

MY LIFE AND BURULI ULCER

(A true life story)

Mr Emmanuel Agumah

Date of birth: June 25, 1981

Hometown: Bugri, Northern region

Grew up at: Goaso, Brong-Ahafo region

Tel: +233 28 516 5424

E-mail: emmanuelagumah@yahoo.co.uk

Dear Distinguished Participants,

First of all, I would like to thank you all for the opportunity to participate in this meeting and to present a summary of my encounter with Buruli ulcer. I sincerely thank WHO for making it possible for me to be here.

Let me start with a little bit of my background:

My father, a peasant farmer, had two wives (this is not an uncommon practice in northern Ghana). Together with my siblings, we were twelve living in a small house. I did enjoy and still remember those days when I was growing up. I am the oldest child. The entire family – men, women, boys, girls and even the very little ones – were always on the farm assisting our father. We the children most often enjoyed catching crabs and sometimes fishing in the ponds and swamps around and on the way to the farm. That was a main means of protein for our evening meals.

My father painstakingly enrolled me in the local primary school when I was six years old. As I passed through school, I however found myself sometimes mending shoes, weaving cane baskets and running errands in order to make some income to supplement the family budget and to get some pocket money... I excelled in school and this made my family very happy. Being the only family member to receive a formal education, I was treated sometimes like a “king” and brought honour to my poor family. But life was not easy. From time to time, my parents had to sacrifice basic needs or even sell valuable items in order to meet my educational needs.

In 1998, I was admitted to the Acherensua Secondary School (a high school) in the Brong Ahafo region to study business. It was a new world all together for me. I excelled academically in high school too and I was always among the best 10 students. During vacation I usually returned to my village to continue with my shoe making, cane basket weaving, etc. so I could raise some money for my school fees as well as to support my family. That I did at the expense of my education because I could not enroll in vacation classes. But looking back, I had no option but to do some vacation work as a necessity. That cycle of vacation jobs continued until my final year in high school.

Now let me come to my encounter with Buruli ulcer:

In the year 2000, whilst I was getting ready to write my final high school exams, I was unfortunately struck by a strange illness. We did not know what the disease was. As a result, I missed the opportunity to write my final high school examination. I think I had the disease at Acherensua where I attended secondary school. I did not know whether someone had the disease at that time. But today, I know a number of people who have had the disease in that community.

This flesh eating disease started on September 2000. I remember having seen a small boil-like lesion on my right elbow joint. This 'boil' was painless and within a few days, without any warning my whole right arm began to swell. My friends drew my attention but it was so painless that I did not pay any particular attention. I was convinced that it would soon go away. I was more interested in getting ready for my exams.

Unfortunately, things did not go as I expected. Within another few days, I realized that my whole right arm had swollen, to the extent that I could not stand upright for a few minutes. The whole of my arm and part of my trunk were very heavy yet painless. I was later to learn that that was the **oedematous** form of the disease. Most of my student friends were scared to see a swollen arm and trunk, yet without any pain. Some of the friends related it to witchcraft, juju (black magic), a curse, etc. As to the cause, I still did not know but I suspected I had been bitten by an insect because I could not remember anything that could have caused the disease. With all the remarks of witchcraft, curse, etc and still not feeling

the pain, I also became very scared. I often asked myself, "What is happening to me? Lord, help me." I prayed and prayed.

When my parents heard the news, they were very upset. My dad quickly came to pick me from school to seek medical attention. Initially, I was taken to three main hospitals viz., St. Elizabeth Hospital, Hwidiem; Goaso Government Hospital and Sunyani Regional Hospital. I was given all sorts of drugs but there was no improvement. Indeed, things even got worse despite taking all the prescribed drugs. My fears were heightened further as suspicion of a curse or bewitching was implicated for my condition. My father therefore took me to consult oracles, fetishes and shrines. Several goats, sheep, chicken and cash were lavished on these shrines but my condition did not improve. In fact, my situation was getting worse every day. People who saw me will look at me again and again. Children ran away when they saw me. Even my own brothers and sisters were reluctant to come near me. I was more or less isolated from society!

