

Enemies at the Gate Storming Montréal's Palais de Congrès, and Makeshift Battle Stations in Fortress San Francisco

By David Barr
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Bodyguarded Investigators

It could be said that NIH-activist relations reached their untenable nadir in 1990. Nearly 30,000 Americans had died of AIDS the previous year, and the National Academy of Sciences announced that the disease would cause more than 50,000 American deaths annually by 1991. Midway through an otherwise unspectacular Bush (père) administration, officials had announced a policy to ban HIV-infected foreigners from entering the United States.

Twelve years on, the image of an international AIDS conference session conducted from behind the barricade of a presumably bullet-proof translucent shield seems either surreal or eerily prophetic. Yet those present at the Moscone Center that stretch of long summer solstice days in 1990 are unlikely to forget the spectacle.

A spring ACT UP attack on the bucolic campus of the National Institutes of Health had upped the stakes with pyrotechnics, blinding walls of colorful smoke, and scores of arrests. Rumor had it that several ACTG researchers had received death threats. And so as the VIth International AIDS Conference convened in June of that year, an auditorium of weary delegates would see only the gray silhouettes of the vilified data presenters (Miami's Fischl, Harvard's Marty Hirsch, Stanford's Tom Merrigan, Seattle's Larry Corey, among others) as they hunkered down in genuine fear for their personal safety.

Activist frustration and fear had become the fear and frustration of these ACTG investigators -- less through any empathic means than through one of insidious infectiousness. A cycle of fear and irrationality had developed, and someone would need to step in to break it. As David Barr continues to chronicle in this final 2002 installment of TAGline, it would require only a few key gestures of courage and generosity to fashion a new dynamic where street trampling storm troopers and the king pins of big pharma could join forces (or at least engage, on occasion, in civilized dialogue) -- and in doing so alter the course of history. Those who would step up to this challenge would be (say what you may) NIAID director Tony Fauci and a handful of forward thinking activists among whom, in San Francisco, included TAG founding director Peter Staley via a heart-wrenching and conciliatory opening plenary address. But wait, this is David's tale.

Montréal 1989

Location, location, location. Whatever lack of activist presence there was in Stockholm was more than made up by Montréal a year later. Only eight hours on the bus from New York enabled ACT UP, then at the height of its golden era, to send bus loads of people. The opening ceremonies did not go as planned. ACT UP had started picketing outside the

conference center. People were walking around in a circle, acting up. Many of us were standing inside the entranceway. Two escalators led to the auditorium upstairs. The hall was not yet open, and we were milling around waiting to go upstairs. The number of demonstrators began to grow. The escalators began to move, a bunch of us got on them. I think I was the second person on the escalator. The security people tried to stop us, but it was too crowded and there was no way they could control the mass moving forward on the escalator. There was no plan. No one thought we were going to take over the conference, but then, it happened.

The demonstrators were the first people in the auditorium. A few hundred of us took the stage, yelling. The hall began to fill up. People seemed supportive -- not that we would have known if they were not. A manifesto was read by Conyers Thompson of ACT UP/New York. He read it again in French. Then we had a problem.

The hardest thing about holding a demonstration is ending it. Unless you get arrested or have managed to get all your demands met, it is difficult to know when to stop. No one was arresting us, and all our shouting wasn't going to end the AIDS crisis at that particular moment. So we just kept yelling.

The supportive crowd got a bit bored and wanted to move on. We didn't want to give up our ground. Finally, we marched off and occupied the front rows of seats that had been reserved for dignitaries. Then the conference organizers got upset and wanted us to move because they had no place to put the Zambian president and the Canadian Prime Minister. We wouldn't budge. This went on for quite some time.

Finally, they started the program. A woman from the Caribbean made a great speech, but used the word victim and the ACT UP members started hissing her. It wasn't pretty. We felt great though. And, we thought that we would be on the front page of every paper all over the world, having taken over the International AIDS Conference what with every reporter watching. Unfortunately for our media hungry selves, another demonstration, in China's Tiannemen Square, shook us off the lead spot. We woke up to a photo of some guy standing in front of a tank.

It was in Montréal that ACT UP released its first Treatment and Data report calling for a parallel track to speed access to drugs. Best of all, no less than Tony Fauci himself told the New York Times that he agreed that it was a good idea. That made the front page and started a round of talks both with government and industry to make expanded access a reality. Bristol-Myers called the ACT UP Treatment and Data Committee and said that they wanted to provide ddl through expanded access and, amazingly, wanted the ACT UP members to assist in developing the protocol.

