

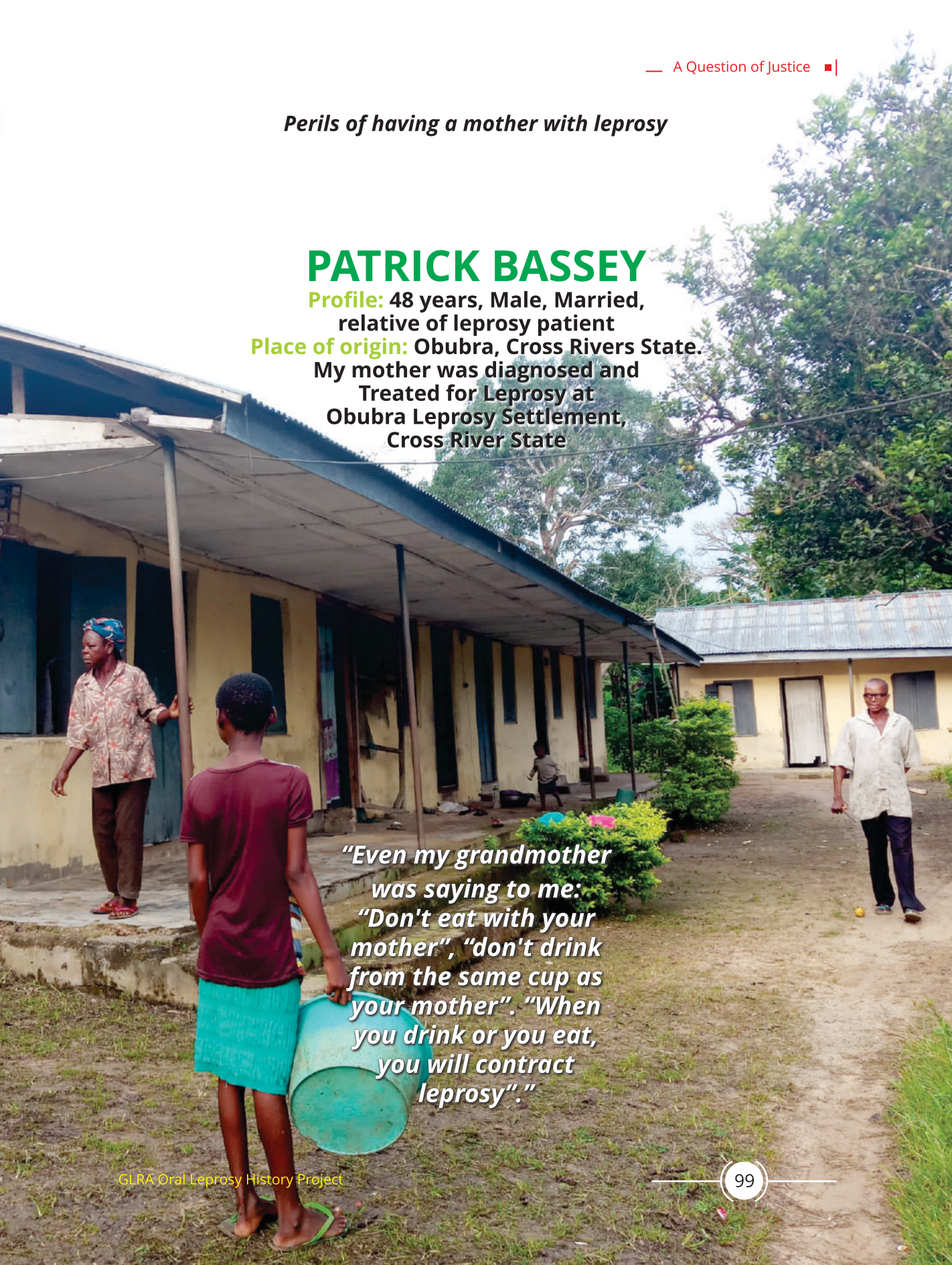
Perils of having a mother with leprosy

PATRICK BASSEY

Profile: 48 years, Male, Married,
relative of leprosy patient

Place of origin: Obubra, Cross Rivers State.

My mother was diagnosed and
Treated for Leprosy at
Obubra Leprosy Settlement,
Cross River State



*“Even my grandmother
was saying to me:
“Don't eat with your
mother”, “don't drink
from the same cup as
your mother”. “When
you drink or you eat,
you will contract
leprosy”.”*

When I grew up, I did not know my mom. I didn't see my father. I was living with my brother and sisters at home; suffering. I ran all errands for them until July 1980 when I finished my primary school at Calabar. I returned home, I lived with my grandmother -she was using me; going to the farm; up and down. So, I asked her, "Where is my mother?" She said; "Your mother is sick". "Where is she?" She said; "She stays at Abakaliki". I asked her how I could go and see my mother but she tried to talk me out of it. I had to ask her if my mother was alive or dead and if she was alive, I would go and see her wherever she was to truly know who my mother was since I had taken my grandmother as both my father and mother.

My uncle accompanied me to this place and when we came here, my brother's (old school) mate when he was schooling here at Community Secondary School told me that my mother was somewhere. From there, my elder brother brought me here. When I came, I saw my mother; no finger on her legs, I was shocked. I began to cry. I began to ask my brother which country he brought me to because the people I was seeing there weren't the kind of people I saw back at home. I told him the woman before us was not our mother. This was when my mother burst into tears and explained to me how everything happened.

She narrated how she contracted it from her own mother and because there was little or no medical attention paid towards her issue, it grew worse. There was nobody to take her to the hospital and that's why she had deformation on her legs and hands. So, I cried. I asked: "so, you weren't born like that?"

I told my mother that I'll not be able to stay with her because of her condition and she cried and asked me to stay because I was her last resort. She asked me not to be afraid of her that she was my mother and that it is God who knows all. She also added that her happiness was since I have come to her, I'd be the person to help her with her problems. Because of her story, I developed sympathy and stayed with her until God took her away. I'm the last child of my mother's 11 children and I so, I had to stay with her. I stayed with her for 15 years before God took her life.

At that time, there were white men and so, she talked to one of them and I was allowed to stay. They enrolled me in a school then which I attended till my class two, when the school stopped functioning. I tried to tell my mother I did not want to stay any longer because of my education but she persuaded me to stay and that was how I did not further my education.

Even my grandmother was saying to me: "Don't eat with your mother", "don't drink from the same cup as your mother". "When you drink or you eat, you will contract

leprosy". My answer was, "she's my mother right? Well, God is not a foolish man to make everybody sick in the family where nobody will help each other. If God says I'll fall sick, I will fall sick. If God says I will not fall sick, I will not fall sick. Even though we drink from one cup". That was the answer I gave to my grandmother.

(There is) nothing concerning leprosy that I cannot tell you from the experiences I have had. I was the one who told my late brother that he was a leprosy patient before he died. At that time when white men were here, they used to give us pamphlet of leprosy patients. They gave it to all patients. So, I took this pamphlet to my elder brother. I told him to use a mirror to view himself and compare with the picture. But his wife was annoyed with me. She started quarrelling (with me for) my actions -for telling her husband he was a leprosy patient. So, the wife was abusing me but I told her that even if she wanted to abuse me, my priority is to secure the life of my elder brother. I brought my brother here. They asked me why I kept my brother till almost death and I told them that, I was not at home with him. But as I went home, I saw him and that's why I had to bring him here.

At that time, when you fall sick, they will place you in the bed. They give you treatments, the doctor will come and check up on you always. If it gets serious, they will prescribe drugs or if it is one that warrants taking you to Itigidi, they would take you.

If they can handle you here, they will prescribe drugs for you and give to you. If you have a wound, like that very woman, they will apply POP on you to curb your movement because when you move, especially in the morning; the morning dew will affect your wound. So, that POP will make you sit at a place to enhance healing. But now, whether you fall sick, no treatment. There is nobody to control the people here. Like this very woman who just left here, it's the farm she is going to as early as that and that makes the wound.

I'm so sad because I know what I'm supposed to be in life. Because my friends; when we were together in school, we knew what to do. The children I got, I have spent my time, labor under the rain and sun, training them. Sit them down, disturb them why I am in this condition today but none of them heard me. Rather, they move about with men and when they get pregnant, they come back. And I will still be the one to take care of them with the pregnancy. So, that makes me, when I sit down, I shed tears; I am not happy.

..... One, the life that God spared for me till date makes me happy; I don't have the money. Two, the children I said I will not have, God gave them to me. My children are all healthy. Even though they don't listen to me that is my own happiness.

*Beyond Justice:
Tortured by Self-stigma*

NKOYO CLEMENT

Profile: 52 years, Female, Widow

Place of origin: Akpabuyo

LGA, Cross River State.

Diagnosed and Treated
for Leprosy in 1977
at Obubra

I didn't like to go to the market then because if I should go, people will stare at me and I mean, stare at my hand instead of me."

My name is Mrs Nkoyo Clement. I am from Akpabuyo in Cross River State.

Leprosy struck me when I was little and was about entering class 6 then and I had to stop schooling. I was in elementary 5 about to move to class 6 when it struck me which made me stop going to school before I was finally brought to this place. I saw sores all over my body and at the same time, I was shining like the moon and I started crying before my people brought me here [Presbyterian TBL Hospital, Mbembe, Obubra, Cross River State].

I withdrew myself because I could not stand the obvious difference between me and my friends. My hands were irritating. The sores had escalated to all parts of my body and I could not move outside any longer. My friends would laugh at me so, that's why I refused to go out except in the evenings when I manage to move out for a while and return home. I was ashamed because of this disease and when all my friends came to see me, I cried. I did not move with them again, because when I looked at them, their bodies were fine but mine had sores and I decided not to move with them. I had been in my father's house before I was brought here and confirmed that I had leprosy.

