

When bleeding won't stop and no one knows why

When a Ugandan family kept losing children to uncontrollable bleeding, swollen joints, and sudden deaths, there were no medical explanations then. Years later, the mystery finally had a name: haemophilia, a genetic bleeding disorder that remains largely undiagnosed in Uganda, often until it is too late.

BY BEATRICE NAKIBUUKA

For Jane Kobusingye's family in Kanungu District, childhood was marked by a pattern of loss that no one could explain.

A younger brother fell in 1970 and began bleeding uncontrollably. He never made it to the hospital. Another brother, often sickly and walking with a limp, suffered repeated bleeding episodes. Their father took him to Mulago National Referral Hospital in search of answers and returned home with crutches and a diagnosis he could not understand: haemophilia. The boy later died at school.

In the village, people had an easier explanation. They said the family was bewitched. Kobusingye's father refused to believe it, but there were no other answers to hold onto.

Then came another loss. A two-year-old child died after a gum injury that would not stop bleeding.

"We were told it was witchcraft," Kobusingye recalls. "But my father never accepted that explanation."

Still, one word lingered in the family's memory, haemophilia, though it meant little at the time and explained nothing.

A nurse with unanswered questions

Years later, Kobusingye trained as a nurse and began working at Kambuga Hospital in western Uganda. It was there she first heard colleagues mention a bleeding disorder that sounded uncomfortably familiar.

"It reminded me of our family," she says. "But I did not really understand it, and I did not pursue it further."

Life moved on. She raised five children, and for a long time, it seemed the past had ended with her parents' generation. It hadn't.

When her grandson began falling ill repeatedly, the old story returned in a new form. His joints swelled painfully, a sign of internal bleeding that went unrecognised for months. Hospitals had no clear answers until the family was referred to CoRSU Hospital, and then to Mulago National Referral Hospital.

At Mulago, doctors suspected haemophilia and ordered tests. When they asked about family history, Kobusingye remembered what her father had once said about Mulago, about haemophilia, about brothers who had died without explanation.

The diagnosis was confirmed.

"For the first time," she says, "I understood what my brothers had died from." Soon after, another grandson, just eight



SLOW PROGRESS, UNEVEN ACCESS

Uganda's response to haemophilia has improved, but unevenly. Two decades ago, only about 15 cases were known. Today, more than 300 have been identified. Treatment centres now exist beyond Mulago, including in Mbarara, Mbale, and Lira. The Haemophilia Foundation of Uganda has played a key role in raising awareness and supporting families.

Yet the gaps remain wide, particularly in rural areas where diagnosis is rare and treatment is often unavailable. Even where care exists, it is heavily centralised. Most specialised services remain concentrated in Kampala, leaving much of the country underserved.

months old, bled for more than 36 hours following a minor injury. He too was diagnosed with haemophilia.

Today, both boys receive treatment at Mulago Hospital, where clotting factor is administered during bleeding episodes.

"At first, I thought they were suffering alone," Kobusingye says. "Then we connected with the Haemophilia Foundation of Uganda. Meeting other families gave us hope."

A hidden national burden

For doctors, Kobusingye's story is not unusual.

Dr Deo Munube, a paediatrician at Mulago National Referral Hospital, says haemophilia remains one of the most underdiagnosed genetic conditions in the country.

"About 369 people are currently known to be living with haemophilia in Uganda," he says. "But we estimate that at least 4,500 should actually have the condition."

That means more than 90 percent of cases may remain undetected.

The reasons are structural and deeply rooted. Diagnostic laboratories are limited. Awareness among health workers remains low. Referral systems are weak. Routine screening does not exist.

"In many cases, diagnosis only comes after a severe bleeding episode," Dr Munube explains.

Signs that are often missed

Haemophilia is present from birth, but it is not always immediately recognised. In many cases, the first signs appear when a child begins to walk, fall, or undergo minor procedures such as circumcision.

Bleeding that does not stop after small injuries, frequent nosebleeds, unexplained bruising, and swollen joints are all early warning signs. In severe cases, symptoms appear in infancy. In milder forms, they can go unnoticed for years.

Treatment involves replacing missing clotting factors in the blood, but access remains inconsistent.

"Factor concentrates are often dependent on donations," Dr Munube says. "Most patients receive treatment only when they are already bleeding. Preventive care is still limited."

In public hospitals, stock-outs are common. Families often travel long distances or wait until bleeding becomes severe before help is available. For many, transport costs and delayed care worsen outcomes.

Between myth and medicine

In communities where diagnosis is delayed, explanations often fill the gap.

"Some families still believe it is witchcraft or punishment," Dr Munube says. "Others confuse it with sickle cell disease."

These beliefs are not just cultural; they are consequential. They delay hospital visits, reduce trust in medical systems, and in some cases, cost lives.

Kobusingye's family lived through this confusion for decades, caught between medical uncertainty and social interpretation.

Living with haemophilia

With proper care, people with haemophilia can live long and active lives. The key is early diagnosis and prompt treatment during bleeding episodes.

Doctors often advise basic first aid measures such as rest, ice, compression, and elevation while seeking medical care. Preventing injury, maintaining good nutrition, and regular follow-up are also important.

But effective care requires more than advice. It requires trained health workers, reliable supplies of clotting factor, laboratory support, and coordinated referral systems. These remain limited in many parts of Uganda.

Diagnosis as a turning point

For Kobusingye, diagnosis came too late for her brothers, but in time for her grandchildren.

"Now we know," she says quietly. "And because we know, we can act."

That knowledge separates generations shaped by silence from those who now have a chance at survival.

For thousands of Ugandan families, however, the condition remains unnamed, untreated, and often misunderstood. The mystery that haunted Kobusingye's childhood is still unfolding in homes across the country, waiting for answers, and sometimes, waiting too long.

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Resilient

"Growing up in Kanungu, I watched my brothers die from uncontrollable bleeding that no one could explain. For years, neighbours blamed witchcraft, but my father held onto the word he once heard at hospital: haemophilia. Today, after my grandsons were diagnosed with the same condition, I finally have answers. I now speak out so other families do not suffer in silence or lose children to a disorder that can be managed if detected early and treated in time," says Jane Kobusingye.

Jane Kobusingye's family lived for decades without answers as children died from uncontrollable bleeding — until a diagnosis of haemophilia changed everything. PHOTO/ BEATRICE NAKIBUUKA