

LETTERS FROM THE WORLD OF AIDS

Loved ones,

We've been filming here in Uganda for ten days now, and our experiences have been so rich and condensed that I want to highlight some of it, and start sorting it out. Making *A Closer Walk* is indeed a journey, and it's good to be able to chart our progress from time to time with these letters as we wend our way through the pitiful excuse for a brave new world that the global village is turning out to be.

I first want to tell you something about the Ugandans themselves. They are the sweetest, loveliest people you could ever hope to meet. At the purely personal level our interactions with everyone—our drivers Isaac and Fred, the folks here at the Sheraton Hotel, all the people in the government and in the AIDS community, the families, the people with AIDS— all the encounters and new friendships we have made have been tremendously satisfying. Ugandans are always ready with a smile or a friendly hello. They rarely complain, even though they have great reason to— this country is extremely poor and has been ravaged, as you know, by AIDS. Ugandans also have a terrific sense of humor. I've had great fun making my Ugandan friends laugh and laughing with them, at just about everything and it's been an absolute



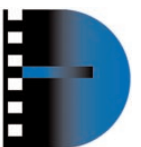
Joyce Nassuna and family

joy to be with these gentle, loving people. I can hardly wait for our return in mid-August when we will be filming an interview with Uganda's President, Yoweri Museveni.

The first experience I want to tell you about is our visit to Joyce Nassuna, a 63-year-old grandmother whose situation is, sadly, a pervasive reality of Ugandan family and social life. There are thousands of grandmothers like Joyce here in Uganda, and tens of thousands of them throughout East, West, and Southern Africa.

Joyce Nassuna is what they call here an "orphan grandmother." Joyce has lost a son and two daughters to AIDS— most of her family, in fact— and as a result is now responsible for the upbringing, education, and care of a total of ten grandchildren— all AIDS orphans. Uganda has more AIDS orphans than any other country in Africa— at least 1.5 million— and Joyce's ten grandchildren represent, to me, one of the saddest, and most alarming, consequences of the AIDS pandemic.

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Kampala
Uganda
By
Robert
Bilheimer





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Model programs are in place here in Uganda to deal with the problem of these orphans— and other AIDS-related issues— but there is no money at present to replicate



Outside Joyce Nassuna's home

these programs on any meaningful scale. So you are, in effect, looking at an entire generation of young people who will themselves become vulnerable to AIDS because they have no roots, no families, no education, no sense of their own identity— “beasts in the wilderness,” as one villager called them.

Against this backdrop of misery and despair, stand grandmothers like Joyce

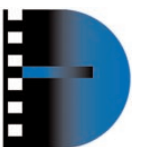
Nassuna. Joyce and thousands like her are dauntless, heroic figures, quietly saying “no” to the impending chaos of massive, nationwide AIDS orphanhood with every ounce of courage and commitment they have.

Consider, to begin with, where Joyce Nassuna lives. I have in previous letters described some of the painfully inadequate, woefully dilapidated homes we have seen— in KwaZulu Natal, in Soweto, in Haiti. But nothing prepared me for Joyce's place. It was a beautiful late afternoon when we arrived at her home in the Mukono District, some ten miles outside Kampala. To get there, we turned off the busy, truck-infested thoroughfare leading west out of Kampala towards the Kenyan border— onto a red dirt road that carved through clusters of makeshift brick and mud homes set against lush, green fields cultivated with coffee, bananas, and vegetables.

When we arrived, I at first thought that Joyce's house was the relatively large bungalow set back a bit on the right. A goat and chicken or two were bleating and scrabbling in the dusty courtyard of this home, and a few kids were kicking a soccer ball around, playing after school. The place was clearly inadequate for a family of eleven, but quite spiffy by the standards of the neighborhood. I was hopeful that this was where Joyce and her ten grandchildren lived. But as we pulled up and parked next to a big pile of red bricks under a large, shady tree, I suddenly saw to the left a tall, handsome woman— her limbs unfolding in seeming slow motion as she gathered her long, colorful dress about her— emerge from what I can only describe as a black hole.

Let me be more precise. Joyce's home once consisted of two rooms, eight feet by eight feet each. The first room no longer exists. What remains of it are two stone

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walls on the left and right, crumbling. The room that remains is vaguely protected from above by an assembly of corrugated tin sheets held down by random rocks and stones. This passes for a roof. A small, doorless entryway leads into the black space that is the remaining room of Joyce's home. In this room there is only a small bed strewn with a few sad artifacts of survival: a toothbrush, a tin cup, some faded photographs, children's clothes, I don't know what else. Peering into this room I felt

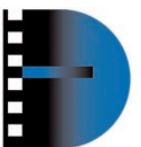


A street light in Uganda (the glass for the red light is imprinted with "AIDS").