After about 9 weeks of hopping from one shrine to the other, a family friend advised my father to take me to the St. Martin's Catholic Hospital at Agroyesum in the Amansie West District of Ashanti Region, about 750 kilometers from my village. The family friend told my parents that the St. Martin's hospital was (and is still) well known for treating chronic ulcers. With desperation setting in, my father reluctantly agreed to send me to Agroyesum. At the hospital, we (my father and I) were told I would need admission and that I would be hospitalized for at least 3 months. We had to return home in order to prepare for the hospital admission the following week. My father though desperate was much afraid of the cost implications involved and was especially frightened by the mention of surgery. Instead of my father taking me back to the hospital, he rather took me to my hometown in the north where he thought he could fight my disease spiritually. In my hometown it was also revealed that we have wronged the gods of the land so the necessary sacrifices were made with the hope that I was going to be well. Alas! The situation was getting worse as the whole of my chest, down to my scrotum had swollen. The size of the swollen scrotum was almost equivalent to my head. "What a disease! What a tragedy!!" I always told myself.

For two weeks I could not sleep. Severe pain has set in. The swollen parts had begun to rupture (ulcerate) with the release of some fluid. I smelled terribly bad!

Back at home I was given a separate room. My arm begun smelling due to razor blade marks made by the traditional healers, and the other part of the arm started rotting. The stench was horrible. I was alive but basically rotten.

On 11th October, 2000, I told my father to take me back to the St. Martins Hospital, Agroyesum because, I would rather prefer to die in a hospital than a fetish priest's house. So that day we traveled all the way from my hometown in the north through Kumasi to Agroyesum. It was a momentous 750-km journey lasting two days. No vehicle was ready to allow me in. Other passengers got off as I entered the vehicle and none joined after I had entered. My daddy could not also afford a chattered vehicle nor an ambulance. What a nightmare! After much struggle and humiliation, we were able to get a vehicle to travel with. We arrived at Agroyesum the following day very weak and exhausted.

I wept bitterly upon my arrival at the hospital when all expressions on everyone's face doubted my survival within the next few days; that only by divine intervention that I could be saved. The doctor could not believe that we had delayed so long in returning to the hospital as promised. I lost all hope. Nonetheless, I was admitted and given all the necessary attention. I thought I received some TB drugs and other antibiotics for a long time. In fact, I thought within myself "my days on earth were numbered" and seeing how I was suffering, I preferred death to life. Life at the hospital was not easy. We arrived at the hospital completely broke. All the money my dad had on him was spent on transport from the north to Agroyesum. How were we going to survive when the hospital operates on "cash and carry" and patients had to feed themselves? Luckily people came to our aid – health staff, Catholic Nuns, and even some patients. But I gathered some courage and was consoled by the fact that other patients especially, children who had extensive ulcers were in severe pain and others had had their arms or legs amputated due to this horrible disease.

The first operation was performed on me within the first four days upon admission. I received one pint of blood. This operation was followed by another major operation in the next two weeks, involving excision of the whole of my right arm and chest leaving a big wound.

In fact, the second operation nearly paralyzed me. It made me very weak. At that point, I became hopeless; even the medical team had little hope for me. All my daily activities of living was performed on my hospital bed with the help of the nurses and my parents. For one and a half years, I was bedridden at the hospital. During that period, the financial situation of my family worsened. My mother who had then joined me at the hospital had to leave me alone to weed people's farm and sometimes beg from sympathetic people before I could eat.

While in that state, I had no appetite therefore, I could not eat and thus grew very lean. I became anemic and weak. I was then transferred from the main males' ward to isolated ward meant for TB patients. As a matter of fact, there was no difference between an end stage AIDS patient and myself.

One day, I asked Dr. Etuaful, the doctor in charge of my care and who is seated here today, how the large wound was going to heal. He said, "We have to take a skin from your thighs to cover the whole wound since that was the only method". Meanwhile, I was too slim for that purpose. After a year and ten months, I was taken to the theatre again for my recovery operation after receiving two pints of blood before the surgery and additional two inside the operation room. During the 3-hour operation skin was taken from both thighs to cover the whole wound.

One month after that operation, I had recovered a little bit but had to learn how to walk again like a little child and one could imagine how I was tottering. I had lost weight and my legs were so weak after many months in bed.

