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GLRA
German Leprosy and
TB Relief Association

A QUESTION OF JUSTICE

Persons affected by Leprosy in Eastern Nigeria tell their stories in their own words

GLRA
ORAL LEPROSY HISTORY
PROJECT

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Persons affected by Leprosy in Eastern Nigeria tell their stories in their own words

Edited by:
Joseph N. Chukwu
Ngozi Ekeke

All correspondence to:
German Leprosy and TB Relief Association (GLRA)
56 Nza Street, Independence Layout, Enugu, Nigeria
glra.nigeria@dahw.org
Phone (office): +234 706 749 0052 and +234 808 055 7461

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German Leprosy and TB Relief Association
56 Nza Street, Independence Layout, Enugu,
P. O. Box 18158 Ogbete, Enugu, Nigeria
Phone: +234 803 668 0252; +234 706 749 0052
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Website: www.glra.org.ng

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Nippon Zaidan Bldg. 5F,
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Foreword

This collection of first person narratives of leprosy control in the defunct eastern region of Nigeria is a monument to a seventy year period in human endeavour and experience, marked with stories of regret and redemption, pain and care, and revealing many of the various ways in which leprosy exacts its unsparing toll, and some of the ways in which it brings people together in the search for a cure and a livelihood. The German Leprosy and TB Relief Association in Nigeria has been involved with care and cure for leprosy and other chronic and painful conditions such as tuberculosis and Buruli Ulcer for over half a century, and its staff and associates have built a deep network of concern for lives lived with leprosy since the early 1960s. The accounts recorded in this wonderful and surprising volume span from 1945 till 2019, a period in which welfare, public health, and political life in Nigeria has undergone huge changes, for better and for worse. These accounts reflect this history, and remind us that human experiences that are commonly said to be at the margins of society tell us as much about the world, and the societies we live in, as the more often-repeated stories of the news cycle.

When a service is cut or reorganised, when a piece of funding doesn't go where it ought to, when infrastructure and other demands make it impossible for people to meet sincere promises and come to meetings, those people at the margins who rely on systems and relationships of care - whose day-to-day life is assembled with the assistance of one kind family member here, one attentive nurse there, someone to help with the farm, the market, the garri mill, and a little church or charity money - can find things unravelling. The bruises and pains of inattention are very keenly felt by those who are recovering from leprosy; both the pains and the pleasures recounted in these pages record how currents in Nigerian life and history impact the lives of its citizens, in all the opportunities and difficulties it presents.

In the past twenty years, I have had the great pleasure of getting to know many people working with leprosy control in Nigeria, and many of those whose life experience has been shaped by experiences with leprosy. At GLRA, in Ogoja and Abakaliki, at Ekpene Obom, Uzuakoli, and Oji River, and in the Nigerian National Archives, I have followed the story of the past hundred years of leprosy control. Nigeria has been central in the global history of leprosy. Research carried out at Uzuakoli and in a network of centres across the south east, much of it between the Second World War and the Nigerian Civil War, was crucial in devising the treatment regime used by leprosy patients across the world today. The role of Nigerian patients, seeking and agreeing to treatment, allowing their bodies and vital signs to be carefully checked and observed, reporting on their experiences with a wide variety of chemical compounds, did a huge amount to make modern therapy not only successful, but possible.

The experiences of the patients at Nigeria's large legacy leprosy centres were also of great cultural significance. The music of Ikoli Harcourt Whyte resonates across Nigeria; this great body of choral work by a composer who lived with leprosy and resided at Uzuakoli for much of his life is kept alive in Christian celebration, in the scholarly work of Prof Achinivu Kanu Achinivu and collaborators, and feted in the work of Ola Rotimi, whose polyglot play Hopes of the Living Dead places patient responses to leprosy at the heart of the Nigerian political imagination. The historical leprosy settlement was a place of intense cultural encounter and invention, and the stories told here echo stories of hope, expectation, struggle, disappointment, networking, and sheer dogged inventiveness. They tell stories of a will to survive, live, thrive, engage and to take part in community life.

These stories inform us, they tell us of what we can and must do to work towards a fairer society, they indicate how history and politics impact lives all around us in ways we commonly fail to notice. They also echo a global story: across the world today, the stories and lives of people who have experienced leprosy are being told, the ways in which it robs our brothers and sisters of their means and livelihood, and the ways in which we can help them repair and make good what we have watched or ignored being taken from them. These stories gathered here form an important monument to a history of care and pain. Dwell with the stories a little while. Let them inform and nourish us. And let us act to help recover opportunities and relations lost to the legacy of leprosy, a disease which can be cured, a source of stigma which must be overcome.

John Manton
Associate Professor in History,
London School of Hygiene and Tropical Medicine, UK

GLRA Nigeria oral leprosy history team with John Manton

IT IS RIGHT AND JUST

An Introduction

'We hold these truths to be self-evident that all men are created equal, that they are endowed by their Creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness'. These hallowed words though originally Jeffersonian and American, readily capture the essence of the United Nations convention on human rights.

Over the years, these hallowed principles have been hollowed by certain actions and inactions of people across the globe. Entire populations and groups have been denied their (unalienable) rights to life, liberty and pursuit of happiness because they happen to be different. Differentness could be in relation to race, creed, gender, sexual orientation, disability or health status, to name a few. The victims suffered varying degrees of deprivation and injustice often owing to ignorance and fear on the part of the majority.

For centuries, leprosy was considered a disease apart, and its sufferers often humiliated and ostracised. In some countries and regions, rights as basic as the right to marriage or indeed procreation were denied by formal legislation or sundry customary practices. Diagnosis of leprosy in a spouse was (and sadly still is, in some countries) sufficient grounds for divorce. Siblings and members of the extended family found leprosy a convenient excuse to disinherit their unfortunate relatives who had been handed the life-changing diagnosis of leprosy.

Arguably, one of the most egregious of deprivations and injustices suffered by persons affected by leprosy over the years has been the lack of opportunity to tell their stories in their own words. As in most human encounters, what is presented as 'history' is often the account according to the dominant party. The history of leprosy has not been any different. Government actors and public health officials believed they did what they did in the larger interest of the people. Accordingly, their versions of the history of leprosy were framed to reflect this perspective.

The narrators in this volume present a different perspective. For most, it is the opportunity of a lifetime which they joyfully seized to tell their own stories the way no other person(s) could. Told with enthralling authenticity, these hitherto 'wretched of the earth' shared gripping tales of rejection by family and friends; depression and sometimes suicidal thoughts; feelings of unworthiness, hopelessness and helplessness. There were silver linings too. Yes, the human instinct of self-preservation found a way to point them to some positive aspects. Not a few expressed great appreciation to

God for sparing their lives. Some were grateful for the privilege to marry (especially if their spouses did not have leprosy) and have children. Almost all of them had words of praise and gratitude to Sasakawa memorial health foundation and German Leprosy and TB Relief Association for providing them a long-denied platform to share their unscripted stories.

We would be remiss not to state that the vast majority of the persons whose stories are outlined here still live in poverty and deprivation. Some are blind, many have physical and mental impairments related to leprosy. As a group, they seem to have receded into the blind spot in the rear mirror of state and national programme managers and accordingly risk being 'left behind'.

This work is a small contribution to the global effort to restore the dignity of persons affected by leprosy and properly acknowledge their experiences as an integral part of our common human heritage. It presents unscripted accounts of the life experiences of individuals who have encountered leprosy either as patients or health workers. These men and women lived and worked in the defunct eastern region of Nigeria. The area now comprises nine states: Abia, Anambra, Ebonyi, Enugu, Imo (in the south-east zone) and Akwa-Ibom, Bayelsa, Cross River and Rivers states (in the south-south zone).

Diverse themes are discernible as one goes through the often keenly told stories. Not surprisingly, many shared lamentations of rejection and betrayal by family and friends; others reminisced over dreams shattered by leprosy with resultant deprivations. Not everything however was seen through the lens of tragedy and loss. Not a few narrators took the view that leprosy was not the worst fate one could suffer; they expressed gratitude to God and the health workers who so selflessly cared for them.

It is our hope that this collection will serve as a cautionary tale to all but especially to the youth in Nigeria and elsewhere that society is poorly served when a person is defined by his/her disease. Never again should a person diagnosed with leprosy be referred to as a 'LEPER'.

As our planet warms, oceans rise and deserts encroach, old health scourges are likely to reemerge and possibly new ones appear, we must resist the temptation to 'blame the victim' and dehumanize those who are unfortunate to find themselves on the other side. A more enlightened response should foster a more humane world.