I was invading a place of such utter deprivation that I had no business being there and I quickly turned away. Joyce and her ten grandchildren somehow live in this hovel. The pile of bricks we parked beside are her hope for a home whose dimensions might one day exceed sixty-four square feet. They are a beginning, no doubt. Joyce's children were all arriving home from school when we arrived, and all were in clean clothes, bright-eyed and beautiful. Laughter and child's play everywhere. Where do they sleep? What do they eat? How are they so clean? Why are they so happy? I decided then and there not to even ask. Survival at this level, it seems to me, has its own set of operating principles, its own set of values, and it's pointless to dwell on the details of how Joyce manages to keep these children alive, let alone clean, happy, and seemingly well-nourished, with no money, no water (except what is fetched), and very little food. The ins-and-outs of accomplishments of this sort are virtually incomprehensible to those of us who spend, without batting an eye, the equivalent of Joyce's annual income on dinner and a movie, a Christmas present, or a night in a hotel room.

Joyce herself, however, is by no means incomprehensible. She is a lean, tall, beautiful African woman in her sixties whose close-cropped hair is flecked with gray, and whose pale gray eyes take you in, impassively, without judgement. A few of my questions prompted her to turn her head down and away and laugh quietly to herself, but it was not a bitter laugh, nor was it derisive. "Reflective" might be a better word, because she would then stop laughing, turn to me, and come up with a one-minute answer to my question that was simple and direct. Joyce was very measured, in this way, very much in command. She told me, for instance, that her greatest fear, and

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the greatest fear of her eldest, Henry, who is 14, is that she herself will get sick and die. She did get very sick, apparently, about six months ago, and was, in fact, afraid she was going to die. She said that Henry cried and cried by her bedside because he didn't want her to "leave him alone" to care for his brothers and sisters. She also said that the immensity of what has happened to her family "and many others" has left her with no alternative, as a survivor, than to do what she is doing. "I will care for these children as long as I am alive," she said. "I do not know why this plague has come to us. But we have to deal with it." She is a woman of immense dignity.

At the end of our visit with Joyce, we went down the road a piece with Henry, to get a shot of him walking away from the camera, alone. The long dusty road was slightly downhill, then up again, straight into the setting sun— it was about 5:30 by this time, and Richard got an absolutely stunning shot. (Richard Young, Director of Photography for *A Closer Walk*] Richard, by the way, continues to do masterful work every time he turns on the camera.

We were walking back to Joyce's with the gear when a young man, about 25, quite tall and thin, with taut, light brown skin and fine features, wearing dark trousers and a bright orange and yellow T-shirt, approached me timidly.

"Can you help me sir?" he asked.

"I don't know. Maybe. What is your problem?"
I answered.

"I feel sick sometimes. I think maybe I need a test," he explained.

"How do you feel sick?"

"I get fever and chills at night. Sometimes headaches too. And this."

At this point the young man— his name is Charles Soози— stopped and pulled up his pant leg to reveal part of his calf, marred by four big dark lesions, about an inch long and 3/4" wide. These lesions are the external manifestations of Kaposi's Sarcoma, one of the deadliest infections— it's an invasive cancer— of full-blown AIDS. Without treatment— and I can say almost categorically that this young man will not receive

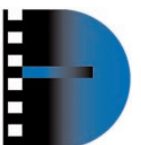
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Hassan Semakula and sister



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what he needs— Charles will die, probably sooner rather than later. I told Charles that I could, indeed, help by introducing him to the social worker who had accompanied us on our visit to Joyce. I did so, and she took over. He promised to visit the hospital the next day. I shook his hand and gave him the money for his cab fare, asking him to promise to use it for that purpose. “No beer!” We both laughed, and he assured me that he would go to the hospital. I found out later that he did.

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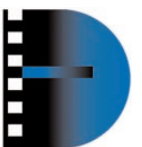
How many young men like Charles are out there, not knowing they are sick until they are so sick they are ready to die? Don't even ask. Rather, let me tell you: Charles, or his female counterpart, is dying of AIDS in our global village every twenty seconds, twenty-four hours a day, 365 days a year. I grow more astonished every day at the depth, breadth, and destructive power of this epidemic. Charles simply brought it home to me, as did Joyce, one more time.

Our principle purpose in coming to Uganda was to document and humanize the plight of the AIDS orphans. Joyce Nassuna is one part of that story. Hassan Semakula another.