(Now) I don't feel shame any more.

When I first came here, I was very little. I grew up here and I saw a man and he wanted us to be together but I was afraid even after all that was being said. I later agreed to live with him and that is how I gave birth to these children. He too was a patient here and because I knew no one

here, I had to keep it on hold until I got accustomed to them, and only by then did I agree to live with a man.

Sometimes, the man (husband) goes to the market to buy things and gives them to me. I didn't like to go to the market then because if I should go, people will stare at me and I mean, stare at my hand instead of me. One day, I went to buy "Okporoko" (stock fish) in the market and the seller was just staring at me and that's why I left and remained at home. She didn't say anything but I have had the mindset that I'm the one they're talking about.

Church is different; when I go to church, I sit at a place and listen to what is said and nobody will look at me. I sit with other members. I don't know whether the person looking at me is thinking that I brought the sickness from the market or something, I don't know.

They (former school mates) see me as one who is sick because if I were not sick, I would have continued with them. Yes, it pains me because others are doing what they like to do but I'm not opportune to do so because of my sickness. If not because of leprosy, there are things I'm supposed to do but now I'm sick, I cannot do them and so, anything that happens, I accept it because I'm not the cause, it's from God.

My happiness even though leprosy has turned life this way, is that God has given me children and that which I was not able to do because of my condition, my children will do it. That is my happiness; my children.

Poverty fuels Injustice and Stigma

PAUL OKORIE

Profile: Male, 58 years,
former Police Officer

Place of origin: Akpet
Central, Biase,
Cross River State.

Diagnosed and treated
for Leprosy in 1989
at PTBL, Mbembe,
Obubra, CRS

"As I became sick and the symptoms manifested, my wife packed out of the house and took my children with her. That was when my house fell."

Because this leprosy affected me, look at my hands. All my fingers, everywhere has cut. I cannot do anything again. It was because of delay.

"That time, Etim Inyang was Inspector General of Police. He said anybody who had medical report should go on compulsory retirement. And that time I had served for 12 years in the Police Force."

My journey into the Police Force

I'm by name, Mr. Paul Okorie from Akpet Central, Biase. I was born in 1960, October 8th. Then I went to school. I finished Elementary 6 in 1973. Then I proceed to secondary school. I did not finish; 1974-75. Then that July 1975, when Murtala Mohammed took over, I joined the Nigerian Police Force because the man was saying that he needs young boys to join the police at that time. So, because of that announcement, I left the school. It think I would be in Class 3 when I joined the police. I wrote an application and the Commissioner of Police invited me for an interview. I went and he recruited me. He is the one who measured me. He recruited me by force because he said I was under-age. That time I was 16 years old. So, because of my height, he said I would join and that he needs people like this.

Leprosy struck: I ignored the early signs

Then before that time, one of my uncles was a leprosy man. Meanwhile, my father died 1969, before the war ended. So, that period, my mother was somewhere. So, I went and lived with that my uncle who had leprosy. So, that time people told me that where I was living then, that something will transfer to me, but I did not understand. Then when I joined the police, the symptom appeared. When I wear the uniform, to trek from here to Kilo, I would sweat, the whole uniform would drench with sweat. Then I have some certain wounds when I used the boot. The heat of the boot peeled my legs. So, that time, one nurse was telling me that this thing seems like symptoms of leprosy, but I did not believe her.

Painful moments: Withdrawn from Police Force

So, 1989 when the symptoms manifested, I saw some tiny spots on my body. So, they carried me to military hospital. The military doctor said there was symptom of leprosy in me. Even till now some part of my head, the spots are there which if I touch at times, I would not feel nothing and the same thing with my hand here. So, there now, 1989, that April, they said I should go to compulsory retirement. That I should go for treatment. That time, Etim Inyang was Inspector General of Police. He said anybody who had medical report should go on compulsory retirement. And that time I had already spent 12 years in the service.

Another tragedy struck!

This my problem; it seems it to be a temptation to me. I think so because those who were supposed to be helping me, they're no more here. Like one of my uncles; my mother's immediate elder, he is a well-known person. He's a retired man, an old man.

He's the one who told me that "Paul, don't worry yourself. Anytime, any moment, I'm here. Come to me." But unfortunately, as I'm here the man died.

The other one, the junior one that is my mother's immediate younger is a principal officer at Niger State College of Education. The man died in a motor accident in Abakaliki when he had made the foundation to come and build a house, a storey-building. For him to go back and collect his money at the bank, that his vehicle summersaulted. His son, an Engineer was the one who drove the car.

He died on the spot at Ogoja. So, my sister and brother died when I was in this condition. There is nobody I have now who can say, "Paul, what is your problem?" all of them are dead. That is the reason why I still remain in this condition. The ones who remain now are children. They don't know me. They only know my children. You see, if you don't have money, you cannot take care of somebody. That's what is there. But those who have the money have died and left me alone. That's why I'm still suffering.

My wife left: our house fell; My important documents destroyed.

My wife, as I became sick, the moment that symptom manifested, she packed out. That was when my house fell, she packed out from the house. Carried my children and left. She only packed her things. My things remained. To even carry my box with my certificates, she would not. Everything melted inside the house when the house fell. Till today, I have nothing to do work, my certificate, nothing. The documents the police gave me, the whole thing melted inside the box. I just cleared them. The woman now went and married another man. Although she's not the woman which I married first. The one I married with my money is the one I sent out after my children's death. I sent that one out because I was told the family killed my children. This one just ran away from her husband and came to marry me. That one wasn't a marriage, it was friendship. Even though she left my house, I don't care because she's not the one I married. I did not marry her.

Such a support. My happiness is that since she's taking care of my child; the only son I have now, that is my happiness. She's taking care of him. She's the one who is struggling to train the child. So, because of that, I did not worry her about anything at all because she's doing a lot of work to take care of that child

Since almost two years now or three years. Since they stopped paying us here, I did not go home again. Because to go home and go with empty hand, coming back, you would beg somebody to give you money. I feel it's very, very shameful. And now, cassava today, how will I start it? If I get two heaps of cassava, who will use it make the garri? **Because this leprosy affected me; look at my hands, because of delay. All my fingers, everywhere has cut. I cannot do anything again.** At this my age, to bend down with hoes and start to do heaps is hard for me. I only pray now that if God can send somebody to me who would come out to fight for my gratuity; that is the only hope I have. Otherwise, things are hard.

A word of encouragement for mothers affected by leprosy

At this juncture now, what I see there is that as a sick person with leprosy, hence you have not died, you'll still be a living soul. Don't allow stigmatization to kill you; saying, "I am no more a human being". You are still a human being. Today, leprosy is when you take the tablet, leprosy gets healed. Even though your leg is cut off, your finger is cut off, hence you are still living and you have no leprosy. Don't allow somebody to stigmatize you. Don't agree. Tell the person that, "I have been treated.

Don't say you're no more alive. Get up and tell somebody that you have been treated. Tell somebody that today, you're still a human being like him. Let the person not deprive you of what you are about to do or what you are about to bring or where you are about to enter because of leprosy. That today leprosy is no more in your body. It has been treated and the moment they treat you, it finished from your body.

Final words

If I knew it will be like this, I would not have delayed accepting treatment on time. Stigma and discrimination comes when you don't have money, not just because of your deformities. Once somebody gets something that will make him earn money, no one will look down on you.

A devastating experience



PAULINA OKWORI

Profile: 70 years, Female, Widow
Place of origin: Yala LGA, Cross River State
Diagnosed and Treated for Leprosy in 1992
at St Benedict Hospital Moniaya Ogoja

"If not for leprosy, I was a very hardworking woman; I had energy and I needed nobody's help in doing my activities. I worked with my husband and when I contracted leprosy, he rejected me and asked me to go and marry a leper like me."

"When you (interviewer) came closer to me to hear my story, I was very happy. I thank God."

My name is Mrs. Paulina Okwori.

The relationship (*with people and family members*) was very poor. People discriminated me, and they ran away from me. People discriminated against us and they find it difficult to use any of our belongings. We are discriminated by people and so due to the poor treatments we received, most of us died; and we are privileged to be among those that survived the harsh conditions.

I can't forget anything; I will narrate my experiences to you.

To start with, the person that looked after me when I was healthy has died. His name is Gbagiri; he is from Okoko. When the leprosy started, Gbagiri was working here {SBH, Maniaya, Ogoja, Cross River State} and he was the one in charge. He usually sent me medications to Okoko. When it (*the sickness*) became more serious, my husband left me for another woman and I went to stay with my father; he was alive then. He rejected me because leprosy is a dangerous disease. I had no choice than to go back to my parents and then, my dad was alive and he took me around to various places for medication.

The illness came after I had given birth and it became persistent. I met Dr. Mike, and he referred me to Leprosy home. He always came to check up on the leprosy patients in the building. I was always complaining, because at that time; my legs were all blackish in color and I couldn't follow others to the farm because of my circumstances. Initially, Gbagiri and his nurse, Sister Teres always come around to give me medications, until I joined him in his clinic. I was given DDF to relieve the pains in my leg.

My father took care of my children till he died; some of them went to school, and others didn't, then I had no choice anymore, when my father died. I didn't participate in any of the community's activities. Because I am a leprosy patient, I was not welcomed in their midst. Everyone will be looking awkwardly at me. We are kept away from the rest of the people.