The program provided ddl to over 25,000 people with AIDS at no cost until the drug was approved. Data from the expanded access program provided important safety data. Not only did we succeed in getting the drug out, but we also proved our argument that expanded access programs and working with patient activists could make for better science and faster drug development.

ACT UP was having a love fest with itself. Montréal was a victory, and we had a great party

not only to celebrate but also to premiere the new safer sex porn video starring Peter Staley -- later, TAG's Founding Director. In it Peter covered Blaine Mosley [the towering and often leather skirt and beads clad ACT UP/New York facilitator] with honey and whipped cream. I went dancing with Gregg Bordowitz, who had directed the video and was popping dextran sulfate, the AIDS cure du jour.

San Francisco 1990

At the 1990 conference in San Francisco, I shared a room with Jay Lipner. Jay was on intravenous gancyclovir by then and had brought all his IV stuff with him. There were boxes of saline solution, needles, plastic tubes, and bandages all over the room. Jay would spend a few hours in the room each day giving himself his infusion. It was a very different view of living with AIDS from the theatrics going on at the new Moscone Center. Most AIDS organizations boycotted the San Francisco conference in protest of the U.S. immigration and travel restrictions on people with HIV. These restrictions are still in place today. Of course, the U.S. has probably exported more HIV than any other country in the world. In fact, its immigration policies forced the deportation of many HIV-positive people back to countries where there was, at the time, little HIV, few prevention services, and no care.

I was working for Gay Men's Health Crisis (GMHC), which had helped to spearhead the boycott. I, however, attended the conference because as the treatment policy guy I needed to attend the sessions. I think there were more demonstrations than presentations. Even the conference organized an official march. Some of the researchers were walking around with armed bodyguards in a belated over-reaction to ACT UP's "Storm the NIH" demonstration of May 1990, and its associated vilification. We were a bit surprised by this since we had never engaged in any violent activity. (Okay, Mark Kostopolis did break a window at the FDA.) The only ones whoever got hurt were the demonstrators -- by the police.

Yet despite the tensions that many researchers were feeling, this was a time when the activists and the research establishment began to come together. First there was the issue of ddC. Hoffmann-La Roche, the drug's producer, absolutely refused to develop an expanded access for their drug. Although Bristol-Myers had had a good experience with their ddl program, the folks at Roche would not consider it. We called, met, wrote, but they wouldn't budge. We started a petition drive and went throughout the San Francisco conference getting many of the leading researchers and docs to sign on.

I remember running after Margaret Fischl and catching up to her outside that ugly Marriott Hotel that looks like a Wurlitzer jukebox. When I approached her, she seemed a bit terrified. But when I asked her if she would sign, her attitude changed completely. She wholeheartedly supported the effort and signed up. She was furious with Roche for not making the drug available, as many of her patients in Miami needed it. It was the first time that we were able to join forces with the researchers a bit and get them to do some advocacy.

Our relationship with NIAID was also rapidly changing, thanks in large part to Tony Fauci. He understood the value of developing a good working relationship with us and proposed creating a representative group of patient advocates within the ACTG. That group became the Community Constituency Group. It was a groundbreaking step in bringing patients into the research process. It is still an active part of both the ACTG and the CPCRA twelve years

later.

Peter Staley, a person with HIV, the founding Director of TAG and a de facto leader of ACT UP (all leaders in ACT UP were de facto as it was officially founded as a leaderless organization), gave a beautiful plenary speech, acknowledging both the recent actions by NIH to create better relationships with activists and blasting government and industry for not doing enough. Peter was asked to give the speech after Vito Russo had to cancel because of his health. Vito died soon after.

I will take credit for suggesting the final demonstration. Louis Sullivan, the Secretary of Health and Human Services, was scheduled to speak at the closing ceremony. ACT UP was meeting at a Ramada motel planning its activities for the week. I proposed that we not allow Secretary Sullivan to speak, that we drown him out with whistles, yelling, etc. It was Dr. Sullivan who had the authority to change the restrictions on HIV immigration and travel, as well as most other AIDS-related policy. If he wanted to do something about AIDS, he should change the policy, not come to the conference and pretend that he was concerned.

There was some debate about whether we should interfere with his freedom of speech. I felt that the First Amendment was there to protect us from the government, not the other way around. Besides, if the HHS Secretary wants to say something about AIDS, he can do it anytime he wants. This was a rare opportunity to tell him what we thought of his Administration.