Hassan, represents another aspect of the effects of the AIDS epidemic at its worst, and this one is actually more common, and more chilling. The new sociological term applied to girls and boys like Hassan is “child head of household,” and it means exactly what it says. There are tens of thousands of children who are heads of households here in Uganda— tens of thousands!

Hassan is sixteen years old. He is small but strong, fine-featured, extremely handsome, and very soft-spoken. He lives in a brick and mud house connected to other similar structures on the outskirts of Kampala. I sat next to him inside his small, neat living room and we had a quiet talk.

Hassan is shell-shocked. It's the only way to put it. Within the space of a year, he has lost both of his parents to AIDS, and suddenly finds himself responsible for his sister and younger brother. At one point in our conversation, tears welling in his warm brown eyes, he ticked off on the fingers of his upturned hand the sad litany of his vanished youth: I was in school and now I am not in school; we had food and now we do not have food; we had hope for our future and now we have no hope; I loved to play soccer, but now you see where my ball is. He pointed to a half-deflated soccer ball gathering dust in a corner of the room. Hassan is enrolled through a TASO (The AIDS Service Organization) program in a vocational school, but at the time of our



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conversation could not begin to scrape together the \$300 he needed for a mattress, personal supplies, books, etc. that are a pre-condition of actually participating in the program. He has enough trouble getting money for food for what's left of his family.

I asked him if he felt his childhood had been stolen. "I feel I have been robbed," he said. "The only comfort I get is from other boys and girls like me. There are many of us." Before we left, we took a beautiful shot of Hassan and his youngest sister— she's only two and Hassan fears she also has AIDS— sitting on the stoop in front of his house, the half-empty soccer ball by his side. She's a sweet little thing, and her tiny arms were wrapped lovingly around Hassan's neck. It was clear that he is both mother and father to her now, and the bond between them was at once moving and heart-wrenching. It's a stunning portrait and magnificent shot. Richard and I are trying to create images that are so beautiful and powerful as to dignify their subjects, and give them the emotive and resonant power of art. Our portrait of Hassan and his sister will speak volumes, I believe.

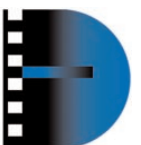
We saw Hassan in the afternoon. In the morning, we visited a family that is described— here's another of those new AIDS terms— "potential orphans." This of course describes a situation where one parent has died, the other parent is HIV positive or has AIDS, and, because it's Uganda and Africa, where no treatment is available, that remaining parent will also die. Perhaps the term should be "eventual orphans," since, eventually, that's what they will be in 95% of the cases.

We interviewed Agnes Nyamayarwo, a 45-year-old woman who contracted AIDS from her husband, a teacher much loved by his family of three daughters and three sons. Agnes' story is important because it's so typical of the decimation that AIDS is causing among African families. As you know, family life and values are enormously important in African culture, and one of the most vicious and destructive things that AIDS is doing on this continent is ripping families apart, rendering the very term "family" almost meaningless, at least in any traditional sense. I don't believe we've even begun to understand the long-term implications of what this virus is doing to these people, this continent, and this world.



Julianne, Agnes, and Annet

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Agnes' husband died six years ago from cryptococcal meningitis, which, by the way, is a treatable, goddamn it, opportunistic infection of HIV/AIDS. (The drug to treat this infection is priced beyond the reach of Agnes and her family, and of most people in the developing world.) It was a horrible, painful death. Agnes tested HIV positive shortly thereafter. What then happened is that the eldest son went into a state of severe depression due to the loss of his father, who he loved deeply. He was treated for his depression, but about a year after the father died, the boy simply disappeared, and to this day they don't know where he is, or even if he is dead or alive. Agnes is a brave, strong woman, but she and two of her daughters, who sat in on our conversation, wept openly when they spoke of him. After the eldest boy disappeared, the youngest boy, a beautiful child— they showed me his pictures— died of AIDS at the age of two. So this family lost its father and its youngest and eldest sons within the space of two years. May I once again say that the experience of Agnes' family is not an exception. To the contrary, this kind of thing is the rule.

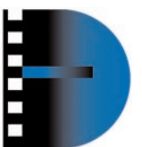
Agnes' family, or what's left of it, continues to struggle, but they've pulled themselves together. Agnes put all their assets into a proper home, became a client of TASO, received certain modest benefits, and is putting her kids through school. She is an extremely strong woman. Julianne, the eldest daughter, is already a second-year student at Makerere University, and on her way to becoming a lawyer.

