LJ's sedated MRI, he was asked what he wanted to be when he grew up. LJ proudly announced, “I want to be the president of Liberia!” Moments later, his parents kissed his forehead as he fell asleep in his father's arms.

As the rumblings of the MRI faded, LJ's parents learned that he had a brain tumor which was increasing his intracranial pressure. These images, which were consistent with a low-grade glioma, were shared with Liberia's only neurosurgeon and oncologists in nearby Ghana and Nigeria. The response was universal: there was nothing that could be done for LJ in West Africa. The prognosis was thought to be poor for such tumors for children in the region given limited

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access to equipped facilities and pediatric neurosurgical providers.<sup>2</sup>

Through the partnership between JFKMC and BCH, the MRI images were shared with neurosurgeons in Boston. They felt LJ would likely have a good prognosis if his intracranial pressure was reduced. Ten year survival rates for low-grade gliomas are as high as 85% to 96% in high-income countries, where comprehensive, multidisciplinary teams for cancer management are concentrated.<sup>3,4</sup> Conversely, as little as 10% of children diagnosed with cancer in low- and middle-income countries survive.<sup>5</sup>

Moving the neurosurgeon to LJ was not possible, but bringing LJ to a neurosurgeon could be, recognizing this may not be available to all children in Liberia. Despite the lack of pediatric oncologists in Liberia, residents at JFKMC had learned to administer chemotherapy and monitor for response and side effects. Such skill development beyond traditional training is common in sub-Saharan Africa, where there are not enough healthcare providers to meet the needs of the populations they serve.<sup>6</sup> Both the providers in Liberia and partners in Boston were confident that if the critical gap of emergent surgical decompression could be filled, LJ may survive a disease that otherwise would be fatal.

As LJ's chemotherapy and long-term management could be provided at JFKMC, BCH approved free care for a necessary endoscopic third ventriculostomy (ETV) as well as pathology, filling this critical gap for a trusted international partner. LJ started taking dexamethasone before his flight to reduce the cerebral edema noted on his MRI. Hypertonic saline and an intravenous (IV) kit were brought on board as a precaution to address any complications LJ might face while flying with elevated intracranial pressure.<sup>7</sup> Fortunately, the only things lost on the transatlantic flight were sleep and LJ's shoes. Though the location of LJ's tumor precluded resection, the biopsy results returned as suspected: low-grade glioma.

LJ returned to Liberia to begin chemotherapy, which was far from routine. Through a local supply chain from Ghana used to obtain medications not on Liberia's essential medical list,<sup>8</sup> carboplatin and granulocyte colony-stimulating factor were waiting for LJ. A central line was not feasible in Liberia due to the heightened infection risk, so once-monthly carboplatin through a peripheral IV was used for LJ's tumor.<sup>9</sup> Owing to the established partnership between JFKMC and BCH, there was regular consultation with the teams on both sides of the Atlantic Ocean and LJ's parents throughout his 13 chemotherapy cycles. Through many febrile illnesses

including malaria and likely early sepsis, LJ successfully completed chemotherapy.

As of April 2022, LJ has been off chemotherapy for 25 months with significant reduction of his tumor burden. Before the pediatrics residency program was in place, LJ would have surely died without his parents ever knowing what he *did* have. There is no doubt that LJ's case is exceptional in its success, but not in its occurrence. Globally, children with cancer lack access to safe surgical care, chemotherapy, and pediatric oncologists. This open and trusting partnership and the development of a residency program that has extended its capacity may serve as a model that can help save children's lives, regardless of the diagnosis or location. Successfully treating the untreatable in Liberia has pushed the young Department of Pediatrics at JFKMC to continue toward the goal of ensuring equitable and high-quality care is available to all Liberian children. We hope LJ's glioma will remain stable and he, and children like him, can run for president of Liberia one day.

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### Author Contributions

Rees, C: contributed to conception; contributed to interpretation; drafted the manuscript; critically revised the manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy. Cooper, L: contributed to conception; contributed to interpretation; critically revised the manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy. Sonii-Koon, H: contributed to conception; contributed to interpretation; critically revised the manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy. Clymer, J: contributed to conception; contributed to interpretation; critically revised the manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy. Niescierenko, M: contributed to conception; contributed to interpretation; critically revised the manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

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