

Dr. Fred Okuku, Cancer Care in Uganda March 30, 2008

Welcome to Yale Cancer Center Answers with Drs. Ed Chu and Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center, and Dr. Miller is a Medical Oncologist specializing in pain and palliative care. He also serves as the Director of the Connecticut Challenge Survivorship Clinic. If you would like to join the discussion, you can contact the doctors directly, at canceranswers@yale.edu or the phone number is 1-888-234-4YCC. This evening, Dr. Miller speaks with Dr. Fred Okuku. Dr. Okuku is a Fellow in Oncology and a Medical Resident at Makerere University in Uganda.

Miller Fred, I want to thank you so much for joining us tonight.

Okuku Thank you Ken.

Miller Tell us about yourself, where did you grow up?

Okuku I grew up in the eastern part of Uganda, which is in East Africa. I know many Americans have not been to Africa so it is good to know that Uganda is a country in eastern Africa. I currently live in Kampala, the main city of Uganda, and this is where I have been living most of my time.

Miller Let me ask you about Kampala. I had the pleasure of being there last summer, but for the audience, is it the size of New Haven, Hartford or is it a bigger city?

Okuku Kampala is a much smaller city. Sorry to say it has many potholes and many people moving on the streets, but with many smiles as well.

Miller Very well said. I found that the people were incredibly friendly and lovely people. When Americans think of Uganda, unfortunately, we tend to think of Idi Amin, and the movie The Last King of Scotland, but is your country at peace now?

Okuku Uganda has had many challenges. It was Idi Amin, then it was HIV, and recently, there has been war going on in the north. I think many people have watched the movie War Dance which basically depicts what has been going on, but there is relative peace in Uganda, and you can actually access all parts of the country without having much trouble. You will not have any problems in Kampala. It is pretty much safe. You can go out late, and it is a good city.

Miller I found it to be that way also, very safe, and again, just wonderful people. Fred, let us talk a little bit more before we start talking about cancer in Uganda. Your country has done an amazing job with HIV. Could you share with us what the incidence was, what was done and what the incidence of HIV is now?

Okuku About 10 years ago, the incidence of HIV in Uganda was 30%, and then there was a 2:56 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-30-08.mp3 this aggressive program by the government. The government was open about this HIV problem, and we got lots of help from friends abroad. There was this strategy of ABC, which has been commended by Uganda by all the other international communities.

Miller What does ABC mean?

Okuku Abstinence, Being faithful, and using a Condom.

Miller Okay.

Okuku And this is the ABC strategy.

Miller So, A is abstinence, B is to be faithful and C is to use condoms or protection.

Okuku Great.

Miller With that active, aggressive work that the government has done, where are things now with HIV?

Okuku Now we are talking about 6% to 7%, and this has been for about the last 5 to 10 years, which is a commendable job, and the government is trying to keep to that level and even bring it lower. There is a lot of strategy aimed at the young

