Conference of the Century

October 1, 2000 By Kai Wright , Gus Cairns , Esther Kaplan , Bob Lederer and David Scondras

Durban, South Africa 7.9.000 - 7.14.00
13th International AIDS Conference

“Bridging the Gap” was the official theme of the 12th World AIDS Conference in 1998, but that meeting merely gestured toward the chasm between the globe’s treatment haves and have-nots. At No. 13 in Durban in July, the first such affair ever held in a developing country, the gap swallowed the conference whole. With Africans constituting a third of the 12,437 delegates (by far, the largest proportion ever), there was no escaping a painful irony: High-tech studies on viral resistance and future meds were irrelevant to many of the doctors and PWAs in attendance. One poignant expression of this disconnect was a march by traditional healers, angry that the conference excluded research into the effectiveness of their widely used, and far cheaper, remedies. But the conference’s mantra was first sounded at the opening plenary, when South African judge Edwin Cameron, an openly positive HAART-taker, made a ferociously moving call for universal access to antiretrovirals. Debates on treatment access dotted the program, while even at clinical-science sessions, the audience raised the issue again and again.

With several demonstrations against drug-price gouging -- also the hot topic of hallway conversations -- pharmaceuticals were on the defensive. The usual Broadway-budget display booths were scaled-back productions this year, many “tastefully” papered with photos of African children. Almost every day, one company or another trumpeted drug giveaways for poor countries -- often with strings attached. (Pfizer’s free-fluconazole offer, for example, was limited to people with meningitis in South Africa and for only two years.)

Meanwhile, South African President Thabo Mbeki’s controversial flirtation with AIDS “dissidents” buzzed around the proceedings like a swarm of gnats: From David Ho, MD, to Anthony Fauci, MD, major researchers drew thunderous applause by uttering the self-evident “HIV causes AIDS.” And with daily talks on microbicides and mother-to-child transmission, the epidemic among women gained new prominence.

There’s no doubt that No. 13 was the scientific conference gone political, a reminder that AIDS has always been as much about society as about science. We hope the following highlights take you into the heat of the moment.

PWA Lounge
Talk amongst yourselves

Depressed by the dismal opening ceremony -- a made-for-TV embarrassment with Lion King staging -- I ducked in to Durban's PWA lounge as an antidote. I found the décor to be decidedly different from Geneva's in 1998. While that lounge was dimly lit and hung with stiff white drapes -- think funeral-parlor chic -- Durban's offered Hampton-summer-home glamour with a bright tropical garden and white patio tables large enough to seat activists from five continents all together.

On the lush green lawn, as treatment advocates clobbered chicken stew and plotted their next moves, I soon found myself engrossed in conversation. Less than two years after South African activist Gugu Dlamini was stoned to death by her neighbors for disclosing her HIV status, a woman beside me says, her story ignited Siyaphile, an AIDS advocacy group. Banding together to come out as well, they began educating rural residents in Gugu's KwaZulu-Natal province. One of the group's members, Thanda, 18, giggled at the bare boys in the safer-sex ads in my magazine, Positive Nation, and told me calmly that she was diagnosed with HIV after being raped at 15. She now tours village schools. Thandwile, 47, a dignified mother of five, saw her husband die of AIDS; she has since adopted six AIDS orphans. Too frail for township excursions, she commands Siyaphile's "office," a bare room with a phone but no chair.

Perhaps because the African epidemic is largely heterosexual, the lounge seemed less queer than at past conferences, so I was less flirtatious. Still, you can admire from a distance, and one fine hetero specimen was Moses Mathathwa, 32, a rascally ex-cop-turned-firebrand advocate. Sipping beer and speaking with a strong local accent, he shared his story, one of universal application: Being diagnosed with HIV during a routine STD checkup. Losing his job. Depression, drinking, suicide attempts, conversation with God. Finally, lying in a gutter one night before gaining a sense of urgency about his life.

Nearly everyone I cozied up to in the lounge reminded me that I was witnessing history. They reminded me of how determination feels, and what activism in Europe and the U.S. was like before activists became career PWAs and the infighting began. Capping off a Castle beer with Moses, I pondered how we have much to teach Africa's new activists, also how much to learn from them. While we may share what has succeeded -- and what has failed miserably -- they can help us rediscover a renewed sense of purpose.

