It’s A Small AIDS World After All

HIVers from across the globe hash out our AIDS future

June 1, 2001 By Staff

ROUNDTABLE PARTICIPANTS

Mercy Makhalemele, 30, South Africa
Director, Tsabotsogo Community Center, home to HIV-related empowerment projects
Tested positive: 1993
“I refer to myself as a township movement person, because my work is driven by the spirit of my community.”

Beri Hull, 45, United States
Advocacy educator for the National Association of People With AIDS
Tested positive: 1993
“I have a passion for holistic health, which is what I love to teach people about. I think it’s important to focus on the whole person.”

Alejandra Trossero, 36, Argentina
Latin America program assistant, International HIV/AIDS Alliance; activist, International Community of Women Living With HIV
Tested positive: 1998
“Positive women in Latin America are invisible, so I try to open up spaces where we can get together and express ourselves.”

Julian Hows, 44, United Kingdom
Consultant to the Global Network of People With AIDS (GNP+); co-organizer of the UK’s first AIDS conference
Tested positive: 1990
"I was lucky to have been involved in activism before AIDS, starting with the Gay

Paul Toh, 33, Thailand
Mobilizes PWAs in southeast Asia for UNAIDS; cofounder of the Asia Pacific Network for People Living With HIV in 1994
Tested positive: 1989
“My main priority is pushing for treatment and access to drugs for people with HIV in the Asia Pacific region.”

MODERATORS

Phill Wilson, 43, United States
Founder, African American AIDS Policy and Training Institute; POZ *contributor*

Tested positive: 1984

Brad Peebles, 30, United States
Publisher, POZ
Tested positive: 1994

Taking advantage of last summer's International AIDS Conference in Durban, South Africa, *POZ* sat down with PWAs from five continents to discuss the *whether*s and *whither*s of a global AIDS movement. Their insights remain as fresh (in both senses of the word) today as a year ago.

But what a difference 12 months make. More than ever, it's the best of times and worst of times in AIDS. Infection rates only continue to climb, especially in Eastern Europe, where a February report showed a doubling in a single year. And here at home, our new president threatens AIDS drug access by tightening pressure on Brazil for manufacturing its own versions of patented pills. But extraordinary victories have been won as well: The cacophony of HIV dissidents quieted in South Africa after President Thabo Mbeki withdrew last October from the "Does HIV causes AIDS?" debate. The same month, local activists illegally imported Thai-produced fluconazole, an anti-meningitis med, challenging the government to approve generic imports. When the pharmaceuticals took the South African government to court in March, U.S. activists took to the streets in support -- and in numbers. Feeling the heat, drug-makers Merck and Bristol-Myers Squibb announced unprecedented price cuts for the developing world.

Most important, the global conversation has undergone a sea-change. As Tina Rosenberg wrote in February's *New York Times Magazine*, "The debate about whether poor countries can treat AIDS is over. The question is how." In the following snatches from our raucous roundtable, our *POZ* pals share not only their secrets and strategies of survival but their faith that PWAs worldwide are essential to fight new infections and win treatment access for all.

Brad Peebles: I'm curious about what the first International AIDS Conference in the developing world was like for each of you.

Paul Toh: At each international conference, we have seen developments for infected people, such as the hope that came in Vancouver in '96 when protease inhibitors were discovered. A lot of my friends at Vancouver were sick, were really almost dying, but that conference gave us hope. Geneva in '98 was the start of developing countries' fight for access to treatment. Living in Asia, I'm lucky to be able to afford my drugs, but a lot of my positive brothers and sisters there are dying every day because they can't. The same goes for Africa and Latin America. Here at Durban, I

saw a strong press for compulsory licensing and parallel importing. I hope we bring it home to our own governments -- and continue to lobby activists in the North to push pharmaceuticals and governments on drug access.