Orientation of Oral history Interviewers at GLRA Nigeria office, Enugu, Nigeria by Dr John Manton on 5th July, 2018

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Appreciation

A Question of Justice

Persons affected by Leprosy
in Eastern Nigeria
tell their stories
in their own
words

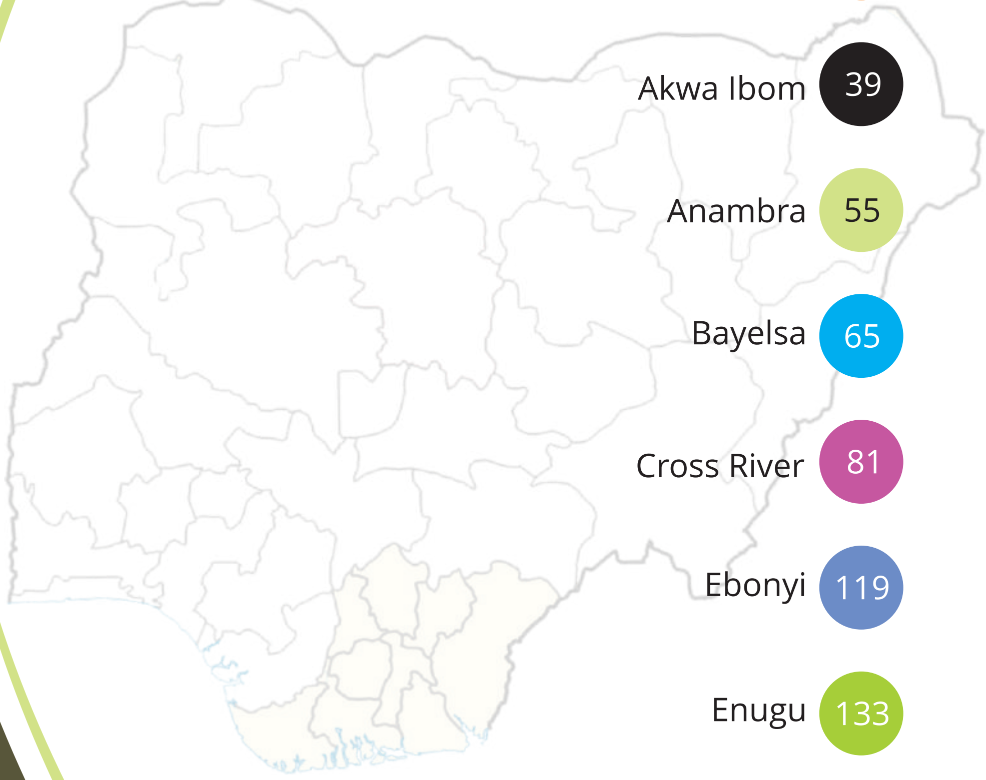
The transcription of audio narrations of persons affected by leprosy and healthcare workers

was done by

Stanley Jachike Onyemechalu
Department of Archaeology and Tourism,
University of Nigeria, Nsukka.
stanley.onyemechalu@unn.edu.ng

Contents

Words from Persons affected by Leprosy in these Eastern Nigeria States: ....

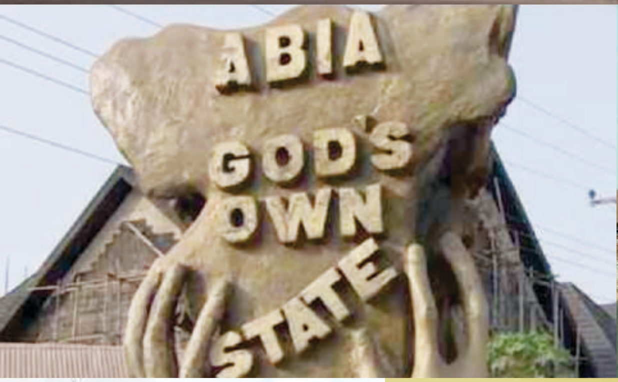


National War Museum, Umuahia

Uzuakoli Leprosy Centre

GLRA Oral Leprosy History Interview Crew on mission to Abia State August 2018

Stories *from* ABIA STATE



National War Museum, Umuahia

Matthias Onyema

Profile: Clergy, Male, Married
Place of origin: Ebonyi State
Diagnosed and Treated
for Leprosy in 1988
at Mile 4 Hospital,
Abakaliki,
Ebonyi State

“I didn't tell my wife I had leprosy.”

“I think leprosy opened more doors for me than if I had not had the disease. I come from a very warped family background and I believe God saved me from a kind of destitution that would have enveloped me if I was without leprosy”

Discovering Leprosy

Shortly after the Nigerian Civil war, during my Primary School age, I saw a patch on my skin. I did not know what it was at the time and people around me did not know either because it was very uncommon. They said "go to herbal, go to this and that"; and I was given all kinds of concoctions and mixtures in the name of treatment. The patches on my skin continued to spread despite all the efforts. Still unaware of what exactly was going on, I started to convince myself that nature was helping me 'bleach' my skin. There was a time I said to myself: "it's okay, since I'm a black man and I've seen something that will bleach me so that I'll become an 'Oyibo'. It's okay, let it go ahead". But the patches persisted and became very disturbing, giving me whitish dusts like during the harmattan season. I would use my saliva or sometimes, *ude-aki* (palm kernel oil) to rub on it.

As time went on, I became very overwhelmed with the sickness, I was feeling weak in my body and my joints and then every part of my body was in pains. I tried to 'be a boy' and suppress those signs then, I was trying to make sure the strength was there. But the sickness said, "there's no way you can do that, I'll tell you that I'm natural." The sickness told me, "I was in the world before you so…". Finally, it subdued me and I could not get up any longer, lying on the bed helplessly. There were sores and I sustained some scars from injuries but I'm grateful to my *Eze* (king) that I had no ulcer – he ensured that I got help.

Treatment

The *Eze* summoned my family, my uncle, and told him: "Look, if you fail to take this boy for treatment, whatever you see, take it. Take him to Uzuakoli." My uncle said he told the *Eze* that there was no money and no means for him to take me there. But the Eze insisted saying; "failure to take him there, I'll have you arrested by the police". Finally, my uncle and his son were able to hire a vehicle to take me to Uzuakoli.

When we got there, in the waiting hall, one of the experts there came and looked at me and said, "why did they wait for you to be in this state before bringing you here? Who are those responsible for you?" I couldn't talk, I was very sick. The people around said my people -my uncle, his son and the driver, had left. I was asked to leave the premises before night time but I couldn't walk, so I said, "if I want to die here, I'm already at Uzuakoli, they have grounds here for me to be buried." They left me to attend to other hospital work and I was lying there alone. After about 40 mins, the workers came back and asked "okay, young man, what really happened?" They examined me, all the scars on my body, everything was checked. Then I was taken to the ward, and given a bed and some clothes. Treatment started. This was April of 1988.

I am grateful to Rosalind, the Welfare Services Officer and a Senior Nurse, Onyejepe, who I thought was a Doctor at first. They took good care of me and in no time, the scars on my body started to peel off and wear off just like a snake trying to shed off its skin. After two months of treatment, all my body started peeling and you'll see the normal skin coming on, not really the skin but you can notice that the healing process had begun.

Rosalind Colwill always went bed to bed checking up on the patients but whenever she came to mine, she spent more time than usual. I enjoyed her conversation and most times, we conversed in Igbo language. One day, she asked me about my educational background and I told her I had attended a private commercial school, where I did Accounting and manual typing. She made sure I had eggs in my diet and that I got paid my allowance, which was N6,000 at the time. Since there was shortage of doctors, Rosalind made sure that doctors and youth corps members from other centres came once in a while to take care of us. I remember Ogbonnaya and his wife, Dr. John and Dr. Chukwu all worked at Uzuakoli for certain periods of time.

Life after leprosy

In 1988, as my health improved, I was discharged from the ward by Dr. Chukwu and put in a different room. Miss Colwill knew I could read and write and so she encouraged me to take over from Mr Eke, the Accounting Clerk, who was leaving at the time. I also helped to dispatch mail with the bicycle they provided and I was efficient. Soon, Miss Colwill sent me for training to go and learn soap making – hot system and cold system – and bought a cutting machine for the tablet soaps. I did a good job and so she bought a vehicle to help with the sales and distribution of the products, and it was a very profitable business. In 1989, when time came for Miss Colwill to move on from the centre to other projects, I followed her and continued to work with her until around 2002 when I decided to join Ministerial Evangelism.

I became an Evangelist, a Pastor, a Reverend, and so on. I went back to the centre as a Chaplain before I was transferred.

Reuniting with Family

One day, Ms. Colwill wrote a letter to the *Eze* after I was discharged saying, “this is the person you people dumped. If you don't come to see him, whatever happens, you'll face it squarely”. When I came back to the office from a dispatch, Ms. Colwill told me that she had written to my *Eze* and I said okay. The *Eze* then summoned my uncle and told him, “so you went to dump that man, look at what the Government has written to me. Whatever happens, you'll face the consequences. Come and go see Matthias and see how he's doing”. So, they sent my uncle's son to see me. I saw him coming but he couldn't recognize me because he saw me on a bicycle. The last time they saw me was about four years ago and I was barely alive then. I told him not to worry, that it is me. I took him to Ms. Colwill and she scolded him so much and told him that she was this close to calling on the army or police to come and arrest them for abandoning me. He left and spread the news that I've been healed. So, I didn't go home until a while later, people were rejoicing and praising God.

'I didn't tell my wife'

Well, you see, I didn't tell my wife about it. But then, she knew because she was a very clever woman. In short, it's God who made it possible that I went to her and was able to seek her hand in marriage. Coupled with the social work she did and so on, if she wants to leave me, I'll tell her "what's the need for your social work, because you have worked at mega agencies, leprosy settlement as a worker, so why do you want to leave me?" So, she didn't know but I think she might have gotten a clue. And even when she later did, I haven't seen any adverse response or negativity from her.

Life as a Normal Person

After treatment, for someone to regard you as a leprosy patient, it's *(because of)* the deformity. So, if I come inside and you don't see anything, I don't think that anybody will suspect me of having anything. Both during my first degree and second degree, even at Nsukka, no one knew that I suffered from leprosy and it's been that way ever since. And this is a civilized world, like an academic world, the level of exposure now has made people, although very few, to understand that Leprosy is just like Malaria or headache, not a serious something. Living with leprosy is easier than HIV because it's treatable. If somebody finds out that I suffered leprosy and for that, I have to give in to the person? Never! Igbo people will tell you, you cannot decide when I die because you are not my God. It's only God who will tell me that I will die.

The Irony

I think leprosy opened more doors for me than if I had not had the disease. I come from a very warped family background and I believe God saved me from a kind of destitution that would have enveloped me if I was without leprosy and remained with my family. God knows that I would have suffered even worse than somebody who has not gotten leprosy if I were to be in my home.

It was at the leprosy centre, because I had leprosy that I met wonderful people that have helped me scale through all of life's challenges and have today, become a better person, even better than some of my family members who did not suffer any disease. I was able to get exposed, find work and further my studies from Bachelors to Masters level (with sponsorship help from Ms Colwill) because I had leprosy. God used leprosy to put a smile on my face.