And then there's Annet. Annet is 25 years old and drop-dead gorgeous. Tall, lithe, beautiful, very outgoing, just fabulous. After we finished filming with Agnes, we were all hanging around, talking, learning more about one another, packing up and unwinding after the intensity of the interview. It turns out that Agnes was a top student in a vocational school, focusing on catering and hotel management. She has basic computer skills and speaks a bit of French— she's a very talented person. She also hasn't worked since 1997— too many applicants, too few jobs. "You have to know someone," she told me.

So now my mind is working: we're staying at the Sheraton Hotel in Kampala, the major hotel in the city, a terrific old place with a long history. It is also the place where a lucky few have jobs and where we're spending thousands of dollars over two weeks for accommodations. "I don't want to get your hopes up," I said to Annet. "But give me your resume." She produced it instantly. Very impressive.

So later in the day we go back to the hotel, and I go up to the administrative floor and barge in on my friend Jennifer, who runs the marketing and sales department. It's a

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friendly barging in, and I we schmooze for a while and in the process I remind her of the large amount of money we are spending at the hotel. (I did not need to do this in fact. Annet is completely qualified, so this isn't about a favor. But I am now on a mission, and failure is not an option.) To cut to the happy ending, Jennifer responds wonderfully, brings Annet in for an interview, is completely taken with her, decides to get personally involved in her career and. . . Annet starts tomorrow!

We are all absolutely thrilled and have been walking around the hotel grinning like idiots. It will make a huge difference to Agnes and the rest of the family. They've suffered enough.

The final part of this story goes back to Hassan, and what I did in his case was to call the TASO folks and arrange to pay personally the \$300.00 he needs to go to vocational school. Diana** spoke to Emily, his social worker, and apparently he is just flabbergasted— "over the moon," as she put it. He had no hope. Now he does.

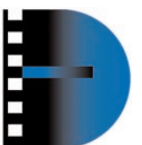
We are, and will be, seeing dozens and dozens of people during the making of *A Closer Walk*, all with stories like those of Agnes and Hassan. And I am completely satisfied that by telling their stories to the world, we are truly going to make a difference. But after seeing both Agnes and Hassan in the space of a few hours, I felt that I simply could not make it through the day without doing something more. And do you know what? I feel wonderful about it in both cases. What it's done is help me keep breathing under these soft blankets of misery that keep floating down on my consciousness day after day after day.

So there's a bit of the spirit of what happened here in Uganda, and you may get some sense of the richness and intensity of it all if I tell you that what I've just written represents only a day and a half of the two weeks we have been here.

To give you a feel for the rest of it, a few cameos:

- Eric Sawyer, who accompanied us on this trip to Uganda answering questions and delivering a lovely message to listeners on "The Capitol Doctor," a call-in radio show focusing principally on AIDS. Hosted by Dr. Donna Kabatesi, the show is unique in Africa, if not the world.
- Beatrice Were, an HIV-positive mother of two who runs a support group for women with AIDS here in Kampala, conceived the memory book project, and spoke to the

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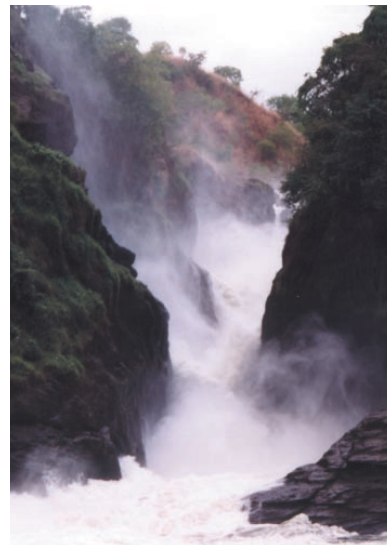
United Nations last World AIDS Day. Beatrice is a tiny powerhouse, a miracle of energy. She's made a huge difference here in Uganda among women living with HIV. Beatrice also got married in a traditional ceremony last Saturday. We filmed a portion of the ceremony because it was such an affirmative event. So you are a black African woman with HIV, and as such, one of the most vulnerable, deprived, put-upon creatures on earth. But that doesn't mean you can't live and love, be happy, be optimistic, carry on. She's a spectacular human being, and her husband, Richard, also HIV positive, is about the sweetest, gentlest person you'd ever want to meet. I wish them well.

- Reverend Gideon, as he is known throughout the country. A slight, modest, but when you get him going, brilliant and fiery Anglican priest, HIV positive, who runs the Kampala Diocese's pioneering AIDS program. I was eager to get at the question of personal and moral responsibility in a global society, so I gave him this quote from one of Jonathan's* speeches:

"Our responsibility is historic. For when the history of AIDS and the global response is written, our most precious contribution may be that at a time of plague we did not hide, we did not flee, we did not separate ourselves."

