



February 20, 2000

LETTERS FROM THE WORLD OF AIDS

Loved ones,

After ten days of location scouting, the film crew has now joined up with me, and we are ready to begin filming. What's interesting about the first few days of a film shoot—especially one as long-anticipated as this—is that there's so much that can be brought to bear upon these days. You get to a point, after the endless negotiations that the production of a major film requires, where everyone involved with the project feels: for God's sake if we have to talk about this project, or get ready for it, or help organize it one minute longer, we will go mad. With the possible exception of Richard (Co-Producer and Director of Photography, whose right knee, and in fact entire right leg, was dancing Wednesday night all during dinner, and who, to boot, didn't sleep one wink, we all made it through Wednesday night and gathered last Thursday morning at 7:00 a.m. neither mad, nor bringing anything to bear upon the task at hand except a heartfelt desire to get on with filming. I'm pleased to report that we've gotten on with it very well. These past few days have been among the most satisfying and successful ones I've ever had as a documentary filmmaker, and I know that Richard, Craig, Diana, and Lee feel the same way. We've shot seventeen rolls of film already, and I want to give you a bit of a feel of what's on those rolls, day by day.

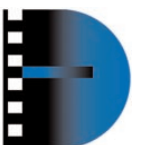
Thursday, February 17**"Pepe" (Pay-Pay)**

The idea for this first day was to document the work of the community-based care teams of the South Coast Hospice that visit the impoverished and AIDS-infested rural areas of KwaZulu Natal, which I described in my first letter. When Diana and I went scouting with the Hospice team last week, the patient they were visiting had died in the 48 hours between the team's most recent visit and ours. We subsequently attended the funeral of that patient on Saturday.

Today, the patients were alive, and they were children.

Let me first tell you the story of Phephile Hlabisa (Fay-feel-ay Labeessa), "Pepe".

Pepe is an eight-year old HIV-positive girl who was raped by her stepfather when she was five. Her mother and sole caregiver, Sandra, is also HIV positive from her first husband, who died of the disease. Sandra's youngest boy, Bheki, from the

***Sandra and Pepe*****Letter 2**
Port
Shepstone
South Africa
By
Robert
Bilheimer



February 20, 2000

LETTERS FROM THE WORLD OF AIDS

stepfather who raped Sandra, is only two, and is also HIV positive. Bheki was in the hospital that we visited Friday. At present, Pepe, and her mother Sandra, live alone. Pepe had to leave school last year because news of her HIV infection got out and she was ridiculed and shunned by her schoolmates.

So what we have here is this: a 28 year-old woman and her eight-year-old daughter who are unspeakably poor (they get exactly \$18.50 a month from the government). They both have a disease that will probably kill them— sooner rather than later. They are pariahs in their own community— even though many of those who shun them are HIV positive themselves (which they will discover in due course, as the widespread HIV infection that was transmitted in the mid-90s throughout sub-Saharan Africa matures into full-blown AIDS). What's important to understand here is that Pepe's and Sandra's story is not unique. The workers we traveled with on Thursday see this story played before their eyes like a continuous-loop videotape five times a day, six days a week. Every weekend they attend at least one funeral.

We arrived at Pepe and Sandra's home around 9:00 a.m.

Picture: a rural hillside of lush green grass and rolling hills facing a bright blue sea. Chickens and other country sounds. Dogs bark. But a peaceful feeling, somehow. Picture: a small winding pathway leading uphill to a building of white-painted cement some 50 feet long, by 15' wide. It's a rural apartment in poverty-land.

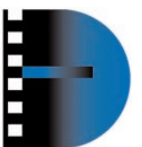


Pepe's Home

The first apartment of this building is nothing: blown-out, dismembered, white concrete walls. No roof. One whole wall is, in fact, missing. Rubble is where the living room is supposed to be. It's a bad introduction to the building. The second apartment, contiguous to the first, is a bit better: there's no one in it, but there's a roof, and a door, but the hospitality of the place ends there. No one lives in it. The inside is empty and dark and the floor is strewn with pebble and concrete shards.