Advocacy

As a leader, any church I man and I see a leprosy victim, I already know where to direct the person. Then I'll announce to the church to bring money so we can take the person there. (For) any church that is fortunate to have me as their pastor, they have heard the word, and have someone who will help them in treatment of leprosy; some get legal (help) because they have someone who knows where to direct them.

Missed opportunity; Avoidable impairment!

"I was a student in 2002 when I noticed the first symptoms, yet no hospital visited was able to diagnose the leprosy until 2008 when I got to Uzuakoli, with a bad wound."

"The wound condemned one of my legs and it was amputated. So, I passed through several challenges – even our community leader asked my parents to take me out of the village."

Chiwendu Innocent

Profile: 33 years, Female, Married
Place of birth: Ibeku, Umuahia, Abia State.
Diagnosed and Treated for Leprosy in 2008 at Leprosy Centre Uzuakoli, Bende LGA.

Dilemma in early detection of leprosy

My name is Chiwendu Innocent; I was born in Ibeku, Umuahia, Abia State on 17th July, 1985. I was 18 years old when the disease first appeared on my skin. Then I was a student in Senior Secondary (SS2) class in 2002. After going to the hospital, they were not able to identify the disease until 2008 when I came to Uzuakoli leprosy centre where it was discovered that what was wrong with me was leprosy.

I started receiving treatment for leprosy and care for the wound on my leg. The hospital staff tried their best but the wound refused to go. This condemned one of my legs and then resulted in amputation (cutting off) of my leg. The organisation, German Leprosy Relief Association (GLRA) tried their best to save my life.

Education life: coping with leprosy at school

When it started first in 2002, it was not so bad then. It was just like a common skin infection we usually call "eczema" on my skin. Therefore, my classmates believed it was just any other skin disease and never stayed away from me. No one knew it was leprosy; they thought it was just a skin disease.

It also affected my schooling at a certain point. I did not finish the exams I was supposed to write. I even wrote my (NABTEB) exams in the hospital. I was able to write my senior secondary certificate examinations (SSCE) and I passed.

Discrimination in the community

The wound on my leg made me pass through a lot of challenges. This happened mostly in my community where I was born. At a point, even the Eze (traditional ruler) of my community asked my parents to take me out of the village.

So, my parents took me out of the village and brought me to the Leprosy Centre, Uzuakoli. Up till today, I don't have a home back there.

Marriage life

I left my home for the Leprosy centre, Uzuakoli at the age of 23. I was not married then. It was here at the hospital that I met my husband. When I completed my treatment, I met someone who was also cured by the German Leprosy Relief Association we became friends. He then took me to see his parents for marriage introduction and told them about me, they then accepted me and we got married. God blessed our marriage with three children - two daughters and a son.

In my own family, they tried their best during the time I had leprosy, no one discriminated against me because they knew that it was what I got and not something I had from birth. It was from 18 years that the symptoms started showing on my skin, I managed it until I was 23 years before it was known I had leprosy and none of my siblings stayed away from me because I was okay before I got the disease. My husband and I are thanking God because He has been the one looking after us. We are not working. It is his family members and few of mine that are helping us.

We did not suffer any discrimination in my husband's village - Mbano, Imo State. The only problem we had was that they requested to see the doctor's report showing in the certificate that we've been cured of the disease. Once they see a doctor's report or you give them the certificate, they will know that there is nothing wrong with you again.

Future plans

If it is possible for me, I would love to do a business of buying clothes and selling outside and still be taking care of my children. The German Leprosy Relief Association tried for me very well.

I want to thank Dr. Micah because he really fought hard for me to get better and the Chief Nurse, Mrs Charity Ekwueme. She tried also and the Reverend looking after us gave me the support needed to go to Mile 4 Hospital, Abakaliki for my leg surgery. May God Almighty bless all of them for me.

IFEANYI AKUMA

Profile: 41 years, Male, Single
Place of origin: Isikwuato, Abia State.
Diagnosed and Treated for Leprosy in 2012 at Uzuakoli

"When it (leprosy) first started, I noticed that my leg was turning white… I went to one native doctor and to so many places but all to no avail."

"…Something cut my leg and it started to bleed but I didn't notice it. It was my friend that told me that my leg was bleeding, when I saw it I was convinced that I don't know what is happening to my leg."

"(During treatment) Nobody knew about it, it was only my mother and my sister. I was in good terms with them, but my immediate junior sister doesn't take anything from me. For example, if I cook all my family members will eat except her."

My name is Ifeanyi Akuma. I am from, Isikwuato, Abia State.

When it *(leprosy)* first started, I noticed that my leg was turning white. Myself and my parents were staying in the North, so I left them and came down to this East. As time went on, my leg was still white and I didn't know the problem. Later something cut my leg and it started to bleed but I didn't notice it. It was my friend that told me that my leg was bleeding, when I saw it I was convinced that I don't know what is happening to my leg. During that time my leg was troubling me a lot, I went to one native doctor and to so many places but all to no avail. Then I called my mum and told her what is happening and she told me to come back to the North.

Then I went to North. When I reached North, they took me to the hospital. One doctor checked me and said that my sickness is leprosy, we asked him whether it can be cured; he said yes that if I take medicine for one year it will clear. Then I took the medicine for one year which after taking the medicine, I returned to the East.

After sometime, the sickness started again so I had to go to a Teaching Hospital. One doctor that was working there told me to come to the hospital in one week. In the process, I met Sister Tella and Brother Micah, they told me that it is leprosy and I told them that I know and I have taken medicine for one year in the North, and he told me to bring the card that I used for my medication and I gave it to him. Brother Goddy tested again and told me that the sickness still remained in my body, that I have to take medicine for another one year. Then I took medicine for another one year.

(During treatment) Nobody knew about it, it was only my mother and my sister. I was in good terms with them, but my immediate junior sister doesn't take anything from me. For example, if I cook all my family member will eat except her, she didn't say it but her behavior says it. I haven't travelled to village since then. We have meetings in Aba which I normally attend but they don't know about my sickness.

I can't walk. I am in the wheelchair that's why am asking for help. I want to get out of this wheelchair; I need to walk because I was a driver and I would like to go back to my work. I'm begging; if there is a way people can help me, let them help me so that I can go back to my normal business.

ABIA KALU

Profile: 55 years, Male, Married

Place of origin: Amaokwe-Item, Abia State.

Diagnosed and Treated for Leprosy in 1980 at Leprosy Centre, Uzuakoli

GLRA Oral Leprosy History Project

My name is Abia Kalu. I am from Amaokwe-Item.

I came here in 1980, when the sanitary workers discovered my illness, I was sent to the colony; and it was Dr. Sunday Mkpa that admitted me here. I was receiving medications every week for one month. I was really in pains and I encountered a lot of difficulties while I was here. Even my wrist and legs were stiff, but the pains in my leg refused to heal. So, the only alternative was to amputate my leg, to save my life. At first, I refused, but after series of negotiations, my leg was amputated and that is how the pains were permanently relieved. Since I was discharged in 1985, I have not experienced any other major problem.

My family discriminated against me, when the sickness started. But when I was discharged, I started interacting with them and they were showering me with gifts and presents. But there was no bad relationship between me and the villagers, I participate in their activities and programmes.

I work here to earn a living for myself; but I do visit the village at intervals and come back. I only stay here because I am working here. God is indeed faithful, as through the work I do here, I was able to build a house of my own and also sustain myself. I pray that all those that work tirelessly to ensure that we keep surviving, that the good Lord will bless them abundantly. I want to thank Dr. Chukwu, Sr. Monique and You; for always being there for us.

Footprints of uncommon legacy
in serving leprosy patients

ISAAC OKWARA ONOH

Profile: Retired Veteran, Married, 92 years
(Born: Tuesday, *Afor,* 16/11/1926)

Designation: Junior Leprosy Inspector
& Research Trainee in Uzuakoli, 1945

Title: Elder, Chief Isaac Okwara Onoh
(Ezeogo XIII of Agbagwu, Arochukwu)

Worked with Europeans who pioneered
leprosy control in the region
(Employed: 1st May, 1945;
Retired: 1st January, 1985)

> ***"Those of us who were staff, "clean", never had leprosy before. Yet it took Dr. Davey some time to explain and convince people why they should allow us to get married."***

When I was a young man at a place called Ihe-Ahaba, Isikwuato, where is called Akara now in Abia state, my father used to be a volunteer evangelist for the Methodist Church. He came from Aroh and established a Methodist Church there, because Reverend came from Bendel and met him. So, he came back here and reported to the Presbyterian Church, the Church of Scotland then, that brought him there that there was another person who was trying to superintend them, so they asked him to continue because at that time, eastern Nigeria had been divided for Protestants; CMS along the Niger, the part of the railway; the Methodist, Oron, Uyo and so on; and then, we of the Presbyterian Church along the Cross-river; and then the Qua Iboe, along the Qua Iboe River, up to Ugbo-Oloko as well. So, that was what happened. So, we were there.

About 1938, I think I was in Infant two, second year in the Primary School, a certain man called Dr. Davey brought a team of Europeans to our village and they were examining people. We were in line. *“Tugharia ihu, tugharia azu. Puo” (turn front, turn back, leave). “Tugharia ihu, tugharia azu. Puo”. “Tugharia ihu gi, tugharia azu. Stay here”.* That is, those found to have some patches of leprosy, 'macules' we call them, were asked to stand on the left-hand side. Those who were not found to have anything, they said, “Go”. And Dr. Davey was seriously learning the Igbo language and we were all interested to hear a white man talk about it, *“o na-afu gi ufu?” (does it hurt?)* that is the man. So, that was all I knew about him. But as for leprosy, I knew about leprosy when I was a younger person living with my mother here. There was a boy who was playing with us, doing everything with us until one day, he was taken to live in the bush. And each time, we were going from my mother's place to the market, we would look inside and we saw him living in a rickety type of house and we were very sorry. He was our playmate. And the mother would go in there and feed him. That was when I knew about leprosy.

