

# HOW TO ERASE THE DARKNESS LIVING IN THE MARROW

Aplastic anaemia is a rare but life-threatening condition leaving thousands of Ugandans without access to life-saving bone marrow transplants locally. As one mother shares her family's costly journey to India, experts and institutions rally to change Uganda's medical landscape forever. Here is the story as told to Agnes Kyotalengerire

**M**y name is Madrine Amuge, and I am a mother of two. My son David Luke was born very healthy. He was approximately 4kg at birth.

He brought joy to everyone who saw him. He was a lovely baby and very handsome. Throughout the first four years of his life, he was healthy and had no issues until 2024, when he was diagnosed with severe aplastic anaemia.

He was prone to infections such as bacterial infections and viral infections because he had no platelets and his white blood cells were low. As such, every week we were spending nights in the hospital, admitted for blood transfusions. All the same, we could not figure out what was wrong with him.

Luke could not go to school because he was bleeding. Later, we received the true diagnosis that Luke was suffering from severe aplastic anaemia; as a result, his body could not produce haemoglobin, enough white blood cells, or platelets.

Dr Henry Ddungu, a senior consultant in haematology/oncology at the Uganda Cancer Institute, said aplastic anaemia is a rare but serious condition where the bone marrow fails to produce enough blood cells – red blood cells, white blood cells, and platelets.

This leads to fatigue, paleness, dizziness, frequent infections, and easy bruising or bleeding, as was the

case for Luke. A patient with aplastic anaemia will present with symptoms such as severe anaemia, bleeding, recurrent infections, and fatigue because all the cells are affected.

Dr Ddungu explains that a child can be born with aplastic anaemia (congenital), meaning they are not able to produce cells from birth. It can also be acquired. Risk factors include exposure to aggressive radiation, for example from drugs used for cancer treatment.

The other cause is an autoimmune disorder where the immune system attacks healthy cells, including stem cells, which then fail to produce blood cells. Viral infections such as hepatitis, Epstein-Barr virus, or HIV may also be associated with aplastic anaemia. Sometimes exposure to toxins and chemicals such as pesticides, benzene, or radiation is

to blame. In some cases, inherited disorders can lead to bone marrow failure.

When we continued to engage the doctors on how best we could support Luke, they mentioned the possibility of a bone marrow transplant. We were excited to know that this boy has a future with a bone marrow transplant. But again, what was very stressful was the fact that we could not get a bone marrow

## MANAGEMENT

**If you are diagnosed with aplastic anaemia, it is important to follow the doctor's treatment plan carefully. Patients are advised to avoid infections by limiting exposure to crowds and wearing face masks when necessary.**

**This is because aplastic anaemia patients often have neutropenia, a condition where the body has an abnormally low number of neutrophils – the white blood cells responsible for fighting infections. With a weakened immune system, patients become highly vulnerable to viruses, bacteria, and fungi that spread easily in crowded places.**

**Regular handwashing and wearing face masks are, therefore, recommended as protective measures.**



**Luke, diagnosed with severe aplastic anaemia at age four, underwent a bone marrow transplant in India – a procedure Uganda cannot yet offer its own children**

transplant done in Uganda.

It was a very large sum of money required, and so we had to look for money through colleagues at work, friends, and relatives to take him to India for a bone marrow transplant. It was quite expensive because we had to incur costs on accommodation, flights, and feeding.

## WHAT DOES A BONE MARROW TRANSPLANT ACTUALLY INVOLVE?

Dr Ddungu describes a bone marrow transplant as a procedure that is done when the bone marrow is failing to make cells in the body. Since blood cells cannot form, it means the primary cell – the stem cell – is not functioning.

When an individual has aplastic anaemia, the best treatment is to replace the stem cells through a bone marrow transplant. In this case, a donor who has the same genetic make-up is required to give stem cells to the recipient.

The preferred donor should be a matched sibling (sister or brother), although it could also be a mother

or father to reduce the chances of rejection. Alternatively, doctors can use a matched unrelated or half-matched donor provided they have the same human leucocyte antigen (HLA) type.

Human leucocyte antigen (HLA) type is a set of protein markers on the surface of most cells that acts as an immune system identifier. In bone marrow or stem cell transplants, HLA typing is a blood or cheek swab test used to match donors and recipients so that the new cells are recognised as “self,” reducing the chances of rejection and graft-versus-host disease.

Before the recipient receives the stem cells, they undergo screening to determine the cause of aplastic anaemia and then receive conditioning treatment to clear anything that could interfere with the uptake of the donated stem cells. In brief, a bone marrow transplant helps rebuild the bone marrow with stem cells from a donor after proper matching is done.