There was a woman called Mama Bisi; she died exactly the day that she was brought here. They (*leprosy patients*) are no longer needed in the society. Everyone is avoiding them, so that they will not be affected also. I was scared of staying close to healthy people. That's the nature of our sickness; you just have to be on your own. When I came here, I was scared of associating with people; but Officer Itana told me that I have nothing to worry about. I only came closer to people when they asked me to do so. I only respond when the individual involved, gives me the chance to do so.

Do you remember Officer Okara? He built a house separately for his wife. The wife refused to stay with him here, she is now late. Most of them have died and it is just a few of us that are alive. While I complained of severe pains in my leg, some got blind; I can remember some of them that passed through hell. Life as a leprosy patient is very tough and it becomes unbearable when you live with others. My sister's hand was amputated as a result of leprosy. There was a leprosy patient whose brother was a soldier; the brother left him immediately he contacted leprosy. Bishop queried him about why he should leave his brother. He was brought to this place by the German Association until he died.

If not for leprosy, I was a very hardworking woman; I had energy and I needed nobody's help in doing my activities. I worked with my husband and when I contacted leprosy, he rejected me and asked me to go and marry a leper like me. No body joked with me then, I will give you trouble to the core. Leprosy really changes a lot in your life.

I thank God for everything; he has been sustaining me. People were maltreating me, just because of the fact that I am helpless and at such, I cannot do things on my own. I am only happy with the Church and the Germans. They were the only people that made me feel happy as a leprosy patient. Since, I have no age group, no brother, no sister, no friends to talk with; I found companion with the Germans and the Church; they gave me everything I needed. When you came closer to me to hear my story, I was very happy. I thank God.

A life of gratitude for a happy family

PIUS ETALONG

Profile: 55 years, Male, Married
Place of origin: Okpaha, Bekwarra LGA, Cross Rivers State.
Diagnosed and Treated for Leprosy in 1984 at St. Benedict Ogoja

"The first girl I wanted to marry was resident here but the parents refused. And they themselves were leprosy patients. The girl did not have leprosy, it was their mother that had leprosy."

"The only thing they said was that they wanted her to go and marry outside so that their in-laws from outside would bring them food."

"If not for the whites, I may not be alive today. Even as I am here, when I think back about my mates back at home, some of them have done so many things, have achieved so many things but I am here. It's all these things that disturb my mind."

My name is Pius Etalong. I'm from Bekwara. It started when I saw a red mark here and even all over my body; just tiny red on my face. There is one of my brothers who makes shoes here; he is the one who makes those leprosy shoes. So, as I visited him, the white man who was a doctor here {St. Benedict Ogoja} saw me and told my brother that I should try to visit the hospital because I had leprosy. So, when my brother told me, I refused. I did not believe it was leprosy until when it became worse and I finally came. So, the white man reminded me of when I was being told and I refused. He took me round; bed to bed, showing me some people that parts of their body had already been amputated. He asked me if I wanted to be like them, and I said no. This was how he showed me different worse patients, (then) assigned me a bed which I accepted and I laid there until I became better. All the marks were gone.

I was schooling at around 1984 but I dropped out after I contracted leprosy. I passed through Primary 1 to 6. And when I passed from 6 to go to secondary school, I did Class 1 to 3 before I contracted the sickness. So, I didn't go further. I just stopped because of the sickness. As my body was all covered with the signs of the sickness, I couldn't go to school again. It's not the school that stopped me. I was bedridden for long, about 2 years and 9 months I was on bed here. I just decided not to (continue schooling) because I would not be happy mingling with people as sick as I was.

I have really suffered because of this sickness. I cannot go anywhere, even my people in the village don't take me as their brother again. Our age group which people are happy to join, I feel shame to even go there because they know of my sickness.

My family has no problem with me. Sometimes, when I go to the village, they receive me. But they cannot come to this place. Some of my friends that knew me before the sickness receive me.

My marriage was late because of this sickness. Sometimes, when I approach a woman, she will accept but when it's time to see the family, they will discourage it and maybe threaten to disown her from the family if she marries someone like me. It really disturbed me from marrying early. I just got married in 1999. The first girl I wanted to marry was a patient here but the parents refused. And they themselves are leprosy patients. The girl did not have leprosy; it was their mother that had leprosy. They refused saying they wanted to go and marry someone who was not a leper, because I had nothing. The only thing they said was that they wanted to go marry outside so that their in-laws from outside would bring them food. Since I'm here with them, I have nothing to feed them with. That's the reason they gave me. But I don't know whether it is just only because of that or I don't know.

But as God wanted it to be, He gave me this my woman. I married her from Iyache. Her family does not suffer leprosy but it was someone who knew how I have suffered because of marriage that took me there to meet the parents of the girl at Iyache. They agreed and I arranged for everything because they do traditional marriages so, I prepared for everything and married her in 1999. That was how I got married. Around here, I tried everything I could but no way. I couldn't get any woman because I was sick.

I just thank God that I'm in the hands of the missionaries because when she had her first pregnancy, she had difficulty in giving



Pius Etalong and family

birth. At that time, it was still the whites that were here and so, they helped out by footing the bills for her operation because she was to be operated upon in order to bring the baby out. The 3 children that I have, the whites paid for the operation that was carried out because my wife had difficulty in giving birth.

If not for the whites, I may not be alive today. Even as I am here, when I think back about my mates back at home, some of them have done so many things, have achieved so many things but I am here. It's all these things that disturb my mind. But I don't worry much because sometimes, it is as God wants it to be. So, I still thank God as I am here and as they really helped us here.

Sometimes, it is myself because I normally think.... Because I am a leper, I think for myself. And not everybody thinks the same way that I am sick. Some persons receive

me. . It's not that I'll go and expose myself that I have leprosy. Those who know me would say that that man is a leper. Some of them would know but they will not talk to my face but they would be pointing at me, saying "that man, see him..." So, it makes me feel ashamed; even though they don't say it in my presence, they will say it behind my back.

Me, even as I am here now, I am very happy. I did not know I'll get married and have children. That alone, makes me happy. So, God made it possible; I have a wife with 3 children and they are here with me, with my wife. All of us. My wife doesn't have leprosy. It's a great thing that God has done for me. So, I'm happy for that; very, very happy for that. Even though when they refused to give me their daughter, I married from outside, came and stayed here with me and they are seeing the woman. So, I am happy for that.

Destitution redefined!

PIUS OBI

Profile: Male, 60 years,
Shoemaker, orphaned at early life,
unmarried at adult life.

Place of origin: Nkim, Ikom,
Cross River State.

Diagnosed and Treated for
leprosy in 1970 at
St. Benedict Hospital,
Ogoja, CRS

*“ . . my parents are dead. They said I was
suffering from leprosy and so, I won't be
able to come close to them.”*

*“ . . . the woman said she won't marry a
leprosy patient, that she can't be with
me because I once had leprosy disease”*

*“God will help me . . .
and I am sure I will marry one day”*

My name is Pius Obi; I live at the leprosy centre here at Ogoja. I have been here with them since I don't have anybody not even to come give me food or come visit me. My mother has been late for a long time and my dad died too when I was a toddler; I don't really know him so, I cater for myself alone, wandering up and down. It's been long I come here because of this leprosy, the disease really disturbed me.

When did you contact leprosy?

It started during the Biafra war, almost 50 years ago. I think, that's when it started. Nobody knew I had leprosy until when the signs started manifesting and it was confirmed that I had leprosy. That was when everything scattered. Everybody started avoiding me. Even my friend that I used to walk with started avoiding every possible contact. I was surprised. Even the parents of my friends warned them not to see me close to them again.

What happened at that time?

Nobody was there, I used to follow the soldiers before I contracted it where I was and so, I came back home. After I came back, some of my friends were telling me that patients were treated here.

They said I was suffering from leprosy and for that, I won't be able to go close to them. So, I was left alone, with nobody; both parents were dead. When I got here, I met a nurse and it was the nurse that fed me but she is late now; from Ikom.

When I started, I heard when they said there was a place where they treated leprosy patients. I didn't know where the place was but I started walking from village to village. As I went, I explained and asked

people if they knew where I was looking for. I walked until I finally saw some people who knew the place but they told me the nurse had gone for the day. They had particular days of working. They told me to go back and come again on a certain day but I explained to them and showed them my body; all the sores and spots and that where I came from was far and so, my legs could not withstand such trekking anymore. I still went back that day since they had nothing to do for me. But my journey back was very painful and slow because I had to stop by to relieve the pains on my legs a little bit before walking again. That day came and I went and met with the same people that told me that was the day the nurses came. I asked them where the place was. They were afraid and so, they could not take me to the place but they directed me on how to locate the place and I went.

And when the nurse saw me, she asked what was wrong with me and I explained how most parts of my body were paining me and how I don't feel anything on some other parts as if they were dead. So, she looked at me and asked where I was from and I told her I was from Nkim. And that I was directed to this place and she affirmed that I was at the right place. They started asking me just like you did, how long it started and I told them since I was little; that I don't know exactly when. I also told them that it was while I was with the soldiers that I started seeing the spots and feeling unimaginable pains all over my body. They confirmed that was the sickness they treated here and that they would give me a place to stay. When they gave me the drugs, they asked if I had anybody and

I told them I didn't have anybody and as you could see, I came alone. My friends are now afraid of me. From there she said, "if you can, go and bring any small thing you have so, they said a white man from Ogoja would be coming to our small clinic and then, he would tell them all the types of drugs I need and I said okay.

I went back that day at daybreak, and picked my second-hand clothes. As I got home, I didn't have anybody that will be like, "have this to eat" while there and so, I managed to go back to the centre. When I got there, they showed me my apartment and asked who I came with but I still told them I had nobody and so, I came alone. They began to provide me with little things until the foreigner came and they took me to him. So, when he saw me, he started asking me when it started, so I told them it's been long since it started and that I hid myself because I didn't know where it was treated but because somebody kept telling me it was treated here.