War of The Words
Excerpts from four speeches that rocked the Durban house

7.9.00 Winnie Madikezela-Mandela
President of the African National Congress Women's League

"Let me start by asserting what appears to have become less obvious in South Africa in the last few months: AIDS exists. HIV causes AIDS. Like the spread of global parasitic imperialism, AIDS is roaming the world, attacking the poor and marginalized. In our beloved Africa, it has already cut a swath of destruction, swallowing up families, communities and villages....

"To claim this century 'the African century' is to declare war on AIDS. Comrades, let us concede that we have failed to take HIV/AIDS seriously. That failure is a betrayal of our struggle for social justice and of our hopes for a better society. We must take responsibility for that failure. We knew that this plague was moving South -- we saw what it had done in the North -- and yet we did nothing. Instead of following the example of Uganda and taking serious action, we wasted time on [the AIDS musical] Sarafina, [a government-backed AIDS drug that proved worthless] Virodene, and [dissident] right-wing American scientists. Our failure to act has made us the murderers of our own people.

"But there is room for hope. If we could give the same attention to the struggle against HIV/AIDS as we gave to the bid to host the World Cup, we could save millions of lives."

7.9.00 Thabo Mbeki
President of South Africa

"As an African, speaking at a conference such as this, convened to discuss a grave problem such as the acquired human deficiency syndrome [sic], I believe that we should speak to one another honestly and frankly, with sufficient tolerance to allow all voices to be heard.

"Had we, as a people, turned our backs on these basic civilized precepts, we would never have achieved the much-acclaimed South African miracle of which all humanity is justly proud.

"Some in our common world consider the questions I and the rest of our government have raised around the HIV/AIDS issue as akin to grave criminal and genocidal misconduct.

"What I hear being said repeatedly, stridently, angrily, is 'Do not ask any questions!'"

7.10.00 Edwin Cameron
Judge, High Court of South Africa

"It is often a source of puzzled reflection how ordinary Germans could have tolerated the moral iniquity that was Nazism. Or how white South Africans could have countenanced the evils of apartheid. Yet the position of persons living with AIDS in Africa poses a comparable moral dilemma for the developed world today: the inequities of a world trade system that weighs the poor with debt while privileging the wealthy with inexpensive materials and labor.

"Those of us who live affluent lives, well-attended by medical care, should not ask how Germans or white South Africans could tolerate living in proximity to moral evil. We do so ourselves today, in proximity to the impending illness and death of many millions of people with AIDS. This will happen because available treatments are denied to those who need them for the sake of aggregating corporate wealth for shareholders who, by African standards, are already unimaginably affluent."

7.14.00 Nelson Mandela
Former president of South Africa

"The scientific community of this country, I know, holds dearly to the principle of freedom of scientific inquiry, unencumbered by undue political interference and direction of science.

"Now, however, the ordinary people of the continent and the world -- and particularly the poor, who on our continent will again carry a disproportionate burden of this scourge -- would, if anyone cared to ask their opinions, wish that the dispute about the primacy of politics or science be put on the back burner and that we proceed to address the needs and concerns of those suffering and dying.

“I come from a long tradition of collective leadership, consultative decision-making and joint action toward the common good. We have overcome much that many thought insurmountable through an adherence to those practices. In the face of the grave threat posed by HIV/AIDS, we have to rise above our differences and combine our efforts to save our people. History will judge us harshly if we fail to do so, and right now.”

The March
A freedom-song refrain

Over and over, the song rang out in Zulu, a cadence that had summoned the strength of black South Africa in its struggle to end white minority rule: “Hold it / you fighters / The sound of your machines / reminds me / of Oliver Tambo!”

Engulfed by 2,500 people belting out the chorus of the famous African National Congress (ANC) tribute to a movement hero, I watched awestruck as protesters danced the toi toi, another expression of the anti-apartheid struggle. I’d seen countless newsreels of this sort of defiant celebration. Now, with apartheid history, I listened as a new generation of fighters told the world that the war for their lives has begun again.

“The toi toi gives me strength. I bring down this foot,” said HIVer-activist Mercy Makhalemele, stamping down one foot while raising the other high, “and I feel it. I bring down the other foot” -- her boot crashed to the cement -- “and I feel it.”

That’s just the reaction that organizers of this July 9 march through downtown Durban sought to spark among the 4.2 million South Africans who are HIV positive: a renewed spirit of resistance against what they consider the nation’s new oppressors -- multinational pharmaceutical companies.

