

# Singing, and waiting for a miracle

## Being diagnosed with lupus has not lowered her ambitions for the future

Although Emily Mwakisachi, 22, has systemic lupus, a condition where blood cells fight each other, she is determined to one day stand up and walk, and pursue a career in law. She told her story to KWAMBOKA OYARO.

**A**t times, my condition is very stressful. Like now, when my right leg is aching so much that I verge on giving up the fight. I cry and ask myself why I should suffer so. But the pain will pass and I will read my books or compose gospel songs.

My elder sister, Schola, will carry me down the stairs to the sitting room and I will watch my favourite programmes on TV.

I read a lot in an effort to understand my condition. The reading makes me sometimes feel like changing my dream career, law, to nursing — so that I can soothe those in pain.

I used to be an active girl. As a student at Bura Girls in Taita, I went with my colleagues every other week to entertain children at an orphanage near the school. We washed their clothes and their compound, then helped to cook their meals.

### Itchy face

Then a month before my final examinations in 1998, my knuckles started swelling and my face was suddenly itchy. I scratched my face until it was red.

I went to the school clinic and the nurses thought I had athritis. They prescribed painkillers, which did not really lessen my pain. By the time the Kenya Certificate of Secondary Education started, my fingers were in a bad shape. Holding a pen was pure punishment.

All in all, I wrote the examinations and when the results came out the following year, I had passed with a mean grade of C+. Before my sickness set in, I had expected to score higher than that but then I accepted the results.

I had been anxiously looking forward to the December holidays, but they loomed sombre and became a sad affair as my condition worsened. My face was swollen from the scratching, and my long hair started falling off. I did not have an appetite and walking was a special difficulty. I became malnourished.

### Tired and weak

Early in 1999, one of my three sisters who live in Nairobi picked me from Mombasa — where I had gone to seek treatment — and brought me to the city for assessment.

We sat at the back of the bus and by the time we arrived in Nairobi I was very tired and weak. I was



Photos/Stephen Mudiari

**EMILY MWAKISACHI: "I know God is using my illness to encourage others for the glory of His name."**

looking bad. I had wounds on the shoulders and elbows, and pus was oozing from them.

When my other two sisters saw me, they wept inconsolably. I was in great pain. They took me to hospital immediately. After running a battery of tests, including one for HIV, the doctor told me all the results were negative.

I was given so many antibiotics. A doctor thought I was suffering from athritis and referred me to a consultant at the Kenya Medical Research Institute.

This consultant, said the doctor, had helped many people with the disease get better.

Any suggestion that promised treatment was welcome. So I went to Kemri and was given medicine for rheumatoid athritis, but it increased the bile levels in my stomach and I threw up anything I ate

or drank.

So I was back to Square One, my problem undiagnosed, untreated.

Finally, in October, 1999, I was diagnosed with systemic lupus, a condition that makes cells fight each other. The white cells, which usually fight germs and bacteria, mistake the red cells for foreign objects and "eat" them.

The doctor explained to me that the condition has no cure but can be controlled by medication.

*Some people could whisper that I had Aids or that I was bewitched*

### Newspaper story

I was curious about the disease and as if in answer to my curiosity, a story appeared in the newspaper featuring a woman suffering from lupus. I contacted her, and she told me a lot about the condition. She

also advised me to see her doctor at a city hospital.

The doctor prescribed steroids. They had an instant effect on my body. I started gaining weight and could walk. I enrolled for my "A" levels the following year and my sisters paid my school fees. I went to church and sang. I actually did everything without pain.

When I was in Form Five, the steroids began to affect me. They made me fat. Anything I did felt uncomfortable. Simple activities like standing or sitting became a heavy task. Then I suffered from osteoporosis, a condition that weakens bones. I would stand up and then I would hear the loud report of a crack in my bones.

My throat also narrowed. If I ate any food, I threw up or it poured out through the nostrils. I was now dependent on porridge and fluids. An endoscopy, where a tube was inserted into the respiratory duct, was done to determine the extent of the throat problem.

I stopped taking the steroids early this year and the fat shed off instantly. One day, I woke up and could not walk.