Julian Hows: I think that this conference made people grow up a great, great deal. We are growing up as a movement -- perhaps because a lot of us are no longer thinking, "We are going to die." Many of us are privileged in the North, with full access to these medications -- but there are marginalized groups everywhere. In the UK, the groups hardest hit by HIV are gay men and Africans. Now we've started to share experiences, to get through the racism and homophobia and actually talk to each other. That has helped us forget the guilt that some of us *are* able to afford, and some of us are *not*, and instead forge the partnerships that are going to change things on a global scale. Whether we are unequal because we are marginalized in our own country, or whether it's the North/South divide, that's the challenge.

Beri Hull: I agree, and I hope this conference has a ripple effect. I know there was talk beforehand of people boycotting it [over President Mbeki's dissident stance], but people who decided not to come really lost out. Another thing that was important to see, as an advocate for women, was the beginning of a dialogue about how to bring men who have sex with *women* to the table. Gay men have been tremendous, vocal advocates, but men who have sex with women -- we're not hearing from them. I know UNAIDS is now putting out literature about how men drive the epidemic, but we have a lot of work to do to bring men who have sex with women along.

Mercy Makhalemele: I have always been disillusioned with the way women's issues are dealt with at AIDS conferences. Women are frustrated and angry. And we are anxious to deal with our issues ourselves -- not wait for governments and other institutions to do so. But this conference gave me hope that we can empower women by giving them information. I'm very grateful that I met a few women from the U.S. and elsewhere who helped set up a women's satellite conference here. We did this with little funding, but even so, local township women -- with HIV and without -- were given the chance by a global community to come together. This experience motivated me to help build a women's movement around AIDS.

Alejandra Trossero: In Latin America, women are the mothers of the self-help groups. There are no specific women's groups there, but when you visit HIV support groups, you see that women are the leaders, even though men are still the public faces of AIDS. These women step back from the public eye, because as women they have got more to lose, especially in these macho societies. Most are widows, with children and very unstable work situations. So if they come out as positive, they face discrimination, stigma, even the loss of their jobs.

For me, this conference was great because I saw all my mates from Latin America. It gave us a chance to address this same problem -- access to treatment -- and to share our experiences with people from other countries. This is the first conference where the Latins were not complaining about our representation. [*Laughter*.] We are always so few, but this time there were lots of us.

Phill Wilson: Let's pick up on the issue Paul mentioned: treatment access. What

challenges do we face around this?

Mercy: In Africa, there are a lot of things to consider. Yes, I would love to have treatment, to see people getting treatment. People are dying. But on our continent, people are not only dying because they don't have treatments. People are dying because of poverty. And compliance is critical: People could die from taking medicine if they don't know what the medications are all about. With the high level of illiteracy in our country, with treatment information written in language that people cannot understand, with the health care system so messed up and health care workers themselves not understanding the treatments, it is very difficult to transmit information that will help people survive.

In our country, I helped start a movement for drugs to prevent mother-to-child transmission. But I woke up one morning and said, "Mercy, for seven years you've been involved in AIDS, you lost one of your own children from HIV infection, but what do you know about AZT?" The reality is that women with HIV don't know anything about these treatments. That is why I now look at HIV as a developmental issue -- we must develop people's knowledge of HIV and treatment, especially women's knowledge. Because women in South Africa have a powerful history of making change.

Alejandra: Obviously, reducing the price of drugs is not the whole solution. There are some countries, such as Brazil and Thailand, that produce several of their own generic HIV drugs. So, in Latin America, people can buy many of the drugs from Brazil for less than half the usual price. Of course in Latin America there are middle-income countries where they can do this, and other countries where they have very few resources at all. Like Mercy, I meet lots of women who have no information. Women who say, "Oh, my husband died four years ago and I had a test three months ago, but my doctor explained that I'm still in the window period." After four years! So there is lots of information for us to disseminate even as we talk about treatment access.

Brad: There's such a strong movement to get drugs into developing countries, yet most of us who have been on the drugs have a lot of suspicions about them.