In the third apartment in this broken-down building— a progression of habitability if you will— we find the living space of Pepe and Sandra. Same structure, same building, but now the third apartment has a paned window; a working, quite lovely door, painted orange-red; a slab of stone that serves as a step into the doorway entrance and, is at times, I suspect, a modest kind of front porch. The room inside is about 15

Letter 2
Port
Shepstone
South Africa
By
Robert
Bilheimer





February 20, 2000

LETTERS FROM THE WORLD OF AIDS

feet by 20 feet and in it there is exactly this: a bed with cover and a few pillows, against the left wall; a tin-surfaced table and a wooden chair against the rear wall; a small chair for Pepe, against the right wall. On the table is almost nothing, a few artifacts, and a few basic food staples. There is of course no running water.

A remarkable thing about rural poverty in this part of Africa is that despite its depth, those who endure it somehow find the wherewithal to maintain their dignity. The tin-surfaced table in Sandra's apartment was scrubbed with a scouring pad to the point where it was light silver and you could see the scratch marks of the steel wool. The cover on the bed was immaculate. The few items in the room were neatly arranged. Both Sandra and Pepe were dressed in clean clothes. I have also found that the children in these poor rural areas, including of course Pepe herself, are impeccably well behaved.



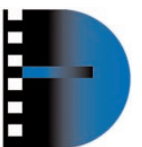
Diana Hyslop (production manager), Pepe, and Sandra

They do not cry, they do not whine, they do not call attention to themselves, they listen to their parents, they sit quietly when other adults are in the room, and yet they respond when they become the subject of attention. Talk about dignity! What lessons we have to learn, with our toys and television, from these impoverished young people. I had Richard train the camera on Pepe for a full two minutes while the workers were talking to her mother. You will see, in the film, what I mean.

Sandra is a warm-smiling, attractive woman in her late twenties, with beautiful white teeth, and an easy, slightly diffident manner. Pepe, who was wearing a dark pleated dress just above her knees, and a light blue jersey, has close cropped hair, fairly dark skin, and eyes that at first seemed to me old beyond her years. She's about threefeet tall, and her legs are marked by bluish blemishes. Pepe's HIV has recently emerged into full-blown AIDS, and as one of the expressions of this, she coughs a fair amount, which means she has tuberculosis. Other complications will follow.

My intention on this visit was to film the Hospice crew at their work, which consists of visiting with patients like Sandra and Pepe roughly once a week, finding out what their current problems are, assessing their medical condition, and offering home-based care in any way they can. Pepe sat in her chair and watched as the big white men entered the room with their equipment. I believe she was a bit frightened, both by the men themselves, because of her rape, and the strangeness of it all, but she didn't show it,

Letter 2
Port
Shepstone
South Africa
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Bilheimer





February 20, 2000

LETTERS FROM THE WORLD OF AIDS

and I was quite proud of her. But when the filming was done, and the crew was outside shooting exteriors and establishing shots,— which took a while, Diana went inside and started playing alphabet and word games and a different Pepe emerged— smart and quick as a whip, impish, and soon given to laughter and delight. She learned about twenty English words in as many minutes, and by the end, wasn't even afraid of me. The Pepe that emerged during our brief visit gave me great hope, and also broke my heart. The hope she gave me was in the resiliency of the human spirit, even in a child who has suffered the most unspeakable trauma and pain. She still can laugh and learn. What broke my heart, of course, is that this child, such a model of dignity and courage, will probably not be with us much longer.

When the shoot was over and we walked back down the winding path to the van, Sandra and Pepe came with us. When we got to the clearing where the van was parked, somehow, from somewhere, a big pink raggedy-Ann doll, almost as big as Pepe, appeared, and she was holding it. I grabbed my camera and— you'll love this— she imperiously stretched her left arm out, palm up, indicating to her mother that this was her shot, and her's alone. She gave me the biggest smile, I took the picture, and when Sandra tried to approach her she put her arm out again. One more! This time she did what a lot of kids do here in KwaZulu Natal when they want to send you a friendly and happy message: she gave me a thumbs-up.

We visited two other homes that day, including one where a grandmother who is caring for two AIDS orphans, both of whom are also HIV positive. At one point the grandmother suddenly started to cry. Not for the child, but for the isolation she is feeling. The need for a closer walk is global, but it's local, too.

Friday, February 18
The Doctors and My New Friend,
Fezile (Fah-zee-lay)

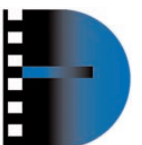
We spent the day at Murchison Hospital near Port Shepstone on Friday.