The village agreed to isolate. Once you have leprosy, they would isolate you. In fact, Mkporo and Edda people are the wisest people about leprosy because they purposely opened a place called Nchara for leprosy. That is why when they see this people talk about Awa, one Chief Awa of Mkporo, Dr. Davey recorded them as the most intelligent persons. Because the Mkporo people had already got an isolation place for everybody, for those who had leprosy. And if they were treated, they were treated by native doctors who used to perform off the place and they will come home but they used to stay long, until we met them there. And that was all I knew about leprosy.

The Methodist College, Uzuakoli, is a center for all Methodists, whether you're at Oron or at Otukpo. And we who didn't go to secondary school, we used to go and do sports at Uzuakoli college. And the staff of the leprosy center used to come and they used to be introduced. Then we, through that, had an idea about leprosy. Six miles away from Uzuakoli, you'll hear them sing; the leprosy patients were singing, they were making merriment, we were just hearing that. So, we were always anxious to know what was going on there.

But that wasn't what took me there. Yeah, I went there by accident. The accident happened this year. My father had wished I was a minister of religion. Then I started by being a teacher in 1944, 2nd February. So, the mission; [Rev, A. B. Magda and Rev. Jacquelin Shear] they were all watching how I was getting on. Fortunately, they said that I was doing well as a teacher and they had hoped that I would continue with Uzuakoli college and get conversant. But we were on holidays about April, Easter holiday. A friend of mine came from there and was sleeping in our house to continue to Jos. So, he said he heard that Uzuakoli was looking for clerks to employ; that I should go and try. At that time, you would only get the job by exam; written exam and interview. So, about 50 of us went there; most of us teachers. So, we took the exams. As we were writing the exams, they were eliminating those they wouldn't want. But I continued to survive until the last interview at 8:00 PM; I was selected. Then when I was selected, there was trouble.

My parents were willing, once it had something to do with the church. But when we came back now, the minister, A.B Magda, very brilliant man, we went to him and said "we've got a new job", he said, "not for you, you're not going there". He now said, "you don't remember what your father said, you'd become a minister of religion. To whom do you want us to give back this castle?" I said, "the Church should have asked me to continue in 1942 at the Methodist College, but they didn't give me that scholarship. Therefore, let me try this place". Fortunately, you know, Dr. Davey had influence. So, when we went and they gave us a letter. We went to him, he read the letter and said, "oh, if I send you back, you will always quarrel with Rev. Magda. No, Alan didn't get it right. I will employ you, but go and complete one month for him". That was why I earned two salaries. And so, they employed me on the 1st of May, 1945 as a leprosy staff. But they sent me back to go and teach, to give some consideration to Alan Magda who was not happy that I left teaching. So, when I went, Magda paid us, these people paid us. So, we brought it back to Dr. Davey and said, "we were paid twice, what do we do?" Then Dr. Davey said, "when you were employed, you are supposed to be on leave after one year, but because of circumstances, I allowed you to be on leave for one month in order to do that. So, take the two salaries". That was how I began. Eight of us started on the 1st of May, 1945. We were employed as Junior Leprosy Inspectors in Training. So, we were just training in the lab to know how to do smearing, we were doing smearing... But when Dr. Davey came one day, all of us were sitting down in the common hall. He came and wrote, "Apple welfare, Ojo Nwagbara, this, that", he wrote many things. When he came to me, he said, "Onoh for tour". If you go to Uzuakoli today and ask anybody, "Onoh for tour", they'll call me. Because Dr. Davey, his words were regarded as something that is very vital. He never used to say many things, but he was such a good person. He was such a trusted person. This is a man, according to him, he said he was to come and teach science at the Methodist College, but his father came back from Synod General Assembly and told him that they were needing a doctor.

GLRA team with Chief Onoh (L-R: Ngozi Ekeke, Chief Onoh, Prof. Achinivu, & Joseph Chukwu)

So, he went back to Manchester and read Medicine to come to be a doctor and take over from Dr. Brown. So, that was how...

Reaction of relatives and community to his working with leprosy patients

The first thing that happened was that my father, being a church-conscious person and my mother the same, anything the white man said towards church is right. If a white man could come all the way from overseas to work in that place and he would want an assistance and this my son, let him go. That was the idea of all of us. And when I talk about Dr. Davey, psychologically, was a very wonderful man. He picked us. Most of them, not me o, we were very handsome. People like Ojo Nwagbara, people like Apo, people like Ezeronye, people like Ugbo, Abor, Duncan Orji, handsome young men. Each time we finished working, we trekked three miles to the town, people would admire us. They knew us not to have had leprosy at all.

Most remarkable events while working with leprosy patients

To work with the expatriates, including Dr. Davey, was a pleasure. I had no opportunity of going to secondary school, but here was a man who saw beyond just treating patients, he saw us as human beings. Dr. Davey at his height would call of us together. Remember, at the time we were treating leprosy, we treated leprosy in the Owerri province that stretched from the whole of River State up to Bende, including Owerri itself, and it was a vast area. And we were all going from one town into another and one town to another because the man had vision. I'll tell you why we didn't have leprosy settlement alone, why we started having leprosy clinics. Even as we were going to Calabar yesterday, I told my driver, “there's a village here called 'ibianiworo' which I founded as a leprosy center. Now, Dr. Davey will call us. He would tell us the amount of money government brought, he would tell us that he would want us to volunteer to go into places to found leprosy clinics. And some of the patients were useful; most patients were very useful to us.

They were useful in the sense that if a man came from, say Arochukwu, to the leprosy settlement, we will ask him, “is there any possibility of getting a piece of land on which we can treat leprosy patients?” he'd say, “yes, I have a piece of land”. He will take us, we will negotiate with the chiefs and we will own it. It must be isolated anyway, it must be isolated. That was why when they first introduced Land Rover, we were the first people to get it. Oxford Foundation gave us a lot of support. They gave us beautiful cars to use, we lacked nothing, we got money. There was a woman, Dr. Davey came back from leave and said that a woman had a large estate and if the woman was... because Dr. Davey was a talker - he would go round the whole of England, talking to all the Methodists and all the groups and he would come back bringing money and he'll just throw the money in. The building, the church there was his own personal money.

The patients were useful. They would be the contact persons. You know, the natives themselves were sympathetic with some of their patients because those patients were people they regarded as useful to them in the village. And anybody who volunteered to treat them was also seen as a friend of the town. Some patients also knew those who had leprosy like themselves and who's hiding. They were helping us.

Why patients hide

As at that time, in *ala Igbo* (in Igbo land), let me say it in Igbo, *na ala Igbo, a na-akpo (we call Leprosy) 'ogu biri na aja ocha',* there was no cure. *'Ogu biri na aja ocha', e gwue gi ili, e lie gi,* you go to the grave. It will end, going to the grave. There was no cure. No known cure. We ourselves were curing them with hydnocarpus oil we got from India. We planted them at Uzuakoli and we were producing the oil, and we used it for injection until this 1950 when Dapsone came. So, as I told you, Dr. Davey was very open. The Europeans were open. All the money they brought, all the planning, if we're going to Mgburuchi, for example, we will look for a patient from Mgburuchi who will tell us everything about their place and then we would go and start it there. And they saw us helping the people and these people were coming and they were being taught so many things; carpentry and so on, children who had leprosy were exposed.

Social challenges faced by patients and health workers

Yeah, some of the communities were hostile. Some of the communities, most communities were hostile. You know, in Nigeria or in Igbo land, you do not contract any disease without somebody saying that somebody poisoned you or that it is as a result of “ihe imetara”, “your sin”. That was that. So, when somebody gets leprosy, then they will say, “ehe, obu ihe o metara” (as a result of his sins).

So, you know why Dr. Davey decided to decentralize Uzuakoli was this; there's a place called Alayi, we went and built a leprosy clinic there because a man from Alayi came to Uzuakoli colony and was being looked after. His people decided that he has “ogu biri na aja ocha”, he wasn't going to come back, as long as he has gone to Uzuakoli that would be the end of his life, he won't come back again. They continued until they decided to hold his second funeral service, “ime okwukwu ya.” So, when they did the second funeral, they shared everything and allowed the wife to go and remarry and this and that and they gave the children away. So, his people did that. So, when Dr. Davey heard it, he went and opened a leprosy clinic at Alayi, the first one, in 1938.

And another one is Obanibegwu that same year. Unfortunately, because of hostility of Alai people, they went and destroyed the one we built there. So, Dr. Davey, “okay, your punishment would be you would go to Igbaria". Igbaria people gave us a nice piece of land where patients could farm and do everything and they were happy. So, Alai people had to trek about eight miles to go and visit there, because they ill-treated the patients. And so, patients who would want to go home and take treatment at home decided to help us. Uturu was one of our largest leprosy clinics in those days and when we were employed, we were employed principally, like I told you, I was sent to Aba on the 1st of June, 1946, to look after Ekwereazu in the north, pass through Umuaro, pass through Umuokara, you'll get to Ekwereazu. Then the second day, I would go to Umuokpo, I go to Akuligbo and then get to Ibeme. If you go to Ibeme, you will see the coconuts I planted there. Then I tried to open another one at Owerenta. Another thing is that some patients wouldn't want their people to know that they were suffering from leprosy. So, if you bring the leprosy clinic near their home, they wouldn't like to go there. The reason is that in some villages, even if you were cured, the people will still isolate you. Take for example, getting married; except you marry somebody who had had leprosy, it isn't easy.

Those of us who were staff, clean, we had never had leprosy before. It took Dr. Davey sometimes to come and explain to people why they should allow us to get married. Because Itu Leprosy Settlement that was started first in Eastern Nigeria in 1928 by Dr. McDonald used ex-treated patients more than clean staff. So, the people who went to Itu had that idea. So, even some of us when we went to marry, the problem was so big that it involved a whole director, Dr. Davey, had to go and campaign to help us out.