people in the primary schools, and targeting their high-risk groups. It seems to be working quite well. Miller With the decrease in the number of people with HIV and people dying of complications of HIV, what is happening in terms of cancer? Okuku Kaposi sarcoma is the biggest killer. It is the largest cause of death among cancer patients in Uganda, among both men and women. Miller For the audience, can you tell us what Kaposi sarcoma is? Okuku There are many types of Kaposi sarcoma, but we are talking about the epidemic type that is associated with HIV. In other words, when you have HIV, your chances of developing Kaposi sarcoma are about 20,000 fold. That study was done here in the US. It is associated with the herpes HHV-8 virus, which is also known as the Kaposi sarcoma virus. Many HIV patients, and also many studies done in Uganda, show that the prevalence of the HHV-8 virus is between 70% to 100%. Miller And that is in people that have HIV.5:33into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-30-08.mp3 Okuku Exactly. Miller So, you are saying a number of people with HIV also have this virus, and then some of them go on to develop Kaposi sarcoma. What are some other common cancers; let us say in men for example? Okuku In men, we have Kaposi sarcoma and then we have cancer of the prostate and esophageal cancer. These are the three main cancers among the men. Miller And in women? Okuku In women, the most common is cervical cancer, and somehow in Uganda it is not associated with HIV. This is something that is being studied. We have cancer of the breast, which is quite common, and also Kaposi sarcoma, the epidemic type, which is quite common. Miller Both in men and women, there are a lot of people with Kaposi sarcoma. Okuku By and large, Kaposi sarcoma and Burkitt's lymphoma form the bulk of cancers in Uganda. Burkitt's lymphoma was first described in Uganda in the 1960s. Denis Burkitt was a surgeon working in East Africa and he was the first to describe this. It has been about 40 years since he did that. Every year the cancer institute in Uganda sees about 150 to 160 children with Burkitt's lymphoma, which is very different from what you see in the US. Burkitt's lymphoma is the jaw type, and even the staging is oriented towards the jaw, so it is quite different from what you see. Miller I remember when I was in Kampala, one of your buildings was primarily children with Burkitt's lymphoma with swelling of the jaw. That has been a tremendous success story; the work that was done at the cancer institute. You were not practicing 40 years ago. Okuku No. Miller But what happened? Okuku The center that you saw was actually named in respect to the work done by Denis Burkitt, and it is called the Lymphoma Treatment Center, the LTC, and more than half of the children there have Burkitt's lymphoma. I must report that we have done some remarkable work, and 86% of the kids that come with Burkitt's lymphoma go into remission. In other words, the cancer totally disappears. We have about 1% that is still a challenge, and we also lose many patients during follow-up, but we must say that we still use the old combination of COM;8:35into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-30-08.mp3 Cytosan, Oncovin, and methotrexate, which was developed 40 years ago, and we are still seeing success with the same regimen. Miller Which I have to say is amazing,

that 40 years ago those three drugs were put together and worked incredibly well, and really taught us some lessons about using combinations. Okuku Yeah, exactly. And, as you know, we are not able to do many genomics of this tumor, we cannot type, we cannot do the cytometry, we depend on the H and E stain that is the basic stain that was used many years ago. This is what our pathologists still use. We think that the 1% tumor that does not respond probably has different genomics, which probably requires different treatment like Rituxan, so this is one of the challenges we are facing. Miller Fred, talking about challenges, let us talk about adults now. If you as the physician feel that the patient needs chemotherapy, do you administer it, do you write a prescription? Okuku Our healthcare is still government based, and one of the challenges is that the government cannot keep up with the growing population, and so, we have patients supplementing and buying the drugs. When I see a patient, I write a prescription, and the patient goes to the store to buy the drug, but many of our patients cannot afford this. As a matter of fact, many of our patients come in late in the advanced stages. For example, cancer of the breast, 95% come in the advanced stage. Only 5% come in stage I and II, and this is a big challenge. Miller We have talked about how in the United States, thankfully, now it is about 85% of our patients that come in with early stage breast cancer. It is a huge challenge that you face. In your country, if people do not have the funds to buy chemotherapy, what happens? Okuku About 10 years ago we had hospice come on board, and this has been very helpful because we cannot treat many of our patients and we're basically palliating them. We have hospice in different parts of the country, and they help control the pain so that people die peacefully. Probably, where we are, is where this country was many years ago, and it is a big challenge. Miller I know there are tremendous efforts being made in your country to diagnose cancers earlier. Okuku It is great. Recently, we've had many people visiting, Ken, you visited last summer, and it is really wonderful. It is great because this van that you are bringing over, the Mammo-Van, is going to do a lot of help to us. It is expensive for us to treat cancer, patients cannot afford the treatment. We do not have12:17into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-30-08.mp3insurance like you have here. The best way is to catch the cancer early, and this van would be very helpful to go down to the villages. Many of our people use traditional medicine, and this is a challenge because they come to us very late. In Uganda, as it is in other African countries, many people first take the traditional herbs, and by the time they come to the hospital, the cancer is advanced. We are hoping that this van will help us in our screening program that we are beginning. We will go out to the villages and to the schools and encourage people to come screen for cancer and teach them about BSE, breast self-exam, and encourage them to come to the cancer institute because this is a program that is beginning, and we want to screen as many women as possible. Miller It would be fantastic to be able to find cancers earlier and hopefully with a much higher success rate. I would like to remind you, our listeners, to please send any questions that you have by e-mail to canceranswers@yale.edu. We are going to take a short break for a medical