So, he said okay, that I was at the right place and that he would give me treatment for it that I shouldn't worry. So, he gave me some drugs which I started taking immediately. They brought supplies with them; some clothes, food; beans, rice. That was where I ate, they gave mine to me till today. When the war became severe, they told us that we would have to go to Ogoja because the health workers there no longer came. Even the nurses and foreigners, nobody came again. I went certain times to Ikom but nothing good came out of it, they just gave me some tablets and by that time, I was already having wounds on my legs. .

Good experience with leprosy care at hospital - by the whites!

There was a man called Phillip Agare, he's late now. He told me to come to Ogoja, then I went. After I came, first of all, while on the road, I thought maternity was the leprosy centre, so I went there and as they saw me and saw I couldn't walk very well, they asked me where I was going and I told them I came to the clinic because I was sick, they said it wasn't there and they gave me the right direction to this place. As I got here, I met Sister Theresa, I told her about my body and after she saw it, she shouted and called people to carry me quickly. They didn't even waste time to show me where to stay and gave me a bed. I stayed on the bed here for almost 2 years. The period when the foreigners were around, they fed me for free, they gave me anything I wanted, they started giving me drugs when they came.

Warmly received and rehabilitated - "I was happy".

I stayed here for a long period of time, the disease starting relieving me, it was then they discharged me and told me that I should go to our clinic. So, I went there and after I was there, they didn't come again because they normally came to visit us at Ikom to check on us and give us drugs but they never came again. The ones I had were all finished and so, I said since I knew my way back to Ogoja that I should go back. And so, I came back and I have been here for a very long time, some people thought I won't go home again but sister Theresa saw me and said my body was healing and so, I should follow some of the nurses going to that our small clinic that

I came from back. I asked her if she was sure of what she was saying and she told me she would from time to time, come to see me while I'm there. I agreed and I followed them back, they kept me back. Not long after, they came to give us drugs, gave us meal; rice and beans, milk; that time the milk was surplus, everybody had their own, we were happy. So, I felt it was becoming serious again, my leg was aching me so, I went there, they gave me a bed. It was that time I stayed here for long before they later put me to learn shoemaking.

Was that the third time you came to Ogoja?

Yes, that was the third time I came here. I finished learning and they began giving me a small token, that time, I think it was 9 Penny that they gave me monthly that I used to buy something.

I was happy because I haven't started working yet, I was receiving money, I was still learning. After I finished learning, they gave me some things to work on and paid me too. We were 3 of us I think that were given works too. Fr. Bonbon was around at the time and we left for our villages. I was happy I had a work to do and also received payments from it too. I stayed for long but came back again and from when I came back here till the end of this year should be 6years. When I came back, the foreigners weren't here anymore, the missionary black priests were in charge and whenever you people send us anything, they give to us and we are always grateful and happy for that. That is how we have been managing.

How did leprosy affect your marriage?

You see, at that time, so many people rejected leprosy patients, they didn't allow us come closer to them. They even go to a

very far distance into the bush to build houses where we would stay but they didn't treat me like that because when I had mine, the foreigners had already started their awareness concerning the disease, telling the people what leprosy was all about. Even at that, they are still afraid of leprosy patients. Even when their children make you their friend, they will advise them not to be with you.

So, what was your own story about the marriage?

I am not yet married. They don't accept me, assuming they do accept me, you would have seen one here with me. As I am like this, the woman (I met earlier) said she won't marry a leprosy patient, she can't be with me because I once had leprosy disease. She said she might contract the disease when she gets married to me or even our children may even contract it too. When I went to my village recently, they told me I am too old to marry. I am willing to marry any woman that accepts to marry me.

Did having leprosy affect you from going to school in any way?

I didn't have a father to send me to school. I knew my grandmother. She called the relatives of my father telling them about how I need to go to school. But they questioned why she was worried about a child whose father was dead. Then my grandmother asked them if a child that the parents were dead should be thrown away. She said there's no problem that I am her grandchild and she will take care of me. So, she was the one that accepted me. But there was no money, otherwise, she would have sent me to school.

So, how did it also affect your participation in the community?

Had it been there were no changes, people would have suffered a lot. Then, even if you had people, they won't come, even if you had many family members. Even when you tell them you're hungry, none of them will help out but I thank God the foreigners that made me happy.

Now, if I go back to the community, I walk freely. I do go to my friend's place, we eat together and there is no problem because now, some of them do tell me that I did not buy the sickness. It was then I realized my people were now getting civilized. They asked me not to stay there for long that I should come back home that the one they are affected with is worse than that of mine. That is what some of my friends told me. They said I should come home and when I come home, I should not just sit down like before but move freely. And anytime my friends are going out, they do come over to my place to take me along and I will tell them I can't walk but they will say we should go till I am tired of walking. There is no problem now, but when I just left them recently, they held me to stay back.

Things have changed now because the village is now getting civilized and most of the old people are dead. Now, if you are sick, they will quickly look for a solution by taking you to the required place for treatment.

As this place is now civilized, how I wish I had someone, at least, that person will be coming closer but my mother had 5 of us but they are dead already remaining the last child who is a woman and she is not here

with me. She is married and is far from here. She doesn't have leprosy. Any time she comes to the village, she does come to my place. It is only the two of us remaining in the whole family.

What do you remember about your Mum who suffered from leprosy?

My mum walked with me to Kakwagon Boki. That was where she went with me when she was infected with the leprosy and her leg was eventually amputated. I never knew my father. I was still a child when my father died and it was when my father died that she was infected with the disease. Then, she began to seek cure and she was told about a place in Boki Kakwagon. Then she went there, she even remarried there. She married the same leprosy patient and I know the man because he was the one that took care of me till I was grown up. Before then, I didn't know he had leprosy but my mother knew. But I know that my Mum's sister had leprosy as my mother do send me to come and give her food. But I never knew I will someday get leprosy.

How will you describe the leprosy centre in those days?

They were more than 200 persons. Houses were all over the compound occupied by lepers. Everybody was living happily! My mother was sick, her elder was sick too, it was myself that I didn't know I would join them but all of them have left leaving me behind. They were the ones that enjoyed this place very well, serious enjoyment at that time. The enjoyment here then, when you come here, you won't like to go back home. You come to see people, you'll see

they're living fine - drinks, dance, happiness here and there. This place was really fine. There was even a market here, I met the market.

What do you plan to do in future?

I have planted so many things there where the community gave me some land. They asked me not to walk too far a distance so I will be able to plant closer to my house. I planted trees like the pear and plantain in my house. I use them to take care of myself.

But nobody stays there because it is a mud house and it has spoilt. So, I am trying to get some zincs (roofing sheets) and use it to cover it and plaster it. While I stay here, they will be able to do a little work there. I had a lot of cocoa planted there but since I was here and wasn't able to manage them. Fire burnt it all. If not that the fire burnt them, I would have showed you. I have some remaining, about 10 stems that I want to plant again. Well, my friends told me that it really hurt them but I reassured them when I have a little money on me, I would come over there. Whenever I go there and see some cocoa, I do buy and store in my backyard so that they are able to reach up to 40 stems. I have used that as a way to help myself.

Even if I marry a wife, that is where we will feed from and even if we give birth, it is from there that we will send the children to school because cocoa gives a lot of gain and plantain also. I don't go far to search for money it is around my backyard. That is how I suffered till now.







Okpuru-Uke Fishing Festival

Stories
from
EBONYI STATE

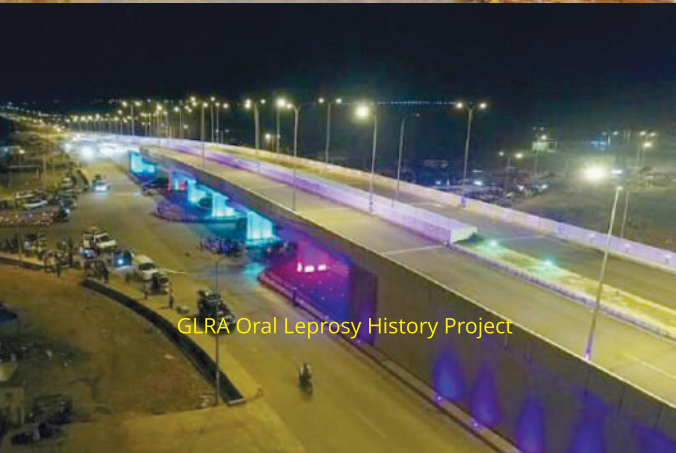


Mile Four Hospital, Abakaliki

Abakaliki Rice



Salt Late, Okposi



GLRA Oral Leprosy History Project



Abandoned by his wife

DONATUS ONWE

Profile: **60 years, Male, Separated, (visually impaired)**
Place of origin: **Ohaukwu, Ebonyi State.**
Diagnosed and treated for Leprosy in 1993 at Mile 4 Hospital, Abakaliki, Ebonyi State

"I was married before now. But immediately I had leprosy, my wife abandoned me and ran away."

My story

My name is Donatus Onwe from Ndegidaka Ekwashi Imbo, in Ohaukwu Local Government Area of Ebonyi State. I am 60 years old.