(“Do you know that Harcourt's first wife, the mother of Godwin and Beatrice, had leprosy and they married? But when she was discharged before Harcourt, she left him. She had become clean, Harcourt was still unclean” It was as bad as that. And they had two children. But because she had been pronounced symptom-free of leprosy....Prof. Achinivu)

This marriage one is one other important thing. There were many others. If there were many others in a place. They will say, “Nna a, ndi ebe I na aru?” (Brother, where are you working?) “o na aru ebe a na agwo ndi okoko” “isi?” (Is he working where they treat leprosy patients?) People will shout and they will leave there. Then, according to the training we heard from Dr. Davey, then you will open up and explain to them, because there is what we call the Propaganda Officer. We were trained as Propaganda Officers explaining “leprosy is just a disease”. That's why it took us time to explain to people that the word “leper” is condemnation. You can't because somebody is suffering from leprosy, you call him a leper. Why? He's a leprosy patient. We took time to explain it to people, “Onye leper, eh-eh”.

“I think that's why the place was also changed from leper colony to...” (Prof Achinivu). When we first saw as small children, we saw “Leper Colony, Uzuakoli”. It was later changed to “Leprosy Settlement, Uzuakoli”. In the World Leprosy Conference of 1938, according to Dr. Davey, in Cairo, they muted it. They said he won't call somebody a leper, it's condemnation. We used to call people who suffer from other diseases ordinary names. Why should it be in that of leprosy, we call them leper?

Experience in leprosy work during or after the Nigerian-Biafran Civil War of 1967 to 1970

You know, I told you I joined the leprosy service, 1st May, 1945 and Uzuakoli was Center. We would go round and come back to Uzuakoli. There was a time I was in charge of the Calabar province. I would come back to Uzuakoli and so on. So, even after our retirement, our ears were always open to know what was going on. When Europeans were asked away, Dr. Honie was in charge of Uzuakoli with the nurse. They were the last people to leave. Fortunately for us, an American trained Medical Officer, [M.A. Thunor had taken interest, being an ex-student of Uzuakoli College, and the parents lived at Uzuakoli. So, there were people who were there. He came and became in charge of the place. So, when in 1968, the federal troops came in to Uzuakoli Colony, he had to manage some of the patients back to Ikwuano. In fact, when Ikwuano fell, he had to bring some of them to Itu Mbuzo, his father's Okoroma Plantation in Itu, Itu Mbuso and then he worked there. In fact, when we were running away in January, 1970, we worked together; himself, his wife. He was carrying his load himself. That is, the doctor. Unfortunately for us, he became ill; not of leprosy. He became so sick and then he never recovered. And then he told the people that he should be buried at Uzuakoli. And fortunately, Dr. Chukwu came to be like that man, he's carrying the brunt of having to work in a leprosy settlement. I was asking him about my friend's son who volunteered to work. I don't know how he was one Nwoga and Mmadukwe. So, people suffered during the war; our patients suffered. Our facilities we had, infrastructure we had were destroyed. In fact, Uzuakoli Colony happened to be a very successful place, because everybody was interested; the government was interested, the church were interested, overseas and local. It was Taylor Woodrow who built some of the first houses.

That was where he lived. Taylor Woodrow was the provincial engineer at the time in 1932. And let me not forget to say that it was Harcourt White and Isaac Nwoho, they were the two leading people they had wanted to kill in Port Harcourt for not agreeing to leave Gborokiri, they were occupying Gborokiri. Because the doctor, the Scottish man, who came and wanted to bring all the leprosy patients together to the settlement could not do much. So, he returned to England. And the government wanted the leprosy patients to return to their homes. They said, “no, no more.

We have heard of the Presbyterian Church opening a leprosy settlement at Itu in 1928. Then it was Harcourt, after punishment upon punishment, because Dr. Gregory who should have looked after them had gone, they were no longer being given food, who went to Rev. Doss of the Methodist Church and convinced him. And again, you see, there was a network. F.L.O. Williams, the Principal of Uzuakoli, knew that particular area to be a troublesome area for administration. The headhunters used to be there because that place, mad people would come Loho, Lodu, and so on and Akoli. So, he was the one who arranged for that place to be bought. He himself was very patriotic and the Uzuakoli people loved him. Yes. So, I think that's the little I can say.

Things to be thankful for during his work with leprosy patients

So many things. In fact, let me give you this; this is my profile. This is some of the things I did. Do you know that I did not go to any secondary school, but they got to me employed. The white man was everything. Rev. Davey's wife was the Principal of Methodist Girls School, Ovine founded in 1930. She was the Principal. That instinct of teaching was still there. And we were having about more than 50 Europeans and their wives. They were always anxious to teach us. If you say something, “sorry, we don't say so in England. That's not how we say it” [Laughter].

They would be teaching our wives, they would be teaching us. If you write something, they would say, “please, remove this. We don't say so in England”. [Laughter]. So, we were learning. When I was at Aba one of them, L.R. Dalton, who became a Minister later on, said nobody was removing me at Aba. So, I was at Aba until I was able to pass my school cert. So, actually, they encouraged us, they looked after us, they reformed us.

I had all the respect; everything. Your wife, if you got married, they would take care of your wife. My first children were twins. I had no problem about them because [Phone rings]. So many things; so many good things. I think God's favor was there too. The people treated us well. They taught us about life. I wouldn't say I was highly religious o, at that time. Because the environment, we were all young people. Alright, for example, Dr. Davey wasn't taking alcohol and there was a social evening every Friday. Apo, Oji Nwagbara, Andrew Ogobeze, Isaac Onoh and all those latest ones, when we come, we will be singing “me mesia, me mesia” (at last, at last). Dr. Davey would come and say, “Okay, give the boys beer.” Then we started chanting songs, “ehe, me mesia, me mesia, me mesia”. The man treated you as his son. How wouldn't you feel happy. We belonged.

That is an example of how we were treated; all of us. I was to go to England for studies. You know why I didn't go to England? Dr. Davey said, “Isaac”, “Sir”. “I would have liked you to go and study Social Welfare in England so that you would come and take over the Welfare Department of this place, but you are the only son and you have a sister and that's your mother. Who would take care of your mother? If you can arrange for somebody to take care of your mother, then I would make sure you go to England”. I said, “I have nobody” he said, “Okay, be patient”.

You heard about the Bishop, Bishop Nwosu, Anglican Bishop? You know the Anglican Bishop at Umuahia. Archbishop, that's his father. The father of the Archbishop was a patient, we treated him and he became a staff. It was because of him that the white men took his son to Cambridge to do his PhD. I mean, what didn't they do?

Before Dr. Davey left in 1959, he had arranged our promotions in order of merit. So, by 1959 December 20, I was already promoted to senior service; they called it that time. You see how the man did that? He allowed all those who came before us to go before us. Because if he had done us, because he loved me, it would have been Nigerian trouble. So many things. If you haven't married, the European wives would ask you, “why haven't you got married? Africans don't waste time, go and get married”. That is why all our workers have beautiful, large families. I think Brother Joseph would know that. All of us had successful married lives. Ask me who did it; Dr. Davey. He would think about your life. He would think about that. He wouldn't allow you to be excessively stupid or trying to do things just because Dr. Davey loves you, no. I remember one day, because we used to go to do morning prayers before going to work, there's a chapel. So, when we finished, we were not regular, we had walked down towards mechanical workshop, he was just as Davey was passing. “Isaac”, “Sir”, “God wants you to work for him”, “Yes, Sir”. After some time, I went to him. I said, “I'm already an old man”. He said, “whatever is of good report...” he quoted Philippians chapter 4: 4 to 8 for me: “whatsoever is of good report, do it”. “Yes sir”. Dr. Davey loved me so much that when he retired, I became the Secretary of the London Methodist Medical Society. He was sending me papers for research. We were in correspondence. When he left back to do leprosy work in India, you know, there was a vacancy. For five years, he was with me. So that when he died of skin cancer in 1983, the wife sent for me. That was why I went to England in 1984. They had finished everything (the burial) but the wife wanted me to come. When I came she said, “nna gi ukwu anwuola” (your master is dead).

Research work at Uzuakoli

When the government took interest, you know, when I was going to Uzuakoli to work, my father thought it was still Methodist, Mission. But a month before I came, April, Governor Bourdilon from Lagos had already taken it over. He had taken over Oji River, Uzuakoli and Oshogbo, near Benin; those three centers. Itu refused to be incorporated into it because Itu was one of the richest, they had money. They taught patients how to cultivate rice. It was from Itu that government borrowed white man that went to Abakaliki and taught how to cultivate rice. So, while we were at Uzuakoli, each time they went to discuss about leprosy work, Uzuakoli will come, Oji River will come. Dr. Gareth from Oji River will come, Dr. Davey will go. Because of infrastructure; because Oji River, Dr. Gareth, was not interested in the infrastructure, he was only interested in the patients. But Dr. Davey would... Do you know that Dr. Davey... one of the European nurses would be sent to go round and see how our houses looked like? “Come to the office; dirty, careless person. You didn't sweep your house today. Why didn't you do it? I saw your bedroom, everything was dirty". And if you were not married, you won't bring your sister. Only married people would bring their sister or young wife, no consideration. So, it was Dr. Davey who attracted the research and when the people employed John Lowe to start it, he had enough house, he had the facilities, so he came. John Lowe continued working, taking patients. So, most of our patients took risks.

Most of our patients took risks. The first set they were using were the Lepromatous cases. Dr. Chukwu understands that, Lepromatous cases. They were the most difficult ones we were treating with Hydnocarpus oil and we didn't succeed much. So, some of the patients came. We were trying dapsone, we were trying B663 and all those things, and Rifampicin too, which was very good for tuberculosis and it also helped us in leprosy. So, that Dr. Lowe, we were bringing him patients from Ughelli. Those patients who were finding it difficult after many years, they will be there somebody would go and they wouldn't go, they were brought to colony. Dr. Davey was making sure that if they had children, they were sent to school. There was a time they gave him 300 pounds arrears. He said, "why do government waste time paying me?" He took the money to Uzuakoli College. It was through that money that your former Bishop of Mbaise was brought up. So, it was through Dr. Davey and influence of Okpara that they brought him up.