minute. Please stay tuned to learn more about cancer care in Uganda with Dr. Fred Okuku. Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller, and I am here with Dr. Fred Okuku who is a resident in internal medicine in Kampala, Uganda. Fred, I want to ask you a little bit about medical care in the villages of Uganda. You grew up in a small village. What was the care like? Okuku The care has since improved. There has been an attempt to build health centers in every country, in every village, and this has helped improve care. The government has an emphasis on primary health care and targeting tubercular diseases such as malaria, which is the biggest killer, and TB and HIV as well. WHO Report 2007 for Uganda indicates that cancer deaths in the last year were about 10,000. Now, this could be under-reported because only 5% of our population seeks medical care. 15:40 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-30-08.mp3 Miller And the other 95% do what? Okuku The other 95% are familiar with home remedies that people use, and people tend to use the herbalists more. There are many drugs sold by herbalists in the local market, and so people tend to go for those because they are cheap and easily accessible. Miller What are some of the reasons why people would not access the government's medical care, or other medical care? Okuku I mentioned that the government has attempted. We have four levels of health care in the rural setting. We have health center one, two, three, and four. Four is where we have an ambulance and we have a doctor. At the other health center levels, we have either what we call a medical assistant or a nurse. So, people have difficulty. These health centers are still very far away from most of the population. They aren't easily accessible because of the infrastructure, and by and large, most of the population earns less than a dollar a day, and so, people are very poor. Miller If someone needs cancer care, they are diagnosed, let us say, with breast cancer, where do they go for that type of care? Okuku You cannot believe it but there is only one cancer center in the whole country, and it is amazing because this cancer center also serves neighboring countries like Rwanda. Rwanda does not have a cancer center. Burundi does not have a cancer center, and the whole of the eastern Congo doesn't either. We see patients from Burundi, from Rwanda, from eastern Congo, and from southern Sudan. There are a lot of patients coming from all these regions, and if you are 300 km away from this cancer center, you will have lots of trouble because you cannot access it easily. A lot of people do not have the money to come over because it is the only unit in the whole country. Imagine somebody who lives 500 miles away coming over to Kampala where this center is located, it is sometimes very difficult. Miller Fred, I want to ask you a little bit about your journey. I know that in an attempt to grow the opportunities for caring for patients in your country, a number of physicians are coming to the United States and other places as well, and it is wonderful having you here. What is it like to be in Connecticut, and then in the United States? Okuku These are two different worlds we are talking about here. Uganda is very different and I had to adjust too many things; the weather, the people, the food and the healthcare system. Many things are very different from what we see back home. Back home, we use

our clinical skill to make a diagnosis. When you look at a patient, you are looking for anemia, what we call pallor, you are looking for19:15into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-30-08.mp3jaundice, and you look at the chest, see the chest movements and make a diagnosis. Many times, a patient cannot afford x-ray, so you are seeing with your hands and eyes to make a diagnosis and start treatment. Here, it is a different world. In 30 minutes a patient is totally worked up, and a decision is made based on what the results are showing. It is very different. It takes two or three weeks to get results and start things moving back home. It is amazing, and is what we call internal medicine, looking at the inside of the person. What we do at home is we look at the outside and make a diagnosis of what the problem is inside the person. Here, you look at the inside and the outside and make a decision, and I think that is very amazing.

Miller I will share with you the other perspective. What I saw when I went to visit Uganda was an incredible physical exam that the doctors in Uganda do, and the careful attention to detail. We have tremendous technology, but I think the clinical skills that you have, and your colleagues have, is pretty amazing.

Okuku Yeah, we do rely on that and there is a lot of emphasis on clinical skills. I have interacted with many residents from Yale through this Yale-Makerere University Collaboration. They come over and they really appreciate the exchange program, and the bedside exposure that they get.

Miller When our residents come to Uganda and spend time there, what do they leave with in terms of new skills, and I want to ask you what some of the skills are that you hope to bring home?