Julian: Yeah, I waited a very long time to start on medications. But to echo what other people have said, this is like starting on a treatment *career*, isn't it? You need all the information and then you need to be able to talk to your doctor about it. Fortunately, in the West, we are now in a situation where the first therapy is not salvage therapy. So we can make our treatment decisions based on all the drugs being available, based on thinking it through. Because pills ain't just for Christmas; they're for life, for most of us.

Alejandra: I think the issue is: My personal ideas about the medications are my personal ideas, but people need to have the option to get into treatment or not.

Beri: Absolutely. People must have the option to get treatment if they want to, and, as a PWA, you need to educate yourself about your health, your body. With these treatments, you can cause problems for yourself if you don't understand how they work. So it's critical for PWAs to link up and share our experiences. Studies can tell you this or that, but frankly when somebody tells me what happened to them personally, I get more out of it.

Information is a big issue in the U.S., too, but here I think it has a lot to do with people not accepting HIV in their lives. Too often, someone will call me and say, “I think I have HIV” -- this is in the U.S. -- and a week later I hear that the person is dead. And that’s because people are afraid to face the reality of HIV. They’re ashamed about it. And that’s deadly. There’s a zillion bugs out there -- why is this one making us so crazy? Other people look down on us, we look down on ourselves, and we have to stop doing that if we’re going to survive.

Paul: The question is, How do you normalize HIV? We have campaigns in Thailand, such as My Positive Life, where we take pictures of healthy people with HIV saying: “I’m a mother living with HIV.” “I’m a banker living with HIV,” to change people’s perception of PWAs. We PWAs have the responsibility to educate the world that we are as normal as you, walking on the street, that I can be your friend and hug you, share a cup with you, and nothing will happen. I won’t transmit the disease to you. So much centers around education, especially in developing countries, because lack of information breeds stigmatization. We as infected people have an important role to play in that education, and policy-makers have to recognize that. For someone to be infected, he has to get HIV from an infected person. But if the infected person takes on responsibility as a peer educator, how can transmission proceed?

Thailand introduced a 100 percent condom use campaign in 1994. According to the World Bank, this program protected close to 2 million people from HIV infection. We promoted a condom-usage culture. So when you walk into a disco and you get picked up by somebody and you tell that person, “Hey, look, I’m HIV positive,” the person will turn around and say, “Big deal, so what? Just use a condom.” That kind of scenario will protect our rights as positive people, affirm our right to live. We want to be recognized as human beings, not isolated from society and discriminated against. In Thailand, we’ve begun to cope with this stigmatization; we’ve been lucky.

Mercy: I wish I could come to Thailand. [*Laughter*.] I say this because I have fears for many sisters and brothers on this continent. My fears come from the fact that we are told by politicians that HIV does not cause AIDS. This strikes my heart, because these statements put people in situations where they will not take precaution one. Because if HIV does not cause AIDS, I can have sex with you and obviously you will never get AIDS. And it’s not only in South Africa, but in Namibia, where the president recently said that HIV may be a form of chemical warfare. That, to me as an African woman, creates anger. He’s the president and he’s still not taking responsibility. Namibia should put its resources toward dealing with the situation that is happening now. People are not dying of AIDS because they are irresponsible; it’s because people they believe in are telling them the wrong message.

Brad: Are these myths present elsewhere?

Julian: Definitely in Eastern Europe. Eastern Europe’s health structure has fallen down, and because the problem is so enormous, there is a great school of thought that refuses to acknowledge that HIV causes AIDS. This goes all the way through the medical and the political systems: Because we simply can’t cope with the problem -- we’ve always been able to provide for our people under the command-and-control economy, and now we’re not able to -- we consequently pretend that there is no scientific basis.

Beri: In listening to Mercy, I was reminded of when Ronald Reagan was president and HIV was emerging in the U.S. It's denial on a presidential, national level, and it's happened all over the world: "We're overwhelmed in dealing with it, so let's just not deal with it at all." But I've been reading the literature that the denialists put out, and I want to hear from them: If HIV doesn't cause AIDS, what causes it? *We* all know, because we live with HIV, that something is going on. I know when my immune system is not working the way it used to. So give me a real explanation!