The place was packed. When he stood up to speak, there were demonstrators everywhere. We stood up and turned our back on him and started yelling, whistling, and some people were setting off loud fog horns. The audience seemed to be in support of our actions. Dr. Sullivan stood there and waited, and waited. Finally, he started giving his speech. The catcalls and noise continued. No one could hear him, yet he continued. The whole thing went on too long and people started throwing things, first crumpled balls of paper, but then oranges and other stuff. It began to feel tense. He finally finished. Paul Volberding got up and thanked him. We gave a final yell and then proceeded to march out of the building. The audience applauded as we left the auditorium (I think in support and not because we were leaving).

We marched out and onto the street, feeling victorious. (Although we hadn't won anything: twelve years later and the immigration restrictions are still in effect. Empowerment isn't always all it's cracked up to be.) We marched down toward Market Street and ran right into the annual Gay Pride parade with thousands of people watching. The crowd started cheering as they saw us and we marched into the parade route, chanting all the way to City Hall. It was a glorious moment.

Florence 1991

Suffice it to say that the most important thing at the Florence conference was dinner. How could AIDS compete with dinner in Florence? It couldn't. Even the most Trotskyite of the AIDS activists were lured by the lasagna. There was also the multitude of Italian guards with several different uniform styles that distracted one's attention from the work at hand. It was the only time I didn't gripe about having to sit at the GMHC booth and hand out stuff, as the guards were very interested in our condom packs. I, of course, offered all types of detailed in depth

instruction in their use.

Still, despite the distractions, some work managed to get done. It was the year I made Max Essex mad. The immigration issues were (and are still) unchanged. GMHC took the lead in calling for a boycott of any future International AIDS Conferences in the U.S. until the ban was lifted. Unfortunately for Dr. Essex and his colleagues at Harvard, the next conference was scheduled for Boston and Harvard was the co-sponsor.

There was a flurry of meetings in Florence about this, since planning was already well under way for the Boston conference. The Harvard group tried to assure us that they agreed with our position and would do everything they could to ensure that people would be able to attend the conference, but we wouldn't budge. We said that there was no way that Harvard could make assurances for the U.S. government and, besides, it was the principle of the thing. Our objection was not merely about conference attendance, but about the policy in general and we wanted the International AIDS Society (IAS) and Harvard to take a stand.

While others from GMHC played the moderates, I played the crazed activist. I told them that they could be assured that there would be pandemonium in the streets of Boston if the conference were held there, that we had a year to plan such demonstrations and that we would be there in force. I explained that while we would only organize peaceful demonstrations, we could not be responsible for the actions of other, more frustrated activists. The Harvard folks were furious, and nervous. They ended up moving the conference to Amsterdam. The hotels and others sued them for breach of contract. I don't know what happened with the lawsuits. I remember being deposed about three years after the conference took place.

The lack of a major scientific discovery or any major political event meant that the Florence conference was sort of a let down. In retrospect, we can see a pattern of this happening. San Francisco was a milestone in political mobilization, not just on the part of a small group of activists as in Montréal, but the embracing of a political agenda by many of the researchers, conference organizers -- and even some people within government (when they were able). In San Francisco, the conference became a political event and has been ever since. Also in San Francisco, we began to get excited about an antiviral treatment strategy, having data not only on AZT in people with AIDS, but some on ddI, ddC, early treatment in people with HIV. In San Francisco, there was the articulation of a treatment strategy, albeit unproven. In Florence, we mostly heard about the progress from the year before. But, ah, dinner. ...

A few food stories -- Greg Lugliani, Communications Officer at GMHC at the time, took the room with the view at the little hotel on the Arno. He had an affair with a busboy from my favorite restaurant, La Cinghiale Bianco. When I returned to Florence a few years later, he was a waiter (not Greg, the busboy). One night, after dinner, a whole bunch of us (I know that Mark Harrington was there) went for gelato at the best place in Florence on the unfortunately named Via Stinchi (pronounced "stinky"). The place was packed as usual.

There was one guy, a Florentine, who was particularly attractive. He couldn't have been more than 20 and was with a group of friends, including someone who was probably his girlfriend. Spencer Cox, in our group, was unabashedly ogling this guy and making comments about him to us. He was really being shameless -- even for Spencer -- who was about 20 himself at the

time.

The guy noticed the attention and, despite his obvious dissatisfaction, Spencer continued to ogle. The guy finally lost it, and approached Spencer very aggressively, yelling Italian about three inches from Spencer's nose. Spencer started to stutter in response. He couldn't get any words out. He finally said, "I, I, I, I, don't, don't speak any English." We all immediately lost it and started laughing. The guy's friends pulled him back, and we apologized for Spencer -- who was now the color of his pistachio gelato.

The third story involves a dinner I had with Mark Harrington, Dan Hoth (then the Director of the NIAID Division of AIDS), and Larry Corey (then the Chair of the ACTG Executive Committee). It was unusual for Mark and I to be socializing with these two, but a good opportunity. It was one of the few times that we really all got to get comfortable and talk. We went to a nice place on the other side of the river.

