

## Opening Session: Welcome from the Sinikithemba Choir

*At the opening session of the 10th Conference on Retroviruses and Opportunistic Infections, Zinhle Tabethe, a member of the Durban, South Africa-based Sinikithemba HIV+ Choir, spoke about living with HIV and her experiences with antiretroviral therapy. Ms Tabethe was asked to speak at the last minute, after travel difficulties prevented choir director and scheduled speaker Nonhlanhla Mhlongo from attending. A transcript of Ms Tabethe's powerful speech is reprinted below. A Webcast of the speech, which begins with a performance by the choir, is also available at <http://www.retroconference.org/2003/webcast.htm>.*

*The Sinikithemba Choir evolved from a support group for HIV-infected patients at Durban's McCord Hospital. To help meet the costs of their care, group members fashioned bead jewelry for sale, singing while they worked. Despite early reservations about disclosing their HIV status, members began to sing in public, and the Sinikithemba Choir now performs to raise awareness of the HIV/AIDS pandemic. The choir also sells beadwork made by support group members, with proceeds going toward medical care and counseling for members of the choir and the McCord Hospital support group.*

*According to clinicians at Boston's Partners AIDS Research Center (PARC), which works with McCord Hospital, many choir and support group members need immediate antiretroviral therapy. At an estimated annual cost of US \$1500 per patient, however, the drugs are currently inaccessible for many. The South African government has recently indicated it may expand the availability of antiretroviral drugs, but this move, while welcome, also carries costs: McCord Hospital officials expect they will need funds to meet an increase in patients seeking support services. Upgrading the hospital's treatment and counseling services will be fundamental to helping patients*

*stay committed to antiretroviral drug therapy.*

*The choir had hoped to use its trip to the United States as an opportunity to raise money for these needs through sales of its beadwork. With support from PARC and the Doris Duke Charitable Foundation, the choir had also produced a compact disc (CD) of its work, intending to sell the collection of traditional Zulu, gospel, and original a cappella pieces at the Retrovirus conference. But the group chose instead to give a free CD to each attendee—3800 in all—as thanks to those whose efforts have made care and treatment possible. The choir missed another chance to sell its work when a scheduled post-conference performance at New York's St. John the Divine Cathedral was cancelled due to a major snowstorm. As a result, group members generated little income from the trip.*

*In recent months, a growing number of Topics in HIV Medicine readers and attendees at International AIDS Society–USA (IAS–USA) symposia have asked how they can help fight HIV/AIDS in the developing world. Assisting the Sinikithemba Choir and the McCord Hospital support group provides one opportunity to do so. PARC and the IAS–USA, among others moved by the choir's appearance at the conference, have established trusts to help care for choir and support group members. Donations to the PARC and IAS–USA funds are tax-deductible and go directly and completely to patients. Contributions may be sent to the address below. Please also include contact information, as support group members hope to individually thank those who help. In addition, the IAS–USA is offering the choir's CDs for sale for US \$20 each; again, 100% of proceeds go directly to patient care. Donations can also be made and CDs purchased by contacting the IAS–USA at (415) 544-9400.*

### Transcript of Welcome Remarks

I want to thank the conference organizers for giving Sinikithemba Choir the opportunity to be here with you tonight and share our voices and music with you. And to the president, Bill Clinton, who has committed himself to fighting against the AIDS pandemic, I'm so honored to share the stage with him.

For those of you who are looking at the programs this evening, you have been expecting to hear from Miss [Nonhlanhla] Mhlongo, who is the director of Sinikithemba HIV+ Choir and its support group for people who are living in Durban, South Africa. I pass my apologies for Miss Mhlongo.

Unfortunately, she was unable to be with us this evening. As a member of Sinikithemba Choir, I was asked to stand in her place tonight.

My name is Zinhle. This week as I was preparing for this trip from home in Durban, I became very excited, thinking that I'm going to see your faces—faces of the world's best scientists and experts in HIV research. To look out and see the people who have been on the front lines in the laboratories and clinics and hospitals, figuring out that things like AZT would fight the virus and discovering triple therapy called HAART, that it would give people life much longer. I know you're way past that, and you're busy thinking up new drugs, and

you're busy thinking about resistance. You're also busy thinking about the new strategies of fighting with HIV, but I am so very excited about this triple therapy, which is so amazing.

Like the members of the Sinikithemba Choir, I am HIV-positive. I'm just like them. Like them, I am living in a country with one of the highest HIV infection rates in the world. You know the [World Health Organization] statistics, but we ARE those statistics. On Saturdays, we go to funerals for our friends, our neighbors, and our families. And in our support group we have lost 10 members this past year to AIDS. At support groups on Tuesday, when you look around the room and see there is

no face, you become very worried if that person is sick or what's going on. We have watched each other lose weight, have the dark spots of KS appear on our skin, listened to the deep cough of TB, wiped each other's tears after one of us lost our 6-year-old child to AIDS.

Like most of the others in the choir, I have battled with opportunistic infections. I have had TB twice in the last 2 years. Eighteen months ago, I had cryptococcal meningitis. I had PCP, and I have had bacterial pneumonia, and I have had thrush. I lost weight until I no longer looked like the same person. I finally came face to face with the end of my life. I was in bed for 3 months. I was too weak to walk and could only crawl back and forth to the bathroom. It was the end of me, then.

But 10 months ago, I became different than most of the people at Sinikithemba. I got in a pilot study that provides antiretroviral drugs. Now I am not like them. I gained back all the weight that I lost. I have not been seriously sick for the past 6 months. My CD4+ count came up from 160 to 480. I wake up every morning at 6 AM and take my 3TC and d4T, and every night at 6 PM I take the same drugs. Before I go to bed, I take 3 efavirenz tablets. I'm never mad that I have to take those

drugs. I know they are allowing me to live and to be able to think about tomorrow. But I am one of the few lucky people in South Africa. I am done asking myself, why me? Why did I have to be infected with HIV? Now I ask myself, why me? And why do I get to live when others next to me are dying without treatment?

Some people say that really poor countries should not get antiretroviral drugs. They say poor people, uneducated people, will not be able to be adherent to antiretroviral drugs. They say they would miss doses and end up with resistant virus that we would then spread. Some people say there are things more urgent that we need to take care of before HIV and AIDS. Things like poverty. Things like malnutrition. And things like high crime, unemployment, violence; diseases like TB, malaria, diarrheal diseases.

I am from a poor family. When I was at my most sick, I was living with my mother, with my 2 sisters, and their 4 children. I had been fired from work, from the job that I was doing, because they found out that I was HIV-infected. So my family was living without any income. Our house had no electricity and had no running water. When there was no money, there was no food. There are no people anywhere who live

more basic than what I've just shared with you. But I am adherent to my ARVs. I can tell you that ever since I started medication, I have never missed a dose. Ever.

So what can I, as one of the HIV-positive persons and we, as the Sinikithemba Choir, say to you? Well, we want to say thank you. Thank you very much for the job that you have done so far. And I want to thank you—thank you in advance for the job that you're still going to do. The word *sinikithemba* means "give us hope." You do that with your job. You give us hope. You give us hope that we will, at one day, or some day, have treatment that will save our lives. Thank you.

### Donation Information

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