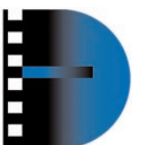
That did it. Gideon proceeded to give us a brilliant 10-minute interpretation of this quote based on the Cain and Abel story, keying off Cain's response to God when asked about Abel: "Am I my brother's keeper?" "I do not believe," Gideon said, "that we can continue to exist as responsible, moral human beings in a world plagued by AIDS until we answer this question and make ourselves accountable not only to God, but to each other." This and more. We all felt that Gideon may be the best interview yet, although it's impossible really, to compare. Ever since we started, it's virtually all been at a very high level— I've never seen anything quite like it.

We ended our filming with a trip to Murchison Falls Game Reserve. I've been to a fair number of game parks here in East Africa over the years, but I have never seen a place where the wildlife is so concentrated and the ecology so rich. This is due to the fact the river Nile runs through the park— water means life— and the results are



**Murchison Falls
Game Reserve**

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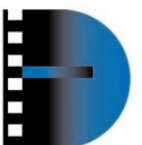
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spectacular. We took an hour boat ride, with our gear, up river to the bottom of the Falls, and during that time saw elephants, giraffes, crocodiles, hundreds of hippos, water buffalo, hartebeests, elands, antelopes, and dozens of species of birds, including kingfishers, cranes, fisher eagles, egrets and so on. Not to mention the 100-200 pound Nile perch gliding around like submarines below the surface. I got to thinking about how *A Closer Walk* is really the story of the way the world is, and how this place, in its harmony and vibrancy— nature at its best— is the way the world was. I think I know a way of making this work in the film, but I have to ponder it some more. In any event, we're going to take a long lens and go back there in August, for sure. We did film the Falls itself— the big, fat, fast Nile narrowing down to a couloir 25 feet wide and then dropping 150— and had a real trek with our gear to the top once we got off the boat: steep, winding paths, up and down, for a good hour. Hard physical work— we were completely drenched with sweat— but we loved every minute of it. Craig** at one point said, in that wonderful sweet way he has, "Thank you Bob, for this," and I know what he meant. We were in God's country.

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Finally, thinking about Murchison leads me to tell you about the game of eight ball I played two nights ago with John K. Livingstone in the pub at the Sheraton Hotel. John is a direct descendant of the explorer of Stanley and Livingstone fame, who trekked all over East Africa in the early part of the century. John is part African, part Scottish, and as we were playing I told him about what we were doing and asked him why he was in Uganda— he's an economist, living in London. "I'm burying my uncle who died of AIDS," he told me, and then proceeded to describe how his Ugandan family, immediate and extended, has been literally destroyed by the epidemic— sons, daughters, cousins, mothers, fathers. "It just goes on and on," he said. As I'm listening to him, and watching him methodically call his shots and slam them into the pockets with hard, almost violent strokes of his cue stick, I think about Hassan, and that word I used to describe him: shell-shocked. John was the same. He said at one point that he was so distraught and flabbergasted by what was happening that he tried to drink himself to death— a heavy-duty binge that lasted a month. I told him, "John, I've only known you ten minutes, but you've got to get past that."

"I know," he said. "I am. That part's over." Then he sank the eight ball and won the game.



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What I've been thinking about since I ran into John last night is the way in which families are being destroyed by this epidemic, all over the world: Joyce's family, Hassan's family, Agnes' family, and John Livingstone's family. And what's becoming more and more clear to me, is that if you begin to destroy families on such a massive scale—locally, regionally, nationally, globally—eventually you destroy the human family itself. We cannot, we must not, ignore any longer what is happening. I leave Uganda wiser, sadder, and more resolved than ever.

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Much love,

Robert

* Jonathan Mann, the visionary public health leader and human rights activist who was the architect of the World Health Organization's program on global AIDS. Dr. Mann died, with his wife, Mary Lou Clements-Mann, in the crash of Swissair 111 on September 2, 1998.

** Craig Braden, Assistant Cameraman

** Diana Hyslop, Production Manager

Editor's Notes:

One of A Closer Walk's Advisory Board members has contributed funds to build a home for Joyce Nassuna and her orphaned grandchildren, and has also underwritten the costs of the primary and secondary school educations of Hassan Semakula and his three siblings.

Annet Nyamayarwo was put in a training program at the Sheraton, Kampala, but her advancement appears to be stalled due to management changes and the sale of the hotel itself.