Nobody remembered them (those that died during the research) in terms of the Nigerian situation. But in those days, Dr. Davey would want to know what happened to the wife and the children. Let me give you one example. There was one particular person they called Thompson Isiaga. Thompson Isiaga is from Amawor, Umunnekwu, Mbelu in Isiukwuato area. He was in the army of 1939-1945. So, he brought in leprosy, like one Sunday Ajonuma, both of them from the Army. So, because of their knowledge, they used him for the research. They didn't just die because they took the drug that they died, but after so many years, they developed problems either of the liver or something like that, we were told, because of the drugs they were used on. That is it.

The man, Dr. Davey

The Rev. Dr. Thomas Frank & Mrs. Katheline Davey
Superintendent, Leper Colony, Uzuakoli (1936-1959)

He was a man of many parts. And that was why I was surprised that the German Leprosy Center didn't mention his name in the Almanac you brought. I got one. They didn't mention his name. That type of man, I don't know. Do you know that Dr. Davis, his knowledge of Igbo made the whole of Methodist Church in Eastern Nigeria asked him to write ekpere na abu (Prayer and songs book) for them in Igbo? (“He wrote songs in Igbo language. He had songs. I know that Dr. Davey was a Research Scientist himself. He was a Chemotherapist, he was a Musician, he was a Minister of Religion. ”...Prof Achinuvu added). He was an accountant too.

Nobody came into Uzuakoli between 1936 and 1959, that wasn't influenced by Dr. Davey. Even in their home, people were giving him their daughters. Most of them; Dr. Ellis, young women, Dr. Cynthia, Fisher, all those young women, Lecturer Peace; this is how they would come. Mag Nauti in the lab, some of them were people related to them. You see? That is one thing the white man did which we Nigerians are not doing. We cut off relationship quickly. It never happens. The person you knew in school camp, like Scripture Union camp or so. You won't forget. You will go and appeal to him, “I'm suffering”. Like Dr. Chukwu is helping us today, we trust him, all because of relationship between our family and his family. That's why he is suffering today in Nigeria. People will ask him, “why are you there? How much money are you making?” “With all the money you have made, what have you been able to do?” “I hulanu” (have you seen) Dr. Wakanma. People have made money. What have they done to help?

Do you know Dr. Davey would even consult us? Even when Dr. Davey would be there, if you are a staff and you are walking for 2 miles to work, and you have surplus money, he would apply to government, get you permission to build a small house. Government will agree. That's why we have so many houses at Uzuakoli. He will consult us, tell us. Imagine it's one person at 3 pounds 6 and 8 pence being consulted by Nna anyi Davey the old man. He was seeing us like a father to a child. If we wanted to drink a beer, he would give us, he would cook for us. He used to cook on Wednesday's for his wife. He would invite us to come to his house. He bought rackets for us to play tennis with him; something like that.

We used to do drama; staff drama. We would go to Elelenwo Girls School, WTC Umuahia, Ibiaku and so on. Sometimes, we'd go to people like IPL. Our wives, sometimes, the white woman would take them in a bus and they'll go on tour. Take our wives out. When your wife comes back, she would bring some little gifts.

Advice to young people on tackling stigma and discrimination

The best thing any Nigerian can do is to spread peace and love and Justice to any human being; it doesn't matter whatever his situation. These three things are very important. You know, these things we are saying now, some of the leprosy patients had to commit suicide. They will kill somebody. We had a prison there, we have our own high court there. Because when they hear about how people treated their wives or their children, they get violent and would try to corner. Leprosy has gone, but we have HIV, which I think is another difficult thing.

Well, it's a question of propaganda and education and information (In response to young medical students' reluctance/refusal to work in a leprosy center). When they see people like you (the Doctor interviewing him), handsome people move about, see your children doing well, then they have to be convinced. Then people are hiding these things. Because for instance now, if they don't treat their leprosy and they have foot drop, that's a very sad sign. Whereas, if you have knowledge of leprosy, you start treating it on time before it is late, according to Dr. Davey, he used to say, “early treatment in leprosy, no deformity”. In those days, we used to go from school to school, lecturing. After lecture, some teachers would come and call you.

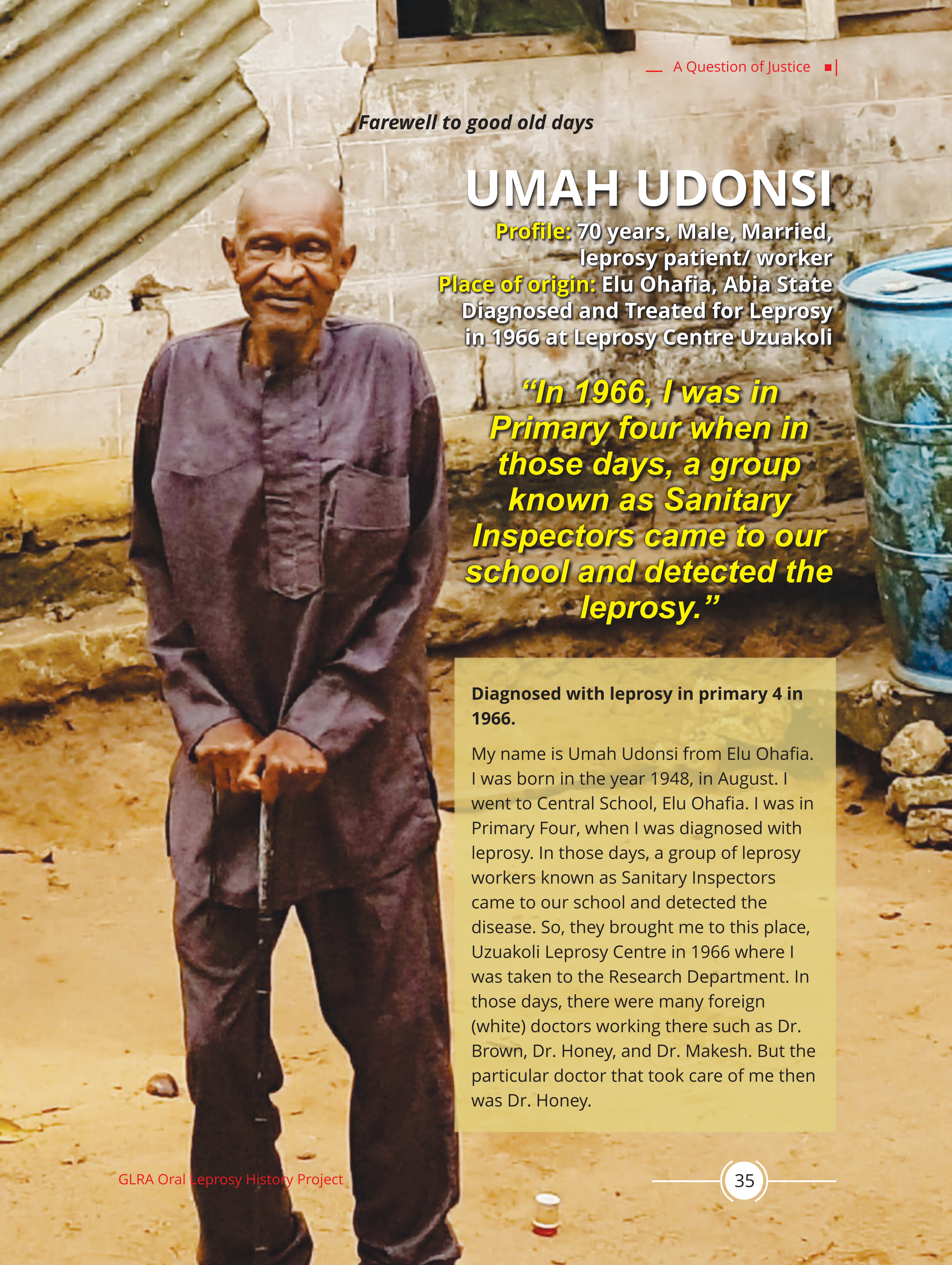
After the war, now, the government said, “okay. Isaac, go to Abakaliki, go and help Mile 4”. We had a very active woman there. One Sharath. When we first came, she said, “Okay, you are in Biafra? Because you have lost your job, you'd go and find another job”. We just left her. We came and stayed at Abakaliki town, doing our work. One day, Hausa people who had ex-leprosy patients, came and occupied houses built by Igbo people, then they started looking for us. So, we went and told her. She came along with us. We came and screened the people and then we released the house to them; that type of thing. As we worked, she realized that we were helpful to her. It was through that service that we were able to get those boys who worked for her into the government service and relived them of the problem. The same thing happened at us at Uburu, you know, Uburu has a leprosy settlement in 1926 by Dr. Hancock Hitchcock. It's only the type of work you're doing now that will help and explain it to people.

All these other diseases are diseases like leprosy, and leprosy is being treated, when some of these other diseases cannot be treated. Cancer is killing people here and there. Even HIV, although they have something now they say if you take it you can live normal life. So, leprosy is being treated today. And so, a leper can be treated and he'll become normal. You are talking of young people who don't understand what it's all about. If you talk to them... “do you know that M.I. Okpara had leprosy, but he became a governor.” Prof Achinivu). Yes, he lost one year in medical school. Still finished... oh, no. Dr. Davey, God will bless that man. While Okpara was having his leprosy treated in one year... There were medical people who were giving him lessons he could have got at Yaba. The place was... I don't know, that it is a wonderful place.