It started in 1993. When it first started, I was at home in my father's house. Then, all of a sudden, my eyes began to pain me and I rushed to the hospital at Mile 4 Hospital to know what is wrong with my eyes. It was there that the doctors and nurses discovered that I am suffering from leprosy. They started treating me, but despite all their efforts, my eye problem became a thorn in the flesh that since 1993, that I started suffering from leprosy till date; I couldn't see with that eye again

I was married before leprosy struck. But immediately I was diagnosed with this disease, she ran away. It was immediately the leprosy came, that she left. My wife is alive. When she called, I told her everything but my efforts were in vain. I even told the nurses, but all to no avail. So, I decided to face my fate. The leprosy was so severe. That was why I lost my sight. The treatment I received there, was so good to me. It was their treatment that kept me alive till now. Had it been that I didn't rush there on time when it started, I would have been dead since 1993, when it started. The nurses treated me so nicely, to the extent that, since I started suffering from this disease, they had never overlooked me till date. Except God Almighty, who created all things;

it is through the assistance of those nurses that kept me alive till now, and they are still my very good friends

After my education, I decided to engage myself in trading. I was into trading business before this sickness started and when it came, everything scattered.

As regards to my relations, only few relates with me; and those that knew about the disease started avoiding me because (he speaks in proverbs). Actually, nobody forbids me from attending any activities or any event because, I am going there for my own welfare and interest like others. So, nobody can stop me from participating. But due to the condition of things, I later became the first son of my parents, so, the little possession I have, for instance plots of land; nobody is taking it away from me. The only thing they do is that, they are so envious of me and wished that I didn't come back after I left for treatment, so that they can easily possess all. It is not only in their words, that it is been manifested; but also, through their actions. But I know that God would not allow them

The only thing I can say, is that pertaining my situation at the moment, the most pressing need in my life is that I need assistance in order to be alive. It is said that "even if one does not make money, at least, let him eat well". So that is all that matters to me now, I can't engage in anything again because I am handicapped. So, I need people's assistance to be alive.

A Question of Justice

I was born in 1960. When the illness started, I was still young. I cannot recall the year but when it came out, I was still young. It appeared first around my waist. My parents saw it and said they didn't know what it was, they then took me to the hospital and started giving me medicines.

What actually caused it to be like this is that by then, I was still a kid, so they gave me medicine to take which I did not take seriously because I was not aware of the nature of the disease at the time. So, the illness persisted and persisted, it was then that I realized that I was suffering from a very dangerous sickness that kept me away from people especially my friends and family. They restricted me from participating in their affairs. They stopped me from coming out in public because I had leprosy and deformities.

When I came to the hospital, they started giving me medicines, everybody including the Doctors and Nurses and even the Reverend Sisters. They all treated me with utmost hospitality as each and every one of them treated me as their own child. They assisted me with food and even finance.

My siblings stay away from me. Yes, everybody detested me. Even my family dispossessed me of my inheritance because of this sickness. They said that I have nothing to do with them anymore and it has really affected me badly. I lost everything we had in common as a family. What caused everything is because of this sickness. I didn't offend anyone.

I got married in 1996. My wife is also a person affected by leprosy. Yes, my wife also suffered from this disease just the same way I did. If I had waited to marry a healthy woman, then I might have ended up not getting married at all. But God in his infinite mercy gave me a patient like me.

I have children - both boys and girls.

Since I started suffering from this sickness, I have never regained myself again. The treatment from my family members is nothing to write home about. This makes me to be thinking about my life all the time and my children cannot engage in any training or education because of lack of finance. One of my children managed to go to school, but since the result is not that satisfactory, he is now learning a trade. It was even someone that assisted him in learning a trade. So, the rest and I are idle at home, with little or nothing to eat.

The good things that happened to me: Firstly, God in his infinite mercy gave me a wife. Secondly, God gave me children. Thirdly, the Reverend Sisters have been supporting me immensely as best they can.



ELOM INNOCENT

Profile: 58 years, Male, Married
Place of origin: Ohaukwu, Ebonyi State
Diagnosed and Treated for Leprosy
in 1975 at Mile Four Hospital, Abakaliki

"My siblings stay away from me. Yes, everybody detested me. Even my family dispossessed me of my inheritance because of this sickness"

A harrowing experience of Injustice

MARIA AGU

Profile: 50 years, Female, Widow, visually impaired
Place of origin: Ezza, Ebonyi State.
Diagnosed and Treated for Leprosy in 1992 at Mile 4 Hospital, Abakaliki

"After treatment, I could not return to my husband's house. They told me to remain at mile 4, I went there three times and each time, they rejected me, stating that I had leprosy."

My name is Maria Agu (maiden name). I married at first. I was at the verge of marrying again before this sickness started. It became so bad that his first son (*from his first wife*) decided to take me back to my parents.

The sickness started in my husband's house. The symptoms started manifesting on my hands. At first, after cooking I could bring down the pot with my two bare hands without any hurt. But, later it became weak and ulcers started (*appearing*). I scratched them with mirror and water started gushing out. I was wondering, what was actually wrong. So, I started crying. As time went on, it became worse. The people I told about it said that it is the symptom (*of leprosy*). The first son of my husband decided to take me back to my parents. He took me home, bathed me and told my brother to hold me tight. That was the last time I heard from him.

I had children with my husband when I was still living with him. But no bride price (*had been*) given to my parents as the custom and traditions of Izza demands. My husband didn't pay my pride price. My children are still alive. Yes, they care for me; they are trying their best. They even trained one of their siblings in school.

Later, my brother took me to a place called Mile 4 to ascertain the nature of my sickness. It was there that they confirmed that I was suffering from leprosy. My brother that brought me to Mile 4 hospital is dead.

People down here at Mile 4 welcomed me, treated me, gave me food, soap, clothes and everything that I needed.

After treatment, I could not return to my husband's house. They told me to remain at Mile 4. I went there three times and each time, they rejected me, stating that I had leprosy. So, I was retained at Mile 4. They asked me what I wanted from them; I tried to explain to them that, I was rejected by both the man and his son. It was not easy at all. Mile 4 (*management*) went to build an apartment for me in my husband's compound and they refused because I suffered from leprosy; then they went and built a house for me in my father's compound. And that is why I still bear my father's name instead of my husband's name.... (*mutters an Igbo proverb, literally, one abandoned by others does not abandon herself!*).

The people there (*at Mile 4 hospital*) are nice and friendly, the nurses treated me with love and care. I did not go to school at all. I am a farmer. Even when the sickness started, the management at Mile 4 gave me money and I also invested it in farming.

I will tell you from the sincerity of my heart that the management at Mile 4 is really trying towards my upkeep. The drugs I took was from them. Even my amputated leg was taken care of by them. Also, the two eye operations I had, was sponsored by Mile 4. There was a particular nurse by name Joseph Ezeh long time ago. He took care of my eye problems.

My brother abandoned me. Throughout my stay at Mile 4, it was only the management of Mile 4 hospitals that cared about me. It was when they (*Mile 4 management*) wanted to build (*an*) apartment for me, that they (*my relatives*) started asking me where I came from.

Resilience triumphed over prejudice

MATTHEW IVOM

Profile: 50 years, Male, Married

Place of origin: Ikwo LGA,
Ebonyi State.

Diagnosed and Treated
for Leprosy in 1994
at Mile 4 Hospital,
Abakaliki

"My father rejected me totally and wished me death after it was disclosed to him that I was suffering from leprosy."

Those around knew it was leprosy but refused to tell me

My name is Matthew Ivom. I am from Ikwo; I started suffering leprosy in 1993. In 1994, I came here and the doctor here checked me up and told me that I am suffering from leprosy. Before then, those that knew me and knew exactly what I was suffering from, decided not to tell me. I was ignorant as well as I didn't know what is happening to me, because of this, my father is alive (even he is still alive till date) but he never said a word at me. His motive was for me to be dead as he had already disowned me among his children. My Father is not too poor but average at least he can provide for the family but he never assisted my education, he prefers to use the finance for another thing rather than to assist me.

My Father rejected me and wished me death

He rejected me totally and wish me death after it was disclosed to him that I was suffering from leprosy. Prior to this illness, I am on the verge of getting married - I am to marry the first daughter of a pastor, so they offered me admission here for four months, after which I was discharged. After I left here, they told my in-law that I went to Mile 4 hospital for treatment. After I came back, my in-law asked me, which hospital did you visit for treatment? I told him that I went to a hospital in Abakaliki but he did not believe me, so he requested for the hospital card; I asked him what he wants to do with the hospital card because I am back and strong. He insisted and told me that I am not fine yet, and then he told me that I should go back and treat myself well before coming back to ask for his daughter's hand in

marriage. That is how my travails of life started. Prior to this illness, I was a very successful Mason before this illness disrupted everything- I lost everything (including those owning me). This sickness actually dealt with me based on the fact that I cannot even help myself any longer. I went and pleaded with my father to assist me with money for my transportation here but he told me that he has no money. I even pleaded with my kinsmen but to no avail.

My father warned them not to even attempt helping me, I was even the one that trained the wife of my in-law, so I went to her to seek assistance and she told me that she would bring the money for me in the evening so that I can transport myself to the hospital; by then, I was so down that I care about nothing again. It was as if God was aware of my situation and how helpless I am, I prayed and he answered me as someone came and gave me one hundred naira for my transportation to the hospital.

After two weeks here, there were no signs or symptoms of the disease or neither would you believe that such a disease existed, it was like this until a point when Sister Dr. Margret asked the nurse to examine and tell me whether there is a place I can stay for 5 years without going back to my parent's house. So, when I heard her, I couldn't actually understand what her response meant, so they stated that there is no place that I can stay for five years. Sr. Margret shook her head and after a short period of time, the sickness vanished and I was discharged and I left home.

A plea for ₦100 denied!