Phill: They say AIDS doesn't exist, period, so we don't have to say what causes it. And then they say that it's caused by poverty, which is curious given that the initial U.S. population at risk was middle-class, white gay men. So I agree, it's about the truth being so frightening that people can't integrate it into their reality.

Beri: But the denialist movement is also a backlash against the tremendous expense of the drugs and the huge profits being made from them. I don't understand why the drugs are so expensive, either. I heard that some drugs cost less than a dollar to produce -- so why *are* we paying so much?

Julian: The thing is, marginalized communities, whatever the disease, will always be the last to hear and the first to fall. But, to pick up on Paul's point, what is really wonderful is positive people. Not only do we have the responsibility -- not to say that the minute we get the virus we get a halo with it, no, sorry, darling -- but we have done really well and continue to do so. As people who are prepared to be out about our status, we really ought to give ourselves a pat on the back because all over this world, through our leadership example, through being responsible ourselves, we have been getting other people to offer support, acknowledge people's fears and actually do the things that governments, doctors, pharmaceuticals -- organizations that *say* they are for us -- *don't* do. We have contained the epidemic to a great extent. I know it's horrific in a load of places, but we've done a lot about containing it.

Phill: Let's talk about the idea of a global community of people living with AIDS. Can there be such a movement?

Alejandra: There already is a global PWA community. We are here, and we have met in different places, or we know each other through magazines or telephone or e-mails. What we need to do is strengthen our community and get more people involved because, as Julian said, it's working -- we've really changed the AIDS epidemic. The main issues that join us now are access to treatment, care and love, and the right not to be discriminated against. And we are working in that direction.

Paul: I agree that there is a global PWA community, but what I'd like to see is global PWA *solidarity*. I'd like to see all PWAs coming together to fight for a common objective. Once you're infected, it doesn't matter whether you are a gay man or an IV-drug user or a woman -- you're just an infected person -- and we should understand each other and come together.

Especially now, if we are talking about living for many more years -- what do we do with our lives? Many of us are still here today because we are lucky to be literate and have resources. People who

are infected in the villages, who are illiterate, who have few resources -- what about them? They are the same as us, they are positive, and we have a responsibility not to forget them.

Phill: Is the virus enough to build solidarity? For example, is the virus enough to build solidarity between a Judge Edwin Cameron, who is a white, HIV positive justice of the constitutional court here in South Africa, and an anonymous homeless person in Mexico City with HIV?

Paul: I don't think so. [*Laughter*.] Sorry, but in certain communities it's so hard to come out as positive because the structures are not in place. If you don't have proper housing, essential food or even enough work, how do you expect to come out? All of us here can speak about our status because we have a good job, we know we won't be discriminated against the minute we go back home, we will still have our families and friends who accept us. But think of communities where the minute people come out, they will be stoned to death, which we saw in South Africa. In the early days in Thailand, people who came out had their houses threatened with bombs. This is real life. Judge Cameron can speak out because he's a judge, he's got money to buy drugs, he's a white man. But can a colored person in the developing world do that?

Mercy: I can do that. I can.

Paul: Which is very brave. I look up to you. We need more people like you to speak up so that we colored people can say that we want to fight for our communities, and we want positive people to come out together. That's why I stress the word *solidarity*, because numbers count.

Mercy: But the possibility of a movement or a common agenda only comes up if we, as people living with HIV from different countries, understand each other's situations. There are some people living with HIV in Europe, in the U.S., who don't even know what the hell we're going through down here. And a lot of people with HIV in Africa have misconceptions about European and U.S. PWAs. We see you guys as gods, as people who have everything. When you are not sharing with us, because you are proud and don't want to tell us that you are as poor as we are, we think, "But these people, they all get drugs, they get everything and they don't give a shit what's happening to us." There cannot be solidarity if we do not understand each other's conditions.