South Africa’s Treatment Action Campaign (TAC) organized the protest in partnership with the U.S.-based Health GAP Coalition, with scores of conferees from abroad joining in. The march, which nearly upstaged the opening of the conference, revealed a growing impatience among black South Africans from poor townships, both with drug-company price gouging and with their own

government’s equivocation about providing basic medications for HIV-related illnesses.

“The drug companies are strong. But we have right on our side,” said Zackie Achmat, a TAC leader. “We did not stop apartheid by not fighting. We can’t stop HIV without a fight.”

The march witnessed the reassembly of the old anti-apartheid coalition -- including a major trade-union confederation, the South African Communist Party and rank-and-filers from the ANC. But the most dramatic link between past and present came when Winnie Madikizela-Mandela, a national hero for her decades-long resistance to apartheid, addressed the rally. Youthful protesters screamed like adoring fans seeing a rap star, but her song went this way: “Today we are marching again. It is part of the long walk to freedom. We brought down apartheid -- who are the pharmaceuticals?”

Women’s Programs
The other epidemic

I was told to head out the side door of the convention center, pass through the rows of food stands serving curry and brai, go two blocks down and one block over, enter a playhouse across from the red-beribboned Durban City Hall and climb the stairs of its musty, Tudor-style left wing. As I reached the stairs, I could already hear women’s quiet questions, exclamations and laughter. After a morning at the official conference, taking in Powerpoint presentations and elbowing my way to the mike for rushed question periods, I had stumbled into an event where real conversations were taking place: Women Helping Women, or, in Zulu, Umbumbano loMama, a six-day women’s satellite conference.

The event was patched together by the International Community of Women Living with AIDS, the International AIDS Society’s (IAS) Women’s Caucus and a scattered group of activists from New York City and around the globe. After watching conferences No. 1 through No. 12 consistently sideline the “second sex,” these women decided to throw their own party at No. 13. Over the course of the week, dozens of women presenters made the trek over to the playhouse, to break down their research for a crowd of South African women with AIDS.

My American mind was bent daily as I spoke with these local PWAs, from ANC activist Mercy Makhalemele, a dashiki-clad human storm of an organizer, to Mpho Babusi, who once camped in front of Mandela’s house after being tossed out by her family for going public with her status, to teenage S’lie, a fashion-conscious charmer who’s doing battle with meningitis in a country where clinics are unable to stock fluconazole. There were women from rural areas where HIV educators don’t venture; women with years of experience in the liberation struggle but who had never been to an AIDS meeting of any kind.

When one presenter, Beverly Greet of Australia, introduced herself by saying she’d been HIV positive for 14 years, murmurs of incredulity washed across the room. When she said that for 10 of those 14 years she didn’t take any drugs at all, the murmurs became a rumble. And when Greet

later mentioned that she'd gone on antiretrovirals, a woman's hand shot up: "Are you still HIV positive?" Many local PWAs had seemingly invested the flawed drugs with near-magical properties, precisely because of their unattainability.

One prevention workshop became the scene of a charged debate. Eka Williams, from Nigeria, challenged each woman to be brutally honest about her husband's infidelities, to encourage him to use condoms with his other women (but how, one woman asked, when he doesn't tell us that's what he's doing?). If all else failed, Williams said, consider divorce (this provoked some scandalized laughter). Blanca Ortiz from Puerto Rico countered by encouraging the women to try alternative sexual practices that did not involve penetration. One woman became angry: No husband would stand for this! But the room had warmed up fast: What acts, exactly, was Ortiz talking about? Then, a voice from the back: "We once had a traditional practice like this -- uxom, thigh sex. We need to get our young people to go back to the roots." Afterward, six women huddled in the corner as Ortiz sketched a clitoris and labia, pointing out areas of arousal outside of the vagina.

Over at the main conference, gender issues were more visible than ever before, with talks on microbicides, maternal transmission and violence against women. I ran into a stunned Joyce Hunter as she came out of researcher Geeta Rao Gupta's plenary speech -- a rousing indictment of how gender inequality fuels the spread of AIDS -- that brought down the house. "You know," whispered Hunter, an IAS Women's Caucus cofounder, "I think our women's program pushed the main conference to include us."