There's another problem. Many people whom we treated, like he mentioned Dr. Okpara, their children wouldn't like you to mention it. As he's struggling to make sure that everything is said about Harcourt White, Abonema people would not like it. I'm not talking about the family; I don't know about the family. But Abonema people, where he comes from, and that was how we lost Itu people, Itu people had already been known as “Itu Leper Colony, go and be treated”. Immediately after the war, they said that nobody should return. Then people came and took the land and the land didn't belong to Itu. You see that type of thing. People we helped wouldn't like you to mention that once you treated them. *Nna anyi* Chukwu will tell you more.

Discharge Services at the Colony helped a great deal to make people now receive their own who suffered from leprosy. Because at initial time, they never worried about them. But when 1949, Harcourt was discharged, that was the biggest discharge service. It was very big. People came from all over the world. And their people came. But Harcourt had this problem of if he went back to his home, his people might not welcome him. And so, he decided to stay Uzuakoli where he was accepted, very well-known doing his musical works. Yes. Discharge Services helped a great deal, because then people came to welcome their own, take them home to reintegrate them (Prof Achinivu). You know, if a man had to share a piece of land with his family. If they didn't like him, they would like him dead in the colony, so that they themselves would share the heritage. Those are the things. This is the same corruption in Nigeria; people not thinking about their relations.

I have a man who lives at Ochi in Owerri. But he's so much interested about what is happening. Social injustice in Nigeria wounds him. So, he writes about Uzuakoli Colony and then I'm helping him too to write.



Farewell to good old days

UMAH UDONSI

Profile: 70 years, Male, Married,
leprosy patient/ worker
Place of origin: Elu Ohafia, Abia State
Diagnosed and Treated for Leprosy
in 1966 at Leprosy Centre Uzuakoli

> ***"In 1966, I was in Primary four when in those days, a group known as Sanitary Inspectors came to our school and detected the leprosy."***

Diagnosed with leprosy in primary 4 in 1966.

My name is Umah Udonsi from Elu Ohafia. I was born in the year 1948, in August. I went to Central School, Elu Ohafia. I was in Primary Four, when I was diagnosed with leprosy. In those days, a group of leprosy workers known as Sanitary Inspectors came to our school and detected the disease. So, they brought me to this place, Uzuakoli Leprosy Centre in 1966 where I was taken to the Research Department. In those days, there were many foreign (white) doctors working there such as Dr. Brown, Dr. Honey, and Dr. Makesh. But the particular doctor that took care of me then was Dr. Honey.

I was admitted for treatment. Thereafter, they took me to Welfare Unit and made proper arrangements for me to continue my primary education in the Leprosy Centre since I was very young. So, they enrolled me into school and I continued from primary four. I stayed there till I finished my primary six. My uncle and brothers also came around to visit me during the period of my admission at the leprosy centre.

Leprosy in the face of civil war

Before the war, I was still young and I used to work around here. Whenever, they wanted someone to do any job or run errand, they called me to help. I was also invited to participate in football activities as well as singing in the choir. We usually went for physiotherapy and when we are done with the physio, we dismissed and went to the field to play football. After the football, we normally went for choir rehearsals. We went for Harcourt Whyte's choir. That was our routine till the civil war came. I was still young and smart then.

The soldiers were shooting from that end and the bullets raining down over here. So, we started running. But my colleagues and I were advised to exercise caution and perhaps wait for a while to know whether the war will advance to where we stayed and it did. Eventually, we had to escape on foot along with by Dr. Nkana and we trekked from here to Ohafia. There was a place called Ukele where we stayed and continued receiving our medications in the clinic until the war took over the area. And so, we had to move again on foot to a different place that we camped for more than two to three months until the intensity of the war reduced. Even at the place we camped, they were still giving us our leprosy medication. We continued to move this way until we heard that the war has come to an end. So, we parked our things and began to find our way back to Uzuakoli leprosy Centre in 1970.

Career as a leprosy worker

When we came back in 1970, they gave me confidential and I went home. So, I went home but the sickness started again and I came back here again in 1971. While I was here I told them that I was jobless. They found that I was strong and able bodied. So, the Ministry employed me to cut firewood for them and I also helped them in the kitchen for which they paid me. I worked there for more than 8 years. In 1978, the Ministry employed us, that is, me and some of my colleagues and so we worked there till they had a new board called HMB and said that people that want to go over to HMB should go and people who still want to be under the ministry should remain. I switched to HMB and I was working there. We came here every Tuesday to take medications.

So, that was how my work continued till I saved money and wanted to get married and so, I went to Okigwe and married the woman I am with now. We got married in 1979. My wife and I stayed together and were blessed with four children and we enrolled them into school while I was still working with the HMB. I retired in 2008.

Community participation as leprosy patient.

I used to travel freely to the community to visit my people. There was what we normally do in our village to qualify to be a member of our village age-grade. So, I performed the ceremony and became a certified member in the age-grade of my community. So, my kinsmen and community members never stayed away from me. We had always related well. My wife usually goes to village just as I do. We usually go together.

Unpleasant memories of leprosy work at Uzuakoli

A time came when we returned to Uzuakoli Leprosy Centre from the civil war we used to play football. Everything was in abundance and there was nothing lacking here at that time. The Red Cross regularly brought food and other materials to us which we shared among ourselves. Occasionally, when these items arrive, Dr. Nkana will just come and take them for himself. He usually collect them and didn't allow us to take what they brought for us. Unfortunately for him, a day came when the relief items arrived in his absence. We did not know where he travelled to. We hurriedly collected the items and shared everything among ourselves before he came back.

When he came back and realized this, he was angry and came to us in the leprosy camp to ask what happened to the materials that were brought. Meanwhile, the items included blankets which some of us had already used to sew clothes. Therefore, he decided that everyone must exit the leprosy settlement for the misconduct. He began to issue confidential to us. He even used the opportunity to carry many people back to their homes. Some of us left the settlement but he left a few of us. The conflict continued until one day we all decided that we were going to march to his office to protest through demonstration. We all got ready and moved.

On arrival, there was someone we met that day in his office called Apu Onyema. The man turned and signaled loudly with his eyes in support of our protest and motioned us to go ahead. But in pretense, he proclaimed (to the hearing of the doctor) that we should not protest. So, we went ahead with our demonstration. The doctor entered his car and drove off but we still followed him to his house to complete our demonstration. Not long after this, Dr. Nkana fell sick and he was advised by the native doctors he visited to go and apologize to us but he refused. He said he could never apologize to the people he was looking after. Later on, his sickness continued and he died. So, from then, I've stayed here till my retirement.

Final words

We are very grateful to German Leprosy and TB Relief Association for all their immense help especially with free medications. They have tried so much for us. We thank them so much especially Dr Chukwu. He tried so much when he was here at Uzuakoli. We pray that it shall be well with him and his family. It pained us and we felt so bad when he left the hospital. But we are happy that he still remembers us and did not forgot us at Uzuakoli Leprosy Centre.


AKWA IBOM STADIUM

Stories from AKWA IBOM STATE

QIC Leprosy Hospital, Ekpene Obom

Defeating Prejudice: Serving the underserved

CHARITY INYANG ETUK

Profile: Retired Leprosy Control Programme Supervisor, AKS.
Place of origin: Uyo, Akwa Ibom State
Period of Leprosy work: 1981 at Qua-Ibo Leprosy Hospital, Ekpene Obom, Akwa-ibom State

"In one of the meetings, when I introduced myself as a worker in the leprosy hospital, everybody shouted and began asking me, what I was doing here, that since I work in the leprosy hospital, it means that I am a leper also."

"Even my senior sister that was a nurse, was afraid of me. She was scared of the word- Leprosy and she does not feel at home with me."

"I noticed that those people living there, their friends and relations abandoned them there."

I am Charity Etuk, from Uyo.

I was first appointed, a leprosy staff in Ekpene Obom on 1st January, 1981. That is when I started work there as a Lab Assistant- I was working in the lab, then deployed to the Leprosy Control Unit. While working in the lab, we did leprosy smears- which I was taught how to do, and I did it very well. Because of how I did mine, I was asked to follow the medical doctor in charge- Dr. Esther Mary Davis, to the field to be taking smears from leprosy patients in the clinic.

My experience that time was that, many of us that were working in the leprosy hospital were avoided by the people. They thought that we would contract the disease, and because of that, they would not like to come close to us, so as not to contract the disease. Even in our homes, even my senior sister that was a nurse, was afraid of me. She was scared of the word- Leprosy and she does not feel at home with me, but as time goes on, I was able to educate her, by telling her that the disease is not contagious.

My experience in the field, concerning leprosy as a staff there- when we are working in the field, it is observed that most of our patients were stigmatized, they were given a separate place to live in the village. Like the place in Ukanafun Local Government, there was a place, created for them- it was a leprosy clinic, but a kind of colony- anyone suffering from leprosy was living there. Many of them were staying there, they have their farms, families, children. So whenever, we are visiting there, we went with Dr. Sr. Esther Davis. I usually accompanied her as a leprosy staff and a Lab. Assistant to take leprosy smears in the field. I noticed that those people living there, their friends and relations abandoned them there.

So, they did not have anything- the place was about 5km away from the community. So, they have their own streams, their markets and everything they needed was there. So, it was a pathetic situation. We were trying to educate people that the disease is not contagious. We started moving those patients to Ekpene Obom; when they come, Dr. Davis will admit them and their stay will be short, and then they go back to their various communities.

Before then, I was appointed as a rehabilitation officer. Whenever they are being discharged, I will take them back to their communities, and not to the colony. So, when we arrive at their various communities, I will hand them over to their families, telling the family members, that the disease is not contagious; that even me, that I sit together with them in the vehicle, that leprosy has nothing to do with anybody as they are completely cured. Most of the times, we usually give them, discharge certificate to go home with and show it to the community leader, so that they would be allowed to stay in their own community.