After two weeks, the sickness continued and became worse than before and I went back to my father to solicit for money in order to go to the hospital. My father told me that he has no money whereas he was preparing for ****Jioke**** (which means Title), that he will continue from where his brother stopped. I pleaded with him to assist me with one hundred naira and he refused as I threw myself to the ground. When I came here, I stayed in the bed for more than ten times, (started praising the management, he have saved many lives with his hospitality). So, when I came here, they welcomed me yet again, and he pitied me when he saw that my condition is bad. So, after the doctor have examined my leg, he told me that there is nothing else he can do that they will have to cut my leg, so I begged the doctor that he should give me three weeks and if there are no changes with my leg, that he should go ahead and do whatever he wants to do with my leg.

So, the doctor pitied me and accepted my request. What am telling you is that before three weeks my leg have healed, so I came back to the doctor and begged him that I need his help, that this help is not money, that I want his advice on what am going to do in this condition, that he can see that am fine but this my leg really caused me a lot of pains, he told me to go and write application with two copies, within 2 days, the administrator approved the letter.

That was how God helped me, if I begin to tell you my experience, then you will understand, why I am grateful to God.

Rejected by family and community

Since my father was alive, he never helped me. The family took my inheritance, sold it and gave me the money to go to the hospital. When it was time for the title ceremony, irrespective of the fact, that celebration was going on, they totally ignored me as I laid on the floor. My prayer that day, which I can never forget is that I told God that it is said in the bible, that the day you created man, it was our breath and not food that sustained him; therefore, I will not die, because I have no food to eat.

Because of my strong belief in God, he used so many people to help me in sustaining myself.

Marriage dream blown up . . . by Leprosy

The lady that I wanted to marry was warned to stay away from me; the same person, I assisted in her education training at the commercial school. The father threatened to disown her if she insists on marrying me. So, the mother told her too to stay away from me. I told them, that since they had rejected me, that I won't visit them again. I was just worried about being alive; for me it is all that really matters. After a short while, about 3 months later, my in-law contracted diabetics and later died.

He has already told his daughter to stay away from me. Though she (my fiancé) felt bitter and wept, I told her not to worry about me, because life is the most important thing.

Happily married at last

It is actually a long story (laughs). It was someone who assisted me in getting a wife. The lady was in her father's house; she came back home after she was

divorced by her husband. So, she stayed there for 4 years without any signs of marrying again. So, both of us accepted each other, she wanted to go with me back home, but I insisted; telling her that I want to follow the right tradition.

I didn't visit the family the day that I was meant to. So, the next day, she packed all her properties and came to my place. The family of the lady had no problem with me marrying their daughter.

The lady knew that I had leprosy. Yes, even the family and they were very okay with it. The only thing was that the brother was telling me about their sister's character, that is whether it will be very convenient for me to live with her.

I thank God that I was able to prove everyone wrong. I was their best in-law among the 10 in-laws that they had. I do take care of them, and occasionally, I bring them food items and gifts

Back to my home where I was rejected:

There was a time, when situations began to get better for me, especially when my wife gave birth, I bought 16 big tubers of yam and travelled back home to visit my father. Initially, when I reached home, he was not at home, he went for a public function. So, I sent someone to call him and tell him that I am back. He replied that he cannot leave the meeting as he was the person in charge. So, I gave the yams and also an envelope of 3,000 naira to his wife; and told her to give them to my father when he comes back.

Two years later, during the Christmas period; I bought 12 tubers of yams again and went to visit my father.

He was sick, when I came and I asked him whether he had been to the hospital, and he said yes. He showed me a bottle filled

with dry gin and then it has a herb known as nka. I warned him not to take that drink again. I went and bought drugs for him. He thanked me so much. Later on, I went back to find out how he was faring. He was so grateful and told me that he has been getting much better, since he took those drugs. Since then, he stopped taking alcoholic drinks. So, he asked me to get him those drugs again!

Indeed, I wanted him to understand the realities of life that the rejected stone can actually become the corner stone in the future.

Early education and career life

Yes, if not for leprosy, I would have continued with my education; as well as my handwork, which was mason (it was flourishing so well then).

Initially, I was not willing to go to school, because there was nobody to help me out; I went into Mason as a means of raising income.

The disadvantage of this leprosy is that it prevented my means of survival. The sickness badly affected my leg and I can't stand properly; and it was swollen and smelling at the same time. When I explained to the doctor the nature of my job, he advised me to quit the work so as to enable me to get much better. He told that cement is dangerous to wounds.

However, at the leprosy hospital, the atmosphere was very nice and lovely. I even assisted my fellow patients in my team with their footwear repairs. So, we lived together as a family; and whatever we are told to do, by the management; we don't fail to comply.

**Over
50 years
of leprosy
service**

SIR, LIVINUS OTUH

Profile:

- **74 years, Retired veteran Leprosy Supervisor, worked in Mile Four Hospital, Abakaliki, Ebonyi State**
- **Served from 1962 to 2017**
- **Award recipient during GLRA Nigeria golden jubilee anniversary in 2014**

“He gave us the water in four tumblers, we drank the water, but after drinking the water, he broke the four tumblers in our presence”.....

“People passing at Mile 4, when they reach the bridge there, they close their nose, so that the breeze from Mile 4 they will not inhale it.....If they inhale the breeze, they would get leprosy”

“Then, when I went to the compound, do you know what they said? They said I have to take my bath. I said, “I’m not dirty” they said, “Take your bath”

How I came to leprosy work

I'm Sir Livinus I. Otuh. I was born on 10th, January, 1945. After my school career, I started with teaching. I taught a while in those days that missionaries were managing the school. Not long, the Reverend Father in charge of the school said he has other places I should go to help the needy. He said it is a hospital, I should go and help to cure the sick. I had never been at Mile 4 before. So, this thing happened on March 12, 1962. He brought me to Mile 4.

This very Mile 4 was started in 1945 by late Bishop Margitic of the Catholic Church. When I first came, I saw the patients. I was marveled. I was moved to go back because I was afraid of leprosy. I had people from Owerri, who started the work before me. One Mr. Oliver Onuoha and one Matthias Njoku, they came up to me and said I should not be afraid. That I should look on them that they had nothing like patch on their body, but they have been doing this work. They reassured me that this disease will not affect me. With their explanation, Oliver went as far as telling me to come to his house see that he has nothing on his body. I agreed to work with the explanation they gave to me.

Separate schools in leprosaria for leprosy sufferers:

And those leprosy patients that are schooling (in the settlement), did so because they were not allowed to attend public schools. The missionaries decided to set schools nearby all the Leprosaria. Now, let me tell you we had 10 schools by then at Mile 4, Iboko, Agbaja, Oriagba, Mgbo,

Esom, Ikwo and Ezza. That was where we had schools with teachers employed by the missionaries because those people who have leprosy were not allowed to mix up in public schools. They were not allowed in public schools because of leprosy.

Stigma against the name, "leprosy" in the community

Then, as time went on, with what we suffered in the communities, some of the communities fear leprosy; that when we go out to do the survey, with the little ones that are knowledgeable, if we introduce ourselves as leprosy supervisors, they will welcome us but anything even very hard for them to shake us.

It happened that one *pot belly* Police Inspector, when we were testing one day, we went to out station to do campaign. We went to him, introduced ourselves as leprosy inspectors. The man welcomed us. I said, "Could you give us water?" He gave us the water in four tumblers, we drank the water, but after drinking the water, he broke the four glass cups (tumblers) in our presence.

Leprosy patients suffered a lot of things in those days. When they know they have leprosy, they are rejected completely and that's why this question of segregation started with the missionaries. They were removed from their communities and we built a house in them that they live in, no more in their communities. The community doesn't do anything for them. In those days, when they have leprosy, even their lands will be taken away from them. They are told, "go away".

Myths about Mile 4 Hospital many decades ago

People passing at Mile 4, when they reach the bridge over there, they close their nose, so that they will not inhale the breeze from Mile 4. If they inhale the breeze, they would get leprosy - that was their belief. Some will take handkerchief and tie their mouth. *But now, everything is okay.*

Difficulty getting married as Leprosy worker

When I grew up, I was matured, I said I would marry. It was difficult for me. People said anybody working in the leprosy hospital had suffered leprosy before. I saw a lady I would marry. When I went, first of all, they said I'm not from Ezza. I said, "Okay. You first will see my home". I hired a vehicle to go to my compound to make sure I belong to Ezza people. . Then, when I went to the compound, do you know what they said? They said I have to take my bath. I said, "I'm not dirty" they said, "Take your bath". They gave me water, I went to their bathroom. They said the lady in question would come to inspect to make sure I have no scratch on my body. I did that and it was true. God so kind, I had no scratch, but that was the time you hear the word 'leprosy', you don't associate. If you're going to marry anybody and the person has leprosy, you'll say, "I'm coming next tomorrow", you're no more going there again, because of leprosy. But thank God, as time went on, with our health education, things are changing.

So much has changed (positively) over the years

I'm happy with the health education we're giving. Do you know one thing? In those days, I told you somebody who had leprosy

will try to cover it. But now, the patients themselves come on what we call 'self-reporting' to this clinic here. Every Wednesday, you'd see. I have a register I said 'complaint register'. Those I screened that had leprosy, I kept them apart, those that are not leprosy, I record it. I reserved a drug for them to take and pay and get themselves cured.