I became hopeful after my third operation so I decided to learn how to use my left hand to write so that one day, I could return to school.

A series of minor operations were also carried on me in addition to the first three major ones alongside regular "appropriate technology" physiotherapy. I was finally discharged from the hospital on 3rd March 2003, in relatively good condition. My right upper limb was swollen although the healing was complete. I was assured that the swelling would reduce over time and that I should regularly apply vaseline over the healed wound so that it does not become dry. I was asked to come for regular reviews.

After I was discharged from the hospital, my arrival at my village should have been joyous with celebrations but it rather turned into sorrow after discovering that my dad had died whilst I was in the hospital. In fact I wept a lot. I never knew he even died a year after my admission to the hospital and that the hospital authorities and my mum decided to hide it from me.

I was not only sad because my father had died, but how to continue my education since I could not do routine activities I used to do to raise some money: I was handicapped.

I thought life was still not treating me fairly. Churches, individuals and other benevolent persons were approached to help me in my education but yielded nothing.

Finally, the National Buruli Ulcer Control Programme-Ghana upon my interaction with Dr. Asiedu and Dr. Etuaful came to my rescue and supported me to complete my two year secondary/high school. Thanks to the Matuoka Fund, Japan, I was able to finish my high school. I also got some support from individuals

As a result of my determination to obtain higher education, I am happy to say that I am a second year student at Kumasi Polytechnic in Ghana where I am enrolled in a Higher National Diploma (first degree) with focus on accounting. I hope to finish in about 2 years' time. Again, I thank the Matuoka Fund in Japan for taking care of my educational expenses. I also thank individuals who are helping me in various ways. I hope to be a chartered accountant one day and begin to contribute to caring for BU victims.

Dear distinguished participants at this 10th anniversary meeting of the Global BU Initiative, I am honoured to be here today with you. I have never dreamt of flying let alone to come to a beautiful place like this. My joy started when I received my invitation letter, my ticket and more especially the day I got the Swiss visa in my passport. I asked myself whether I had been unfortunate or lucky. I still can't answer this question. But I know there are others who have suffered like me but have not been fortunate like me to have an education.

To conclude, ladies and gentlemen, I am happy to be alive today and to be part of this important meeting. Although I cannot bend my right elbow nor fully raise my shoulder,

these are minor problems for me compared to the suffering I have gone through. My story is not for myself. My story is for all those who have suffered, are suffering and will suffer as a result of Buruli ulcer. The neglect, the shame, the pain and humiliation that come with the disease can be very big. But was it or is it our fault to contract the disease or could we have done something better to avoid getting the disease? I am sure the distinguished audience gathered here today has no definite answer to these questions but, I know a lot of work has been done within the past 10 years. It is my hope that one day (not too long), you will have the right answers.

Through my story, let us unite in the common front to remove pain, shame, neglect and bring hope and smile to people like me.

Thank you all for your attention and God Bless you.

Acknowledgment

The Matuoka Fund, Japan

Dr. Samuel Etuaful

Dr. Kingsley Asiedu

Dr. Edwin Ampadu

Mrs. Ellen A.S. Whitney

Mr. Joseph Adomako

Mrs. Hiroe Soyagime

Dr. Gerald Mumma

Mr. William Opare

Mag. Branko Orasche

Staff of St. Martin's Hospital at Agroyesum and

WHO

My life at a glance

| Date | What happened |
|---|---|
| June 25, 1981 | Date of birth |
| 1986 | Started primary school |
| 1993 | Completed primary school |
| 1994 | Started junior high school |
| 1997 | Completed junior high school |
| 1998 | Started senior high school |
| September 2000 | Contracted Buruli ulcer |
| October 2000 | Admitted to St Martin's Hospital, Agroyesum |
| March 3 rd 2003 | Discharged from St. Martin's Hospital |
| November 1 st 2003 | Re-entered into Acherensua Sec. Sch for two yrs |
| July 2005 | Completed senior high school |
| November 2006 | Entered Kumasi Polytechnic for HND (first degree-Accounting). |
| March 2008 | Second year, second semester at Kumasi Polytechnic |
| March 30 th –April 4 th | Geneva, Switzerland for a WHO meeting on BU |