Yes, after giving them the discharge certificate, we took them home and gave them vocational training or loan to start up a new life, which they would accept and then we made regular visits to see how they were doing. With this technique, the communities started believing us and then the stigmatization was reduced.

My intention on working in the leprosy hospital was to stay briefly, then go back to school. But when I visited there, I met Dr. Davis, whom I have told you about; Dr. Davis had interest in me, and the only thing she did to me was to motivate me by taking me to meetings (especially the Control Officers Meetings). Whenever she is going to the meetings, she always took me along with her as her house maid; I would not attend the meeting but I will be there with her, to assist her in picking up things, from her handbag. I think it was one of the ways that she used in asking me to stay. So, when I got attached to her, the interest of leaving and going back to school was not there, so that was how I continued there. I worked there, and she was able to send me to Ethiopia, I was there for 4 months. On coming back, the interest of reading was not there; so, I continued. Then, secondly, I saw how she makes friends with the patients; she will be giving out gifts to these patients, visiting them at her own spare time, she will ask me if I can spare some days in order to visit her friends. So that was how the interest kept growing in me, then I could not think of leaving the job any longer.

Meanwhile, my sister, that was afraid of me; something happened one day - her husband fell sick, so she did not have anywhere to go to. So, she came and met me and I said that she should not be scared, I know what is happening -can you give him some tablets? Because, my sister told me that he is having a 'running stomach'. I also told her that we need to consult some lab tests before any further treatment, so she was very shocked and exclaimed - ooh, so this people are actually teaching my sister an important thing in life! Since then, she started coming closer to me, then I explained to her that leprosy is never a disease that can be transferred to somebody; that it is curable.

For my family, to be frank, my husband just saw me in leprosy hospital; that was where we met. I did not even know; I saw someone coming to the lab with a small girl, and he asked me whether I can help him out, that he needs a lab result. I thought it is his daughter, so I quickly made the result for him, and he took it to the doctor. I was surprised, that the next day, he came back still to the lab, and he told me that he is very happy; that day that I treated him well, and I said thank you. That was how the relationship started, until we got married.

When I came in to the hospital newly, if a lepromatous case comes to the hospital, we would not allow that patient to go home until after 6 weeks, at least to get the infection reduced.

So as time went on, in 1985-drug trial came, and told us that after giving them the drugs for six weeks, they will be free of the disease, and they can be discharged from the hospital. So, we treated them for 6 weeks, they will go home and continue with Dapsone for at least 2 weeks, that was when the stigma started coming down that after six weeks, of intensive treatment, there will not be active symptom of leprosy- you can share food with the patient, you can do whatever you like with them.

One came from Ini Local Government- though he did not disclose to us, that he was driven out of the community because of leprosy. But after discharge, the doctor asked me to take the patient home and we went as a team- the rehabilitation officer, the leprosy control officer, the driver (that is how we usually move). Arriving the village, the man took us to his family compound and everybody became furious, saying that we should take him back, that they do not want to see him in their community- that, he is a leper. I did not know what to do, so I asked them to show me the Chief's house and they directed me to his compound.

On seeing me, he asked me where am I coming from? “I hope that you are not coming from the leprosy hospital?”. I told him that I am just a visitor, and he gave us a sit, and we sat down as he invited other village council members to come and listen to what I have for them. So, as they came in, the chief offered us, a drink- as usually done in the village setting (one glass to everybody). So as the chief, he poured in the drink, wash the glass and then drank from it before offering it to me. So, I took some drink, gave it to my clients, he took some and I collected it back from him, finished it and then, dropped the glass on the table. All of them, looked amazed and kept wondering why I share things with the leprosy patients- is the disease not contagious? or maybe she is a leper too. So, when we finished that, they were rushing to get the glass and drink. So, at the end, they started asking questions; “Madam, does it mean that this man is no more suffering from leprosy?” I said “yes, here is a letter from the hospital that he is free, that is he is no more suffering from the disease”. They told me that, they have been hearing the stories that, whosoever contracts leprosy will be receiving treatment for life, I told them yes, but it is no longer obtainable now, we have a treatment that, after one year, the patient is free; even if you see a leprosy patient today, you can eat, drink, share with him because he is not contagious. So, that was how the man, was accepted in the community and since then, he has not visited the hospital.

In the hospital, no problem because whoever comes in, believes to receive treatment from us. But in the community, there was a little problem; I remembered, my husband was appointed a chairman of internal revenue and we had Association of Permanent Secretaries' Wives. In one of the meetings, I was there, when I introduced myself as a worker in the leprosy hospital, everybody shouted and began asking me, what I was doing here, that since I work in the leprosy hospital, it means that I am a leper also. I was so embarrassed, and I just managed to be there till the end of the meeting. The subsequent meetings, I ignored them, when I get home, I told my husband and he told me that I should keep attending the meetings.

Discrimination defeated!

CYRIL ITON NNOKU

Profile: 65 years, Male, Married

Place of origin: Ikpe Ikot Otun, Ikpe Annang, Essien Udim, Akwa Ibom State. Diagnosed and Treated for Leprosy in 1960 at the Leprosy Centre, Uzuakoli

“When the sickness started, they took me and my mum, and built a separate house for us to stay until one day . . .”

“I believe I got leprosy through my mother's womb”!

“I got leprosy through my mother's womb”!

My name is Cyril Iton Nnoku, from Ikpe Ikot Otun, Ikpe Annang, Essien Udim Local Government Area of Akwa Ibom State of Nigeria.

I am not very sure when this disease started because (I believe) this disease affected me through my mother's womb. Yes, from my mother's womb. I think so because my mother suffered from leprosy (according to my grandmother's story). She told me that I didn't suck my mother's breast because of the sickness.

When I was still a small kid, my mother nursed me as much as she could. After my mother died, my grandmother took me to Ikpe Ikot Otun, where she had lived with my mum.

Discrimination by community at early years of suffering leprosy

When the sickness started, they took me and my mum, and built a separate house for us. I was there until, one leprosy staff (I can't remember his name), came to the village council and ask the villagers whether they have someone, who is sick. My mother reported me to them. So, one day, a pickup vehicle, with the leprosy inspector, stopped in front of our house and picked me up with my mother - straight to Uzuakoli Leprosy Settlement. By then, I was about 10 years old. It was there that we remained, but unfortunately, my mother died in 1960, so I was left with other patients. The missionaries, who were working there under the Methodist church; took good care of me and I received early education at Methodist Settlement School (then, it was at Umuahia province) but now in Abia State. I completed my primary education in 1965. After that I was sent by the white woman in charge of the school, to learn some hand crafts - carpet making.

The “carpet making” craft with wood was disrupted because of the Nigerian-Biafra civil war. But I thank God, that I survived the civil war, I joined others in the struggle for survival during the war. In the early 70's, after the war, I decided to go back to my base. My father married so many wives; my mother was the sixth among them and I was the only child of my mother, before my father died. I was still very young when my father died, it was only my relations who loved me that looked after me.

So, my mum and I went to my grandmother's place at Ikpe Ikot Otun. Initially, when I came back after the civil war, my relations took me as a prodigal son but I lived with them till now. We are 10 males in the family, but 8 are dead and we are two remaining.

I don't really keep records of dates, but all I know is that I finished my primary school in 1965, and I came back from the war in January 1970. Well, my family members received me freely especially, Paul Iton (a pastor in St. Peter's Apostolic Church) and the second son (a preacher at Methodist Church), who didn't allow me to change my faith till today.

In the village here, I participate with others. There is no form of discrimination anymore. It was only this deformity on my hands that refrained me from doing what others do.

Marriage and family life

Cyril Nnoku's wife

Well, after the civil war, I remained here and started making brooms in order to feed myself. In the year 2001, I had an ulcer on my leg and I was referred to Ekpene Obom Leprosy Hospital. I stayed there, and my leg was amputated in 2002. By the grace of God, I stayed there in the bed for 1 year and 9 months, but through my conversation with others there, I discovered a beautiful lady and she agreed to stay marry me. (laughs). Then I told her my address and she is also from Akwa-Ibom State; a native of Obot Akara Local Government. She lives with me happily up till today. As for my family, I served them as a secretary for so many years, then for the village, I served them as a sanitation officer for so many years. There was never any form of discrimination.

Experience during the civil war – any leprosy discrimination?

When I was in Uzuakoli when I heard it over the news, that there is going to be a war. On the fateful day, the war broke out. So, I had to run with others to so many places for about 2-3 years before the war ended. The experience was so bitter, we slept at any available spot and we were scared at the sound of every gun shot. I ran across 15 villages before the war ended. It was never an easy experience - no food to eat, children suffered from kwashiorkor. It was the grace of God that kept us alive throughout. Even when I came back, I saw a lot of dead bodies littered everywhere - both soldiers and civilians were killed. From my own experience, there was no discrimination of any form against persons with leprosy. The only thing on the mind of everyone then was how to survive till the next day.

Most pleasant experience in life amidst deformities

As I had already said earlier, that this is the wish of God. Each day, I thank God for the gift of life till now, because, despite the challenges, there is nothing more than being alive. Again, the discovery of this beautiful lady in Ekpene Obom (laughs), was memorable. My mother was the brain behind everything. Unfortunately, I lost three of my children, I am now left with 4 females.

Again, the health workers were caring. I thank God for them, because they didn't allow me to suffer. I do visit Ekpenebom often. They took good care of me and am even happy seeing some of them once more; even though, they have retired. Both the doctors and the staff are very caring and they don't discriminate against patients. They look after people with conditions even worse than mine.

Future plans

If I see a newly leprosy patient, I will advise the person to report him/herself to the hospital for treatment. As for me personally, I don't have an occupation, but thank God for people like you who care for us. My only income is this petty farm - very small scale. At times, I purchase lands or rent them for planting cassava and other crops. At the moment, my leg did not allow me to work all day. I wish to solicit for assistance and support. Since am now in my old age, I wish that the government will assist me financially so that I can settle down with my family and then, cater for my family and children.