Okay, let me tell you something now, because of my experience in the job. I want to tell you that there are a group of persons with leprosy, because of their status, they hide it now. Now, I will tell you a story. Somebody came, I told him that he has leprosy. He said he cannot. I said leprosy is not done as a private something, that's why I'm happy. Either you register or if you're leaving here, you can go to register through me. I accept that because of social problems. I don't want your friends to know what you have. We can register you and you'll be collecting treatment. That's what I do and it's happening. I know of somebody, a barrister on treatment, but nobody knows. But with arrangement, we cover them. You know, during the time of one Dr. Udoh, he put what we call clinic register and he put that register in OPD. That was the time leprosy was not properly recorded, but now, it's spaced out. I used another way, "tell me where you can go and collect this treatment, so that we'll record it.

Final words

I'm grateful to GLRA. The time I was working, they cooperated very well with me. That's why I was able to perform the work. And I think such will continue to exist. Any time they need me, I'm always at your disposal.



Statue of 1914 Enugu State Coal Mine Riot

Stories
from
ENUGU STATE



Akanu Ibiam International Airport

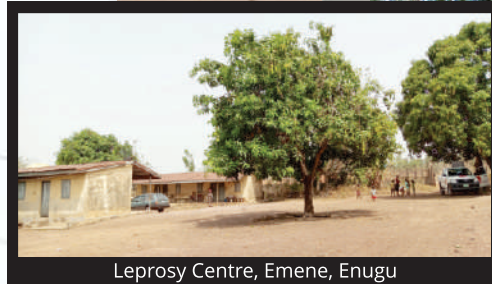


Michael Okpara Square

Oti-Igba Junction



GLRA Oral Leprosy History Project



Leprosy Centre, Emene, Enugu



Ngwo Pine Forest



A frustrating experience!

ABRAHAM ANI

Profile: 68 years,
Male, Married
Place of origin:
Amechi Idodo,
Enugu State.
Diagnosed
and Treated
for Leprosy
in 1982
at Oji River
Leprosy
Settlement,
Enugu

"I wasn't born with leprosy, it made me quit my job at PWD in 1984 after serving for 14 years and 14 days. No pensions! I did not believe I'd still be alive today."

Early life and experience with leprosy

My name is Abraham Ani. I am a native of Amechi-Idodo, Enugu State.

I was not born with leprosy. I noticed the symptoms of leprosy first around 1981. Then I bought some drugs on my own and stayed indoors taking the medicines. This continued until I was taken to experts who advised that staying indoors to take drugs does not help matters. They insisted I must go to the hospital.

Then I was directed to Oji River Leprosy Centre for treatment in 1982. When I started receiving treatment for leprosy, I saw others who suffered same illness and also attempted self-medication before coming.

At the treatment centre at Oji River, those who treated me there took good care of me. Especially people like *Skesco*, *Ekwempu* and lest I forget, another important person was Dr. Gareth, a white man from Germany who was also present. He was the person that gave me my discharge later. Then I asked him what I should do after my discharge. He directed me to this place (Marist Brothers) saying that it will be a good place for me to stay. I could not go to the community, since life was not palatable there either. Dr Gareth was the person who gave me the paper I presented to the Marist Brothers.

Hope made alive through Marist Brothers and GLRA

Since I came here, I've been living very well with the Brothers. I heard that the brothers help whoever that came here and there is more comfort here than in the village where there's nothing for one to do. In the village, people go about their duties and come

home. So, I thank God for people like German Leprosy Relief Association (GLRA) who are helping people like us. The Brothers started taking care of us before GLRA came to assist us.

I have been here for a long time, with my wife, who is taking care of me. The children God gave me are also fine, one is with me here, my daughter who is already married.



Abraham Ani and wife

Painful experience with leprosy and career life

It was leprosy that made me quit my job at PWD (*Public Works Department*), Ministry of Works on 1st June 1984. These happened after I had served for 14 years and 14 days, I did not receive any pension at all, even

after I pursued the process with my wife and children. My retirement wasn't pleasant at all. Through this ugly experience, I never believed I would still be alive today. In fact, leprosy turned life upside down for me!

When anyone stops working, he or she is paid *gratuity*. I took my documents to Dr. Gareth, that foreign doctor I told you about that came to Oji River. He also took the papers to the office at PWD and when he came back, he told me that I should take my mind off it because they were saying that I didn't complete the number of years at which the government pays pension after retirement. And so, I took my mind off it and I took all those documents and threw them into the bush and said, "God, if you wish, take me." But God gave me hope which has kept me till today. Overall, what made me bitter was that as I brought those papers here, termites destroyed my papers. If it were to be when it was neat, you would have read the contents yourself.

Life in the community

We are living well, there's nothing I can say is going wrong. But it is like what I told you that my village is like if we travel tomorrow, we'll stay for 2 weeks. Just as Christmas is approaching, we will go to the village to celebrate Christmas but we stay for just 2 weeks. Once it's New Year, Brother will use his car to bring us back here because for someone to go and dodge in the village with items from here, once those items are finished, that person is stuck.

So, it is better for that person to stay with his colleagues just the way we are here. It was someone that built this hall where we have our gatherings now. When people bring us things, we stay and share but when that person reaches the village, depression will kill him quickly. Like me, accommodation troubles me a lot even though I've explained to the women who come to look after us. House is a problem, I don't have a house. I wanted to start building but now the whole thing is just lying there crumbled, this pains me and is part of my tribulations, because if I should leave this world now, then you know I will be buried outside.

At the moment, I feel free to attend church and social functions in my community. But, I cannot go because, as you can see, my legs are bad. If it is somewhere I can go, I'll go but if it's somewhere I can't, those who went will bring me up to speed when they are back.

What's next?

And you people should help us with new foot wears when you get back to the office. Tell them to bring foot wears for us. It has been more than one year when German Leprosy Relief Association brought us foot wears. They were brought by those ladies that usually visit us from their office (rehabilitation staff).

Triumph over misery

ELIAS NWOKOCHA

Profile: 75 years,
Male, Married
Place of origin:
Uturu, Isikwuato,
Abia State.
Diagnosed and
Treated for
Leprosy in 1968
at Mile 4 Hospital,
Abakaliki

"My kinsmen had taken all my landed property before I returned from Leprosy Centre (Mile 4 Hospital) and shared my land amongst themselves."

"This ailment started in 1968, during the war. I must have been between 20 and 30 years when I was diagnosed with leprosy"

"I didn't marry early because of leprosy"

My name is Elias Nwokocha, from Uturu in Isikwuato Local Government in Abia State.

Confronting leprosy in the face of civil war

This ailment started in 1968, during the war. I was one of those who went to fight in the civil war. When this happened, I withdrew from the war front. Then, I didn't know it was leprosy, I thought it was some other illness. I received treatments until I felt better and I continued farming. Then in 1969, it started again. This time, it grew worse that I was not able to go the farm anymore. So, I called a priest (he was a Brother then but now he may have become a priest), so I told him and we agreed I'll have my last confession and so, Brother went to call the priest. When the priest came, he took me to Red Cross Hospital then in Uturu during the war. I started receiving treatment there but while receiving treatment, my condition continued to get worse.

So, the head of the Red Cross Hospital came from Lagos to check on us. So, he took me to Afikpo for 2 weeks and got me to do a laboratory test. This was during the war and sick people were so many at the hospital. At some point, I was taken to the Teaching Hospital here in Enugu. As you know, someone who is very sick cannot refuse a transfer from one hospital to another. From there we moved to Abakaliki where someone suggested he knows a

Specialist in a place called 'Mile 4' that could help. I was also taken there in search of solution. When we got to Mile 4, the doctor examined me and said that I was disease free but a lady there suggested to the doctor that I had to go for a proper laboratory test since there was no physical trace of leprosy on my body. So, I had some lab tests around 12th December, 1969. When the results were ready, one of the tests revealed that I had leprosy deep in my system. I started receiving treatment till I came back.

My sister, my only sibling was the one helping then but she is dead now. I have no one except God, one with God is majority because it is God that made sure that people with leprosy are even treated and helped here. It was through God's grace that I came here and got married. I didn't marry early because of leprosy, I got married in 1972.

But another trouble was that for 18 years, she has been bedridden by stroke.

She can't lift her limbs, her body is decomposing. She has been carried from one place to another. My children are still young and they're learning skills, so that is it. Then, Satan came again and gave me eye problems. You can see how this one looks (pointing to the eye). Yes, it was operated upon for cataract. That was why you heard the Brother ask me when I was going for my checkup. He always takes me

every Tuesdays or Wednesdays. So, that's it and I thank God because a sick person is better than a dead person. By God's grace, we came here and German Leprosy and TB Relief Association has been of great help to us. They are God sent.

What were the attitude of your community members and immediate family towards you when they discovered you had leprosy?

To be honest, when I was taken to Mile 4, none of my family members came there. I think it's chiefly because I had no sibling or anyone to care for me. My kinsmen had taken all my lands before I could come out from Mile 4 and shared my land amongst themselves. They didn't know where I was. No one knew that I was taken to Abakaliki. It was a Reverend Sister from our area that came to Mile 4 and was shocked when she saw me, she thought I was dead. It was around July in 1970 that I traveled home and my people discovered that I was still alive. Nobody came to look for me because they didn't know where I was.

When they realized you were still alive, did they return any of your land to you?

Although we live in harmony, but they have held back the lands they took from me. Because I'm just one man; and no single individual will be strong enough to face many adversaries to win. Just like our proverb says, *"If a child is unduly inquisitive about what killed his father, whatever killed his father may also turn around to kill him."*

So, as this happened, I thank God I'm still alive, land is not priority, life first.