On the last day of the women's event, 100 participants gathered in a bare university classroom to plan the beginnings of a national network of women with AIDS. As woman after woman volunteered to be a township coordinator, the others cheered. Mpho Babusi stood up at the close and said, nearly shouting, "I learned that I can't wait for someone else to speak up for Mpho, that I must speak up for myself. I have a right to, and I can." There's no sight like the birth of an activist, and the sweet, exhausted singing that followed felt like it was rising right out of my chest.

The HIV Controversy
Face-off with the flat-earthers

As I sat in Kingsmead Cricket Stadium waiting for the conference's opening ceremony to begin, in a city on the warm waters of the Indian Ocean, with roads better paved than in my Boston home, surf-boarders, Internet cafés and fine restaurants, my thoughts floated back to the letter I'd received this spring. It was from President Thabo Mbeki, inviting me, as head of the HIV-treatment advocacy group Search for a Cure, to join his advisory panel on AIDS. Besides asking us to address the notorious question of whether HIV causes AIDS, Mbeki challenged us to determine why the disease attacks such different populations in his country and in the North, and what responses make sense given South Africa's economic realities. The panel was to meet twice and submit a report before the Durban conference.

I had misgivings about serving: I didn't want to lend any credence to Peter Duesberg and the other HIV-doesn't-cause-AIDS adherents invited by Mbeki. I spoke with other HIV believers named to the panel about whether to boycott the meeting, but we decided that our presence could help give Mbeki a graceful way out of this controversy.

In the end, 24 of the 34 who showed up at the May meeting in Pretoria were HIV believers. But the panel itself was a theater of the absurd. There was no chance of crafting practical AIDS strategies with a crowd that spent every moment challenging the cornerstones of our scientific knowledge. After the opening reception, the 24 believers, aware that the two sides would agree on nothing, decided to ask for the panel to meet in separate groups -- a structure that soon took effect.

At the end of the first panel, many of us were shocked when the official creation of a subcommittee comprising two "denialists" (as we labeled the dissidents) and two "round-earthers" (as we referred to ourselves) was announced. The purpose? To develop an experiment that would answer the question "Does HIV cause AIDS?".

Between May and July, round-earthers and denialists held separate Internet discussions, framing advice to Mbeki. By the time the panel held its second meeting in Johannesburg on the eve of the International AIDS Conference, the Durban Declaration, which emphatically asserts the bases for concluding that HIV causes AIDS, had been signed by 5,000 doctors and scientists worldwide.

At the second meeting -- another parallel-universe talkfest -- Mbeki was presented with two options: We round-earthers recommended using antiretrovirals in late-stage illness, offering nevirapine to prevent mother-to-child transmission, treating STDs and other possible AIDS cofactors, and improving nutrition and public health. The denialists urged not treating HIV, but rather reducing drug addiction and such "immune stressors" as malnutrition. The best way to end the epidemic, said David Rasnick, MD, of the University of California at Berkeley, would be to "get rid of the HIV test." Out of the blue, the health minister publicly announced that the panel would launch a study of whether HIV antibody tests were accurate in South Africa -- and thus would continue working through December. Yet another delay in ending this needless argument.

Most of the round-earthers were with me at the stadium listening to the president's defensive opening speech. At a conference whose theme was "Break the Silence," Mbeki flatly refused to say HIV causes AIDS. He linked AIDS to poverty instead, and then simply recited his government's existing AIDS policies -- promote safe sex, improve nutrition, fight STDs and TB, and support further research on antiretrovirals. He didn't mention providing meds to anyone with HIV.

Throughout the conference, numerous speakers and newspapers attacked Mbeki for his lack of leadership. But one round-earther, William Makgopa, MD, head of South Africa's Medical Research Council and a friend of Mbeki's, was angry at the press play. Citing Mbeki's mention of antiretrovirals and his use of the phrase HIV/AIDS, Makgopa told me he thought Mbeki had moved as much as he could and still save face.

On the last day, Mbeki's predecessor, Nelson Mandela, walked into the convention center to wild

cheers. In a nationally televised address, he did what Mbeki would not: He issued a call for action. Mandela spoke movingly against stigma, called for the fight over causes and treatments to be “put on the back burner” and urged people to “focus on what we know works.” He received a deafening standing ovation.

With a few eloquent words, Mandela gave Mbeki the opportunity to set aside the HIV dispute and move forward. From the stage, conference chair Jerry Coovadia, MD (a South African doctor and member of our panel), called Mandela’s speech “music to our ears.” As we round-earthers press President Mbeki to respond to our recommendations, we hope that he’ll soon be playing from the same score.

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