Alejandra: At the same time, we learned from our experience in Latin America how powerful we can be when we are in solidarity. Last year, the Brazilian government said they didn't have the budget to provide AIDS care for the next year. Immediately, we bombed the Brazilian government with e-mails and letters saying, "Please don't stop these programs!" -- people from everywhere in the world. Within three days, the Brazilian government had to review that position. So there are some successes with solidarity. I feel very positive. [*Laughter*.]

Brad: Does solidarity take a different form for PWAs in the U.S. or Europe than it does for PWAs in Africa or Asia?

Julian: It's not always about focusing on our respective strengths. It's also about creating the space where we as PWAs can share our fears. It's by sharing our fears -- of death, of not being acknowledged -- that we build those bonds from which solidarity comes. I am quite privileged, but

I have the same fears as you, and those shared fears drag us together so that we can start taking action.

There's that phrase, "Think globally, act locally." In the West, what I want to do is get people to write a letter to a government development agency saying, "What the hell do you think you're doing with Africa, not giving enough money?" On another level, I want people to do what I'm doing at the moment, building one-to-one relationships with people from Africa, seeing what interchange we can have. It's about creating that human contact *and* lobbying your own government.

Paul: I don't really see a difference in solidarity in the developed and developing world. If you trace back history, how did ACT UP and all the groups in the developed world achieve what they did? Through solidarity. It was because infected people came together, marched in the streets, changed policies -- that's why they got to where they are today. Now this is happening in the developing world, but we have bigger hurdles because we are fighting more stigmatization. We face not just the risk of being HIV positive, but the risk of being killed if we come out openly.

Phill: I know the world views ACT UP as being a solidarity movement, but as a black, gay man in America, that's not my perception. Not to denigrate the real power of that movement, but my experience is that it was mostly white, mostly male and mostly gay. And that often they were not talking about me or for me. And that their ways of activism were not useful in my community.

Mercy: In Geneva, ACT UP was wearing t-shirts that said, "Africa is burning." You know my first thought? "How do you know it's burning? Have you ever been there? And if it's burning, how is it that you're walking away from the burning without me?" Because I'm the one who feels the flames.

You can never make solidarity if you don't understand what is happening with other PWAs. I took the chance I had to travel to learn about other people. I worked hard to spend my time in Switzerland seeing how the Swiss people live with HIV. And that knowledge opened my brain to say, "Mercy, you are not as poor as you thought. There are lots of people, even in Europe, who are struggling on a daily basis." That experience empowered me to understand things differently.

Brad: As gay white men, we were motivated by life and death. Maybe we didn't try to change the world, but we wanted to save our lives. So how is it that, with so many millions of people in developing countries dying, there isn't civil unrest?

Phill: Because as a white man, you are raised with a sense of "I deserve to live." Not everyone gets that message.

Alejandra: It's also what Mbeki said in his speech to the conference: There are many viruses, but the problem here is poverty. On the last day of the conference I was looking around and I thought, "What are we doing here?" Because there are so many problems to solve, not just HIV. And we are *not* dealing with poverty.

Beri: I think if, as PWAs, we focus on the fact that we're dealing with a life-threatening disease, *that* creates solidarity. Our coming together is a win-win situation. Either we gain hope or we gain

humility and gratitude. In the U.S., there’s a lot of vying for power and resources around AIDS -- this or that group is not getting its share of the funding -- but that’s not about people with HIV trying to survive. A lot of times that’s just people who are HIV negative running the show. But it’s such a powerful experience to go to an international AIDS conference and see people with HIV from all over the world. It makes you feel part of a real community. We all have so much to deal with, trying to keep our health up, our spirit up, not being stigmatized because of a disease that we didn’t expect and didn’t want. We have to hold on to each other. A lot of times, that’s all we may have.

Paul: I do see light at the end of the tunnel. Every conference I come to, we bring more and more people in the PWA community together to voice the real issues that we face. And we push governments, policy-makers, UN agencies, to recognize that HIV requires a bottom-up approach. They have to realize that it is the community that moves HIV, not decisions from the top. They need the PWA community. They need people infected in each community to help them save the world.

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