Okuku Your residents, when they come over to Uganda, get exposed to a huge number of patients. Our ordinary admission in a day would be between 50 to 70 patients. We have many patients on the floor because the beds are not enough, and you have people who are very sick, you have people with advanced disease, advanced immunosuppression, HIV, you have people with huge tumors, people with huge pleural effusions, and your residents are usually amazed. How are we able to detect a pleural effusion, how do we detect consolidation, and you can find those patients here in the US because everyone goes to the doctor, but back home, it is a different story. You will find patients with amazing clinical signs. Many residents from Yale have never seen an EMF case.

Miller What is EMF?

Okuku EMF is endomyocardial fibrosis. This is a kind of infiltrative disease that infiltrates the heart and makes the heart smaller. The heart muscles are huge, and the patient becomes so thin. We describe it as a potato on a stick. They are so big up here and the feet are so small so it is like you are supporting a whole potato on a stick. This is unique to Uganda because you cannot find these cases elsewhere.

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Miller Our residents leave having learned new abilities to do a physical exam and to recognize diseases that they've never seen before. What are some of the skills that you hope to bring home?

Okuku It is amazing, the ability to look at the inside and the outside of a person, and it is the best way to take care of a patient. My clinical exam might be good, but I may need to see something inside. One thing is to try to improve our labs, and I know this will take a long

time, but how do we integrate this into our system where we lack good labs? We are not able to do chest x-rays, we do not have MRIs, we cannot do CTs on everyone. Many times we are looking at the most important investigation in a patient, and this is one of the things that I am trying to learn. Amidst everything that I have seen here, what would be most appropriate for this particular patient, so that they do not have to spend so much? Miller Here, we tend to do a lot of investigations, a lot of studies, and what I think I am hearing you say is that back home you are going to need to focus on one or two things that you can do and use them to the best of your ability. Okuku Exactly. Miller You are faced with a big challenge when you go home. You will eventually be one of the few oncologists in Uganda, which gives a sense of optimism. Okuku I am hopeful and what I am doing is to improve my skills. There are lots of resources here and lots of people trying to be helpful to my people because back home, as you know, we only have two oncologists, and one of the oncologists is retired. So, effectively, we have one oncologist for 29 to 30 million people in Uganda. It is going to be a great opportunity when I get back. My emphasis will be on health education because this is important. My country cannot afford to treat people with cancers. It is too expensive, but we can catch the cancer early, because, as you know, the earlier you present with your cancer the better the outcome. We want to have people come early with resectable tumors, and also we hope to improve our healthcare. We cannot do just the basics like ER status, or PR status of some of the breast cancer tumors, and yet tamoxifen, Arimidex, these are wonderful drugs that can be helpful to these patients. We want our pathologists to also have these skills. Currently we have been giving everyone tamoxifen, and I do not think that is fair because of the side effects. Miller You will be able to eventually bring some of the technology, some of the techniques, back to Uganda. What you are talking about in terms of earlier detection may make a world of difference. I know that you are involved with working on a research project while you are visiting, can you tell us a little bit about it? 26:58 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-30-08.mp3 Okuku I am involved in looking at DCIS. Miller What is that? Okuku Ductal carcinoma in situ, which is a very early cancer of the breast. We are looking at how it changes with treatment. We look at women who come in with DCIS, pre-chemotherapy, and then we look at them after they have had neoadjuvant therapy and see if there is any change. It is interesting to see how the DCIS tumor, this very early type of cancer, changes with treatment. It is a very exciting study. Miller One of the projects I hope that we can work on together when you return, is to perhaps look at the biology of breast cancer in women from Uganda. Okuku We see young women, younger than 40, probably because of life expectancy. It is about 47 for women and about 45 for men, and we tend to see young women. It would be interesting to see whether there is any genomics behind this and look at the biology of this tumor. It would be very interesting to compare that with the American population. Miller I have one last question. What was it like seeing snow for the first time? Okuku It was a different experience. I have been battling with the cold of course,

having many jackets on me and a lot of warm clothing. It has been very cold indeed. Miller Fred, I want to thank you for joining us on the program. Okuku Thank you. Miller Until next week, I want to wish all of you a safe and healthy week from the Yale Cancer Center. If you have questions, comments, or would like to subscribe to our podcast, go to yalecancercenter.org where you will also find transcripts of past broadcasts in written form. Next week, we will learn about the treatment of brain tumors with neurosurgeon Dr. Joseph Piepmeier.