

A UGANDAN HEALS FROM SICKLE THROUGH GENE THERAPY

By Sam Wakhakha

At 35, Allan Byamukama's life had been defined by pain and regular hospital visits because of sickle cell disease. Diagnosed with the condition at five months, emergency units of health facilities in Uganda and the US had become his second home.

He had several forms of treatment, including a hip replacement and red blood cell exchange, but little improvement was registered.

In the first 25 years of his life, his condition was being managed in Uganda, until 2015, when he moved to the US, where part of his family was living.

TREATMENT IN AMERICA

"When I moved to the US in 2015, a new form of sickle cell treatment known as gene therapy was still on trial. My haematologist recommended that I undergo this form of treatment after the US Food and Drug Administration approved it. After a lengthy procedure in laboratories and hospitals, the doctors at Massachusetts General Hospital declared me free of sickle cell disease in August last year and indeed I have not had any complications since then," he says.

Based on the medical experts' reports at the US-based hospital, Byamukama is now the first Ugandan to be completely healed of sickle cell disease through gene therapy.

He was the 15th person worldwide to be treated using the gene therapy method that was approved by the Food and Drug Administration of the US in December 2023.

In 2008, seven-year-old Miriam Mulumba became the first Ugandan to be cured of the condition, but through a bone marrow transplant. Several others have also been treated using the same method.

Speaking to *New Vision* at the office of the director general of Health Services in Kampala last Thursday, Byamukama could not hide the joy of getting a new lease of life after years of surviving on heavy doses of painkillers and constant treatment procedures.

"I could not believe it when the doctors broke the news. I had asked God to at least grant me a pain-free life of one year before I die. But he has done more than that and I am grateful to him," he said.

ABOUT GENE THERAPY

Gene therapy is a cutting-edge medical approach that treats or prevents disease by correcting or altering a person's genetic

material (DNA or RNA) to change how cells function, often by replacing faulty genes, inactivating harmful ones, or adding new genetic instructions to achieve particular results.

Scientists are vouching for gene therapy as an alternative because it is less tedious.

EXPENSIVE, PAINFUL

Byamukama's treatment did not come cheap; it cost a whopping \$2.1m (about sh7.5b) and involved a process known as stem cell harvesting and cell editing. "The cost of my treatment was covered under insurance in the US. This would have been impossible in Uganda," he narrated.

Byamukama says that in 2024, he was admitted to the emergency unit 42 times in March 2025.

The first procedure involved harvesting stem cells from his own body, which took three days.

"It is the cells editing that took about seven months. I then rested and the edited cells were again reintroduced into my body. I underwent a short chemotherapy and after a while, I was tested and found to be sickle cell free," he said.

Byamukama encouraged people with sickle cell disease not to lose hope, explaining that the experts are working hard to ensure that remedies are available. He also appealed to the Government and other stakeholders to ensure that the cost of treatment and groundbreaking procedures,



Byamukama with doctors in the US hospital. His treatment cost about sh7.5b under insurance which involved a process known as stem cell harvesting and cells editing

GOVERNMENT EFFORTS

In October last year, health minister Dr Jane Ruth Aceng announced that Ugandan pharmaceutical company Qcil will soon begin manufacturing hydroxyurea for sickle cell disease. She added that having the drug produced locally will make treatment more accessible.

The director general of Health Services, Dr Charles Olaro, also said the Government is committed towards lowering the cost of sickle cell remedies and eradication of the disease, adding that couples are urged by the Government to test for sickle cell before marriage so that they avoid bearing children with the condition.

such as gene therapy, are affordable.

BYAMUKAMA'S MESSAGE

"When I was a child, I thought I could not make it to 18, but here I am at 35 and free of

sickle cell disease. I appeal to the Government to do more sensitisations and provide treatment in lower health facilities. There are areas in Uganda where people with sickle cell disease still depend

on paracetamol to manage the disease," Byamukama stressed.

Evelyn Mwesigwa, the Joint Clinical Research Centre Coordinator for Gene Therapy Initiative, welcomed the news of Byamukama's healing and appealed to the Government and other stakeholders to lower the cost of treatment to ensure that more Ugandan doctors are trained in such groundbreaking treatment procedures. "Together with the Government and other stakeholders, we can lower the cost of treatment so that we save more lives. And it is possible. In the past, the cost of a bone marrow transplant was over \$1m (about sh3.6b). Today it is about \$30,000 (about sh100m). Once the technology becomes

affordable, more people will be saved," she said.

TESTING

Sickle cell testing is free of charge in all government hospitals for newborns and not more than sh50,000 for adults, and in the private sector.

NATIONAL BURDEN

During World Sickle Cell Day in June, the health ministry issued a renewed call for Ugandans to know their sickle cell status before bearing children.

In an earlier interview, Dr Charles Kiyaga, who heads the ministry's Sickle Cell Programme, said: "A carrier is not a sickle cell patient. They are healthy individuals with one mutated gene, inherited from either parent. But if two carriers marry and have children, there is a high risk of passing on the full-blown sickle cell disease to the offspring."

According to the ministry's data, the national sickle cell carrier rate was estimated at 13.3% in the 2014 national survey. However, more recent findings from just targeted newborn screenings suggest the actual national prevalence could be more than 15%.

Some regions, such as Lango, Acholi and Busoga, are seeing even higher rates – as high as one in four people carrying the gene. Uganda still records over 2,000 babies born each year with sickle cell disease, many of whom face repeated hospitalisation, pain crises and premature death if not properly managed.



ADDENDUM 1 TO TENDER NOTICE

Reference is made to the bid notice published in the new vision of 18th December 2025 for Procurement of Assorted Stationery and Small Office Equipment under a framework contract for 24 Months.

This is to notify you that the deadline for submission of bids has been extended as indicated in the table below;

Activity	Current Date & Time	New Date & Time
a. Bid closing date	13 th January 2026 at 11:a.m	20 th January 2026 at 11:00a.m
b. Bid Opening date	13 th January 2026 at 11:30a.m	20 th January 2026 at 11:30a.m
c. Evaluation process	Within 10 Working days from receipt & opening of Bids	Within 10 Working days from receipt & opening of Bids
d. Display and communication of best evaluated bidder notice	Within 5 working days from the approval of valuation report	Within 5 working days from the approval of evaluation report
e. Contract signature	Within 5 days upon expiry of Best Evaluated Bidder Notice and clearance of contract by Solicitor General.	Within 5 days upon expiry of Best Evaluated Bidder Notice and clearance of contract by Solicitor General.

All other terms and conditions of the tender remain **unchanged**.
NIRA regrets any inconvenience caused.

ACCOUNTING OFFICER



Job Opportunity

Who is Water Mission?

Water Mission is a Christian engineering nonprofit that builds safe water solutions for people in developing countries, refugee camps, and disaster areas. Since 2001, Water Mission has served more than 8 million people in 60 countries, sharing safe water and the message of God's love. Working at Water Mission is as much a calling as it is a career, and we are searching for people with the courage, passion, and drive to help us change the world. Read more about our Statement of Faith and Our Christian Mission.

What is the opportunity?

Managing Director

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