We proceeded to order and started drinking wine. I had my share and so did Mark, but Dan and Larry got sloshed. We went through all the ACTG politics. It was a friendly evening. At one point, Larry described his approach to AIDS research, based on his work with herpes. He explained that when he went to work on the herpes virus, he, "looked that virus in the eye and said to it, 'I know you, and I am going to fuck you.'" I appreciated his macho bravado but suggested that he not take quite the same approach with HIV, as it could be dangerous. After dinner, we all went for ice cream and Dan spent a good amount of time trying to psychoanalyze Mark. Of course, finding an AIDS vaccine is an easier task.

Next month: Virus laden activist lymph nodes bask in Amsterdam limelight. And ACTG 155 presenter's sleazy sleight of hand spawns angry exodus in Berlin.

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Necessary Diversions The Boston AIDS Conference That Never Was -- And Other Grim Tales

By David Barr

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A Sick Lymph Node Makes Its Début

TAGline catches up with its peripatetic international scribe as he negotiates a perilous course around canals and through abandoned railway yards en route from the North Sea to a recently liberated East Berlin. (And, knowing David, straight on to Prague?) The penultimate installment of David Barr's "irreverent, more factual than you might imagine, and sort of self-serving recollection with digressions" history of the international AIDS conference continues unapologetically below.

Amsterdam 1992

Two days before I left for the Amsterdam conference, a march and rally was held in Times Square with over 25,000 people demanding a better government response to AIDS. I developed and coordinated that project, United for AIDS Action, a coalition of over 400 AIDS organizations, unions, advocacy groups, and religious organizations. It was held in conjunction with the Democratic National Convention.

United for AIDS Action was a tremendous amount of work and it was very successful, so getting to Amsterdam was in itself a great relief. Amsterdam is a wonderful place and the Dutch AIDS policies are particularly sane. I think that for many of the activists, it felt as if we were on our turf. Certainly, being there was in and of itself a victory because we were supposed to be in dreary Boston but had successfully moved the conference to Amsterdam in protest of the U.S. HIV immigration policies. The weather was great, and I bicycled every day to the conference center.

Mark Harrington's plenary talk was the high point. Mark was able to present a scientific agenda for AIDS research by using the results of the biopsy of one of his lymph nodes as a basis for discussion. He showed the slides of the lymph node, "crammed with virus" and articulated research questions that were raised from the findings of the biopsy. It was a brilliant coming together of abstract science, policy, and the personal. I think that particularly for many of the researchers in the audience, this combination was very powerful.

For the activists, it was equally powerful because one of our own was talking about science in a very sophisticated way. The speech was very well received -- with a standing ovation. Of course, the underlying story is a bit more convoluted, since Mark had never really had an HIV antibody test before. He had assumed that he was infected for some time, but had not actually tested. He would get his T cells checked every once in awhile, but that confirmatory piece of information was never dealt with.

By 1992, many of us were strongly encouraging Mark to get tested. So, rather than go to the testing site, like everyone else, Mark, in typical fashion, goes to St. Luke's Roosevelt Hospital and has Donald Kotler remove a lymph node and send it to Tony Fauci's laboratory. Mark's speech in Amsterdam was not only an analysis of his lymph node biopsy; it was also a disclosure of his HIV status, though most people didn't know that part of the story. Drama queen. ...

Elizabeth Taylor made her annual big splash at the conference.

(I forgot to mention her speech at the amfAR reception in the Florence villa, where she made special mention of the activists on the street. I got to chat with her, a gay man's wet dream. She decided to go jewelry shopping on the Ponte Vecchio and caused such a commotion that the police had to be called. In San Francisco, the reception was at Wolfgang Puck's Postrio. Ms. Taylor made her first appearance after a very well publicized and very serious bout of pneumonia. She didn't look too well. Her hair was in frenzy, though I don't think that was the pneumonia. As always, she spoke well and forcefully about AIDS and the lack of a sufficient government response.)

In Amsterdam, the amfAR reception was at the Bourse, and Ms. Taylor wore an incredibly unfortunate white puffy dress with black polka dots on it. The press went berserk at her press conference. GMHC's Richard Elovich managed to approach her and started talking about needle exchange with her. She got very interested and started talking to the press about it. She and amfAR have been champions for needle exchange ever since. The U.S. government still does not put a dime into what is probably the most effective form of HIV prevention other than antiviral therapy to prevent mother-to-child transmission (MTCT) of HIV.