My friends do not understand my changing moods: sometimes I am okay, with hair on, and the next time they see me, I am thin and without hair. But they do not ask me what is happening. They have been a great encouragement.

When I was still at home in Taita, some people could whisper that I had Aids or that I was bewitched. My strong moral background made me ignore such gossip and I just prayed for them to be enlightened.

### God's glory

At times, I asked God what sin I had committed to deserve such punishment. I know God is using my illness to encourage others for the glory of His name. When this has been fulfilled I will stand and walk. People who know me and what I have gone through will see me and believe in the miracles of God.

Since I love composing gospel songs, I take time to polish my singing and hope that one day, I will record them in a studio to advance God's kingdom.

Gospel music appeals to me because I grew up in a religious home and my parents always encouraged us to have a close relationship with God.

I don't know how I could have made it this far without the love of my sisters, brothers, parents and other family members.

My father suffers from advanced cancer but when he visits me, he really encourages me until I forget that he is also in pain. When he is around, I actually forget that I am in pain.

My mother is a bit distressed about my illness and Dad's too. For consolation, she moved in with my other sister who teaches in Kwale.

As I wait for my miracle, I continue humming a song about God and His mighty works.

### FACTFILE

## The tricky disease of a thousand faces

**L**upus is a condition whereby the body's immune system goes into overdrive and starts to attack itself. It is hard to diagnose due to its ability to mimic so many other diseases. That is why it is called the disease with a thousand faces.

■ It can start with scratching and swelling of the cheeks and progress to extreme fatigue, depression, hair loss, anaemia and a facial rash.

■ Over 40,000 people are believed to suffer with the disease in the UK of whom 90 per cent are female. (local statistics)

■ It can cause serious rashes across the cheeks and nose (resembling the face of a wolf), hence its name, *Lupus* (Latin for wolf).

■ Lupus is a form of arthritis that mainly affects women during their child-bearing years. It is one of the auto-immune rheumatic diseases, caused by a fault in the body's

immune system.

■ In severe forms, lupus can cause damage to various organs, including the kidneys, heart, lungs, skin and brain.

■ For many people, lupus represents not much more than a nuisance condition, but for some, the disease is very troublesome, even life-threatening.

■ There are two types of lupus: discoid, which affects the skin, and systemic, which involves the joints and may involve the internal organs as well.

■ Lupus is neither infectious nor contagious. The cause is not known, though research has provided evidence implicating heredity, hormones and infection, including viruses. The disease lies dormant in the body until some trigger from outside the body sets the process in motion.

■ It is triggered at puberty, after childbirth, through sunlight, after a

prolonged course of medication, during menopause, after viral infections or as a result of trauma.

■ More people have lupus than Aids, sickle cell anaemia, cerebral palsy, multiple sclerosis and cystic fibrosis combined.

■ It is rare to find two people with exactly the same symptoms but the most common symptoms of lupus include joint aches and pains; rash over cheeks; extreme fatigue and weakness; increased risk of miscarriage; rashes from sunlight, recurring flu-like symptoms and night sweats; inflammation of the tissues covering internal organs, with associated chest and abdominal pain; poor blood circulation, causing the tips of fingers and toes to turn white then blue on exposure to cold; haematological disorders, including anaemia, seizures, mental illness or other cerebral problems.

■ Lupus can cause high blood pressure, particularly if the kidneys are involved. Steroid tablets in high

doses may also cause an increase in blood pressure. Treatment with drugs to suppress the immune system can often control and occasionally cure high blood pressure caused by kidney involvement. There are also various drugs available, specifically to control blood pressure.

■ Lupus patients should be assessed regularly by rheumatologists with an interest in this condition and the patient should take precautions like keeping out of the sun, as too much ultra-violet radiation can flare both the skin rash and sometimes the lupus in the internal organs.

■ If you have lupus, then you are more susceptible to infection. Take sensible precautions. Avoid stress.

■ Lupus cannot be cured but it can be controlled. When the condition is severe, steroids are administered but they must not be stopped suddenly. The dose must be gradually reduced. The dose prescribed will be kept as low as possible to minimise possible side effects.

—Kwamboka Oyaro

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