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# WHY UGANDA NEEDS A FUNCTIONAL BONE MARROW TRANSPLANT CENTRE



**Amuge, mother of Luke, whose battle with severe aplastic anaemia forced her family to seek abroad what Uganda cannot yet**

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What was more frustrating was the fact that after doing all the required tests, the donor turned out to be a 50% match, which meant that the cost had to increase.

For a bone marrow transplant, depending on the hospital you attend in some of these countries, if you have, say, a 100% donor match, it could cost you approximately \$30,000. In my case, I had a 50% donor match for the bone marrow transplant alone. This automatically pushed the cost to \$50,000 for the transplant alone.

Dr Ddungu said a bone marrow transplant failures can occur when matching is not done properly, for example when HLA typing is not carried out correctly. There can also be graft rejection, known as graft-versus-host disease, meaning there is a conflict between the host body and the donated stem cells.

Rejection can also happen if the donor is elderly and does not have enough stem cells. For better results, Dr Ddungu advised that patients undergo transplantation when they are still young.

Immune system attacks can also result in transplant failure. He said the recipient has fighting cells called T-cells, and when they recognise a graft as foreign, they begin destroying it. That is why conditioning treatment is carried out before the transplant process to reduce the risk of rejection.

"If we do not do sufficient conditioning, then the risk of rejection is high," he said.

Ddungu added that the blood used is treated through irradiation to

ensure it does not carry infections or viruses. Failure can also occur if the number of transplanted stem cells is insufficient.

"If these cells fail to germinate, then you can be in very serious trouble," Dr Ddungu said. In such cases, doctors must urgently seek another donor.

After the bone marrow transplant was done, Luke required post-care management. In this regard, we needed a doctor back at home to help us continue that journey with Luke.

To my amazement, the Joint Clinical Research Center (JCRC) walked my son and me through the entire post-transplant process. During times when my child had very low immunity, I always turned to Dr Ssali, and he supported us with bone marrow treatment and advice.

After patients who have undergone bone marrow transplants abroad

return to Uganda, they require post-transplant care. Currently, the Joint Clinical Research Center (JCRC) has a clinic that is caring for 17 people who have had bone marrow transplants in India, said the executive director of JCRC, Dr Cissy Kityo.

The Uganda Cancer Institute in Mulago Hospital also offers post-transplant care.

Dr Ddungu said after a bone marrow transplant the body is expected to begin taking up the transplanted cells. Usually within about 10 days, the red blood cells, white blood cells, and platelets begin to develop at different times, and full recovery happens after about 100 days.

After that, the patient continues with follow-up care because they remain on treatment to prevent graft rejection, which can also cause side effects. He advised that patients planning a transplant should have

co-ordination between doctors in Uganda and doctors abroad where the transplant procedure is performed.

Some patients return after a transplant and develop serious complications yet have nowhere to turn.

Fortunately, Luke is now healthy. His immunity is good. He talks and plays well. I continue to refer to him as a miracle child and a success story.

His body now produces enough haemoglobin, red blood cells, and platelets, which was not the case before.

As a mother who has gone through this experience firsthand, I know what it feels like. I know the weight it carries on a family and caretakers.

In 2023, President Museveni commissioned the first bone marrow transplant centre at JCRC headquarters in Lubowa and laid the foundation stone for the

proposed cell and gene therapy facility.

However, the centre still requires funding of about \$4m (approximately shs14.3b) to become fully functional.

Recently, the JCRC, in partnership with Rotary Clubs of Uganda and Pearl Bank Uganda, launched a national fundraising initiative to establish Uganda's first Bone Marrow Transplant Centre.

Dr Cissy Kityo, the executive director of JCRC, said the funds will help equip the clinical facility by purchasing air handling units for infection control and procuring essential clinical and laboratory equipment. Part of the funding will also support additional training for the medical team.

## DIET

Andrew Ssekitoleko, a clinical nutritionist at Kiruddu National Referral Hospital, says patients with aplastic anaemia should consume a nutrient-dense, well-cooked, and safe diet to manage fatigue and strengthen their immune system.

This includes iron-rich foods such as lean meats, leafy greens, and beans, as well as foods rich in folate and vitamin C to support iron absorption.

## TREATMENT

Dr Ddungu said aplastic anaemia is treatable and in some cases curable. Treatment depends on the severity of the condition. Blood transfusions are often used to temporarily relieve symptoms by increasing red blood cells and platelets.

Immunosuppressant drugs may also be used to suppress the immune system and allow the bone marrow to recover,

especially when the disease is caused by the immune system attacking the bone marrow. Medicines such as anti-thymocyte globulin are used to challenge the immune system to stop damaging the cells.

Bone marrow or stem cell transplantation remains the only curative treatment in many young patients, particularly if a suitable donor is available.



**With specialised treatment, Luke won the battle against aplastic anaemia**