



photos: Alex Bediako

A Pioneer at Age 5

by Julia Q. Long

Kojo and little sister Maame Akua Serwaa: Kojo is one of the few patients in Ghana to receive factor.

Nana Kojo Opoku Bediako is a big name for a small boy. “Kojo,” who will be six on August 9, has sparkling brown eyes, a beaming smile and factor VIII deficiency. In February Kojo became the first Project SHARESM factor recipient in Ghana, and possibly one of only two children in Ghana ever to receive factor concentrate.

Kojo was born in a gold mining town in the Ashanti Region, and is the elder of Alex and Georgia Opoku Bediako’s two children. “We realized something was wrong with his blood clotting during his circumcision,” recalls Alex. Although they managed to contain this bleed and “other signs of internal bleeding during inoculations and vaccinations” for several years, Alex and Georgia naturally were distraught when Kojo suffered for days and weeks with no real idea of what was wrong. Doctors told Alex and Georgia to try to prevent injuries, and to use painkillers when Kojo’s pain became unbearable. Keeping a toddler away from injuries is difficult enough, but having to decide when pain becomes “unbearable” is a heartbreaking task for any parent.

In September 2004, after a month-long knee bleed that was not eased by pain medication, Kojo was officially diagnosed at Ghana’s main hospital, the Korle Bu Teaching Hospital. The family was relieved to receive a proper diagnosis for Kojo’s problem, but their worst fears were confirmed: there is no hemophilia care in Ghana. “We asked for help from hemophilia societies in the UK, Australia and South Africa via the Internet,” says Alex. “One

member of the Haemophilia Society (UK) recommended I seek help from Project SHARE. I wrote to SHARE and they replied immediately with an offer to send factor for Kojo.”

SHARE contacted Kojo’s doctor and sent illustrated instructions on infusing. With physician contact established through email, and customs cleared, SHARE sent a trial shipment of factor. The infusion was successful, and the Bediakos were overjoyed.

Although Kojo missed six months of kindergarten, his teacher sent assignments home so he could keep up with his classmates. Alex says proudly that Kojo is a “brilliant” student and loves to read. When he is not doing schoolwork, Kojo enjoys playing with building blocks, or having fun with his little sister, Maame Akua Serwaa.

Kojo’s story demonstrates how the needs of one child can pioneer hemophilia care in a developing country. The collaborative efforts of Alex and Georgia, the Haemophilia Society, Project SHARE, and Kojo’s teacher and doctors have helped give Kojo what he needs to be a healthier, happier boy. These efforts may also pave the way to help many more children like Kojo. 🇬🇭



Kojo’s knee before help arrives from Project SHARE.

To learn more about Project SHARESM and how you can help patients like Kojo, please visit www.kelleycom.com/iha/projshare.html or contact Director Julia Q. Long at (978) 352-7657 or julia@kelleycom.com.