Murchison is a wonderful old mission hospital that's seen just about everything in its 50 or so years of service to the people of KwaZulu Natal, and now of course it's seeing AIDS. I interviewed the hospital's two principal doctors— Terry Gilpin, who I interviewed at his home nearby because he's



Fezile

Letter 2
Port
Shepstone
South Africa
By
Robert
Bilheimer





February 20, 2000

LETTERS FROM THE WORLD OF AIDS

recovering from hip surgery (he's a surgeon himself), and Bill Hardy, an absolutely sweet fortyish man, about my height, but a bit plumper and softer around the edges, with a pale face, thinning brown hair, blue eyes, and beautiful smile. Picture a comfortable, rumped figure in a white, short-sleeved shirt damped by bits of sweat here and there— it's hot and humid here— khakis, stethoscope around his neck, walking the compound, often deep in thought, kids trailing behind him.

Bill comes to life when he is with patients. To me, he is Essence of Doctor. In fact, I think some of the best parts of this film are going to be Essence of Doctor, and I'm going to pursue that theme. You meet such great doctors in these parts, such great human beings. I could go on and on about Bill and Terry, but I want to get to my new friend Fezile, so let me summarize my interviews with both. A doctor in sub-Saharan Africa in the early years of the new millennium is increasingly an AIDS doctor. But an AIDS doctor with no money for treatment, no means to cure the dying. These new



Fezile and Robert Bilheimer

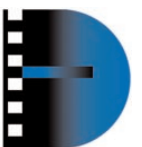
AIDS doctors are being tested to the limit because they are dealing with a tidal wave of incurable disease that in effect is

saying to them: you are powerless. They are heroic figures I think, because even though they may long to be back in the operating theatre, or simply healing people, they have accepted this new tragedy as a reality and are adjusting to it as best they can. Both Terry and Bill's

interviews were inspiring.

While we were at the hospital, we filmed in the infant's ward, and one child caught my eye. Lying in his bed, covered by a light blanket, this child was clearly emaciated, but not skeletally so. He lay so still, that it was apparent he had little strength. His face, chocolate-colored, was to me a thing of nearly perfect beauty, as I think it will be to those who see it. It's a delicate face, almost feminine, but that's where you see the beauty of the boy, cheekbones prominent of course, a small mouth whose lips want, but no longer have, the strength to smile. But what struck me most was the movement of Fezile's big, bright, all seeing black eyes. This movement is his lifeline now, and it covers the room and all that goes on

Letter 2
Port
Shepstone
South Africa
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A
CLOSER
WALK

A film about AIDS in the world. A film about the way the world is.



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LETTERS FROM THE WORLD OF AIDS

in it. We interviewed Bill Hardy at Fezile's bedside and he told us that Fezile was born HIV positive but up until three or so was a big and bouncy roly-poly laughing child who loved interaction with people and still does— a far cry from the nearly still-life portrait of a human being I am seeing now in his crib at the age of five. It is the usual litany: parents both dead of AIDS, one sister dead, an auntie who comes to see him in the hospital now. They've got him back to accepting food and basic treatments that will allow him to go home in due course to die. Bill told us at the boy's bedside that "he's nearing the end of his road."

Once the bedside interview with Fezile and his doctor was over and everyone left, I lingered by the boy, drawn to him. After a few minutes I was called away, and as I turned to leave I stopped and wiggled my five fingers from pinkie to thumb like a little wave as a goodbye gesture. Astonishingly, up raises the boy's forearm from the fulcrum of his elbow, revealing a pink palm and delicate long fingers. Then his fingers too form a little wave, also from pinkie to thumb. Then I waved again, and he waved again. I asked those who were calling me to wait some minutes, and sat by the boy, stroking his palm, and giving him my index finger to hold, which he did. I could swear he worked hard at a smile.

Then I left. What's happened since then is this. We are going to be here another week, and I've decided, independently of the film, that I'm going to spend half an hour or so each day with this boy, reading to him from a book, showing him pictures, and just being with him. The doctor says he was enormously outgoing once, and loves company and attention. The hospital and its staff can't give him what he needs though of course they do what they can. Richard thinks we should film a few moments of my being with Fezile each day and that's OK with me. But that's not why I'm doing it. I've got a friend here. It's as simple as that.

Much love,

Robert

PS: The third day, the funeral, is part of a bigger and ongoing story. More anon. I'll try to keep up.

Letter 2
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