Berlin 1993

Amsterdam was not a milestone conference, but it was invigorating. Berlin was a milestone, but a very depressing one, sort of a bitter pill not to swallow. Berlin heralded the collapse of the antiviral treatment strategy that industry, academia and community were all pushing so hard.

In Berlin, two central ideas at the heart of the treatment strategy were disproved. The first was that early use of AZT was beneficial. This was not a surprise, as the results from the Concorde study only proved what most people with AIDS on AZT found out the hard way: the drug stops working when used alone. The recommendation to use AZT monotherapy based on a T-cell rise was flat out wrong and people who started AZT early only became resistant to it before it could really help alleviate symptoms of AIDS-related illness and prolong survival. The drug got wasted.

But we pretty much knew this going into Berlin. The research and drug development establishment had moved on, pushing the notion of dual nucleoside therapy either to replace failing AZT monotherapy or as a starting regimen. Two drugs would be better than one -- and overcome the possibility of resistance. The results of ACTG 155 (a study which compared AZT or ddC monotherapy to dual therapy with both drugs) were released in Berlin, and the study showed that the two drugs did no better than one in helping people failing on AZT monotherapy. The bug was still mightier than the drug.

This was depressing enough. What made it even more depressing -- and infuriating -- was that NIAID and the researchers involved in the study skewed their reports on the study results. Instead of presenting the results of the planned analysis, which showed the AZT+ddC combo as ineffective, an unplanned and statistically underpowered substudy analysis was performed which showed, in one of the arbitrary T-cell groupings, that patients on two drugs did "better" than the other patients.

This was hogwash. But when I got to Berlin, already knowing the outcome of the study, and picked up a copy of the NIAID press release, only the substudy analysis was described. And a wonderful spin about positive study results was promoted. My comrades and I went ballistic. We were upset enough about the bad results, but to also have to deal with lies about it was really infuriating. We talked to the communications people at NIAID, who didn't have much to say. So we went straight to Tony Fauci, who listened to our concerns, agreed with our position, and ordered the press release rewritten to reflect the real results of the study.

Then we went to the presentation of the study results given by Margaret Fischl. Before the

study was ever finished, Dr. Fischl was known to say, "I can tell which patients are on combo therapy. I know its working." Dr. Fischl presented the best possible case for randomized blinded trials ever in the history of clinical research. She began her presentation by saying that she was going to present the first data showing the effectiveness of combo therapy. She started presenting the post hoc substudy analysis, and we all lost it.

Mark Harrington, Gregg Gonsalves, Derek Link and I were all there, and we got up and just started to scream that this was a pack of lies. Dr. Fischl got all flustered. I got up from my seat and went to the microphone and started yelling that she was not telling the truth. She responded and had to admit that the planned results of the study were the exact opposite of what she was presenting. We continued to yell. The audience knew we were right and started applauding our comments. Finally, we all walked out of the auditorium.

We left the conference site and starting walking down the street. We were all worked up. On the one hand, we were exhilarated from our yelling and getting a good response from the audience, feeling that we had prevented the false presentation from being successful. And we were angry. But we were also depressed, as we knew that this news signaled a very dark time for us, our friends, and for people with AIDS. The treatment strategy that was being so heavily promoted by industry, upon which the clinical research infrastructure had been built, the strategy for which we as treatment activists pushed so hard to get early access, the strategy that provided hope to people with HIV around the world, had just collapsed.

We kept walking down the street, chattering away about how outrageous the presentation was and how angry we were, and how pleased we were with our performance. We were really worked up and needed to calm down. We walked into this park, and there was this big grassy open area full of naked German sunbathers. It was just down the block from the conference center and there were all these naked people lying in the grass. We were a bit taken aback, sat down, and began to relax, the unusual scene capturing our attention and taking us away from the scene we had just been through.

The ACTG 155 presentation was a life-changing incident for me. Not only was the news upsetting personally, but also professionally. I felt I learned an important lesson, which is that as a treatment activist, to the greatest extent possible, let study results determine the policy positions I support and for which I advocate. My hopes and dreams and fears should not guide that which I advocate for.

I was as responsible as anyone in pushing for early access and use of both mono- and dual-therapy treatment. But that recommendation was premature, never based on reliable data, and ended up not only being wrong, but making the situation worse for tens, perhaps hundreds of thousands of people. How many people followed the recommendations for early use of antivirals and became resistant to the drugs before ever becoming sick? How many people suffered from debilitating side effects without getting any benefits from the drugs?

The FDA allowed overly broad indications to be approved and never followed through in demanding that post-marketing studies be carried out. The NIH led the way in developing recommendations for early use of drugs without planning appropriate clinical studies to determine