Moreover, my children advised me not to go for the land. I pray my God to keep them alive. They shall one day find where they will live. When I travel home, for instance, during Christmas, I interact freely with them. Remember I told you I had no relations. And there's a difference between blood-relations and kinsmen. There's a popular Owerri artist that sang, *'izu ka mma na nne ji'* (which implies that blood-relations are always the best confidants anyone can trust). So, I go for meetings. I went in May and again we have one in December. Anytime there is a meeting, they do invite me. In a nutshell, no one comes to visit but when I travel, they come to my house to see me. But they don't come here at all. No matter what happens, I forget wrongs easily, that's just how I chose to live.

How satisfied were you with the quality of care the health workers at leprosy treatment centre gave you?

To be honest, doctors were sent by the Nigerian Government and they really took good care of me, especially because I was handed over to them by the head of Red Cross. I was taken care of until I got better. I was also offered a mason job there, where I helped in the tiling and plumbing work. After some time, they discharged me and I left. When I was there, I had troubles with no one and no one had troubles with me.

Knocked down, but not out!

FELIX OKWUABA

Profile: 76 years, Male, Married

Place of origin: Edem-Iheakpu,
Nsukka, Enugu State

Diagnosed and Treated for Leprosy
at Mile 4 Hospital, Abakaliki

“When I completed my treatment, I returned home and my wife told me that she is not staying with me anymore, I pleaded with her . . . but she left”

My name is Felix Okwuaba, from Edem-Iheakpu, Igboeze South, Nsukka.

A dreadful experience at early childhood

The story I have about this sickness is too much. To start with, I don't know whether it was when I was born that this leprosy disease started. The records are not available since I was told that my father died when I was young. Thereafter, my uncle that is my father's immediate brother sent my mother away to another man's house, and my mother later gave birth to two kids outside while I was left alone at my uncle's house. My uncle maltreated severely and during our market days when my mother would be passing by our house I always ran to her to tell her all I suffered. He would not allow me to go with my mother but continued maltreating me. My uncle told me that when my father was about to die, his last words were that since

my uncle had no child, he should take me as his child. This made him adopt me as his child when my father died. So, when I was growing up, they didn't send me to school. So, today I'm uneducated.

Early education and career amidst leprosy affliction

Though I am uneducated, I went to school where they taught me how to write letters. I stopped at Form 3 because of my sickness, which didn't allow me to go further.

Thereafter, I joined a truck driver as a transporter. I used to follow 911 trucks up and down but this sickness stopped me. It happened one day that the driver saw my condition and asked me to stop work and go and treat myself. Then after treating myself, I started masonry which I later stopped because of the sickness.

A tour of care-seeking for leprosy

When I started having eruptions and skin patches on my skin, I went to a hospital at Enugu-Ezike, where the doctor advised that I should be admitted in hospital while receiving my treatment. Despite all the medication, there was no improvement, so I came back home. After some time, one of our relatives visited from western region and I told him all my conditions. At that time I had just one child. He agreed to help me and took me to the west where I received another medication. After sometime, when my condition seemed to be better I came back. Unfortunately, my son had died (*sobs*).

Years later, one of my relatives told me of another place where I could be healed of my illness. He also agreed to take me there. I told my wife that we should go but she refused to go with me. Things were hard for me that time. I had a bicycle which I wanted us to sell so as to raise money for the treatment. But she refused and instead suggested we should sell our land.

So, I met my uncle and we divided our land into two and I sold one for the amount of N3200 naira. So, I set out for the journey. When we reached there, we met Dr. Mark, an English doctor, who took care of me and treated me.

My wife abandoned me on return from hospital

When I completed my treatment and returned home, my wife told me that she was not staying with me anymore, I pleaded with her to tell me the problem or any way that I have wronged her but she refused to stay with me anymore. In fact,

she left me for another man abandoning our four young children with me. So, I went back to Dr. Mark and explained my predicament, asking him to help me as I was unable to take care of my little children. Moved with compassion, he asked me to bring my kids along with me. Eventually, he successfully enrolled them in school at Mile 4, Abakaliki. At some point, Dr. Mark was transferred out.

So, everything turned sour. Another doctor called Dr. Okagbuo replaced him and gave me N15,000 naira and urged me go home. He insisted that he doesn't want people to be living in the hospital except bedridden patients. So, I went home with my kids. I didn't know what to do! So, I mapped out one plot from my remaining piece of land, molded some blocks with which I used to build a small room where my kids and I stayed.

Light at the end of the tunnel

Over time, life became increasingly miserable. Things were tough for me and my family. I decided to learn masonry but my sickness could not allow me to continue. Fortune smiled at me again when my neighbour told me about a group of Brothers who usually helped people in my condition. So, I visited the brothers. On arrival, I met Brother Francis and I narrated my plight to him and he agreed to help me.

By this time, two of my daughters got married, while one was stuck at Senior Secondary School class 3. So, Brother Francis helped in sponsoring her through the remaining year after which she got married. So, three of my daughters are married except the last one. Then my

daughters suggested that I should remarry but I told them that I don't have money to marry but they persisted that I should remarry. So, I sold one plot of land from the remaining land and used the money to get married to my second wife and she also bore me four children. During this time, there were these German people who were looking for five people to offer scholarship. My son, Chinedu, who was attending community primary school then was lucky to be among those selected.

Two of my children, Chinenye and Chinedu and three other people were lucky to be selected. That was how my son finished his elementary education, because that time things were very hard for me and I didn't have any helping hand. My uncle that I told you, took my land but my mother told me to not engage him over the land because if anything happens to me, there will be no other person to take care of my family.

Attitude of my community members and the church

The people of my community in Edem don't keep away from me. Whenever I come around, we usually gather and discuss. They even advised me to meet the priest so that my name will be included in the list of people the church prays for. I freely go to church with them. So that in case anything happens to me, the church will bury me. Though my kinsmen are around, but the tradition is that if I was not a believer then only my kinsmen will bury me. But if I am a believer, then the priest will come and my kinsmen will join and bury me.

Moreover, if they are paying any dues for projects, where everyone is expected to contribute a particular amount such as *ten thousand naira*, they will allow me to contribute whatever I can because of my condition.

Right here in the leprosy settlement, we also go to church. Even me and this my second wife wedded in the church, her name is Gladys. We go to church here and bishop was the one who gave me the sacrament of confirmation and Father Mike wedded us. We even registered in our kindred and we are contributing the little we have.

Unfortunately, my worry was that of my uncle who took my landed property at Ibagwa from me. I think it was because I am the only one left and if I drag it with them I might be killed.

My experience during Nigeria-Biafra civil war

When it started was on *Orie* market day, because our people came back on *Nkwo* market day and on *Orie* market day, they started the war. They were killing people and destroying properties, so we had to run for safety.

I ran from here to Opi junction with my legs but all thanks to God, they told us that the war had ended and Nnamdi Azikiwe who brought independence said that there will be no division and that we were going to be one Nigeria.

A harrowing experience: Rejected by Father



HANNAH OKONKWO

Profile: 79 years,
Female, Widow

Place of origin:
Mgbukotu, Ebonyi State.
Diagnosed when very
young and Treated
for Leprosy at
Mile 4 Hospital,
Abakaliki

"...My dad rejected me, saying that the illness had transformed me and that none of his children was like the way I was. He told the Whites to take me back to where they brought me from because no matter what happens, he cannot take me back."

I'm from Mgbukotu, Ebonyi State.

I don't really know when I developed this ailment. I was very tender when my mother died and people deserted me after she passed on.

My father and I stayed (*at home*) because he said he didn't know what to do about my sickness, that he was confused about the right treatment for my illness and so, it was getting worse because I was left out without healthcare. I grew worse until when the white people came to our village to administer vaccinations and immunizations to children that I was then taken to Mile 4.

I gained actual cognition in Mile 4. They started searching to know where I was from because I wasn't able to say anything about my origin due to the fact that I was very tender when I was taken. The white people had to hand me over to the welfare department in Isiangwu and asked them to search for my town, relations or family members. The Welfare people were able to find my town, family and father's name before the whites were able to take me back home.

My dad rejected me, saying that the illness had transformed me and that none of his children was like the way I was. He told the whites to take me back to where they brought me from because no matter what happens, he would not take me back. I could understand everything they said because I had gained cognition. The whites took me back to Mile 4 after all said and done.

They gave a condition that if I agreed to be married, they would come and pick me from there if not, I would remain in Mile 4 hospital. Sister Amadi said because I was an Igbo indigene, she would try her best to make sure I got married. Then, the brothers agreed and brought a man who was amputated on both legs due to leprosy complications and said he was my husband. Someone like me suffering and helpless,

what could I do? I had to accept him and their wishes and married him, just so that I could receive the care of the Church. That was how I left Mile 4 to this place to live with him. The man has died now; it has been long he died. He was from Nimo in Anambra State. He died long ago, like 20 years now.

They took good care of me (*at Mile 4*). No one treated me badly, they were very generous to me and they called me "Nwa Sister" (*meaning: Sister's child*), so they were good to me. But after some time, they said my name was no longer on their list and that I would have to start paying for treatments. So, the brothers gave me money saying 'things are hard now' -but they were trying and I understand. So, I managed (*any*) new ailments the best I could.

I went to school while at Mile 4, but the teachers did not allow me to stay in the classroom because of my illness. My body was dry and rough like a piece of stone and I smelled. When I scratch my body, my skin particles fall to the floor. So, the teachers said I can't stay in class because I could transfer my ailment to other pupils. I only studied for two classes. When I was about to go into Class 3, my illness got worse and did not allow me to continue.

I have a son; he's in Anambra, in his father's house. He visits, he comes sometimes to check up on his children here. He has two children; a boy and a girl - they just left for school not long ago. My relatives in Ebonyi come to check on me sometimes. My mother did not have a male child. She gave birth to girls only; they're married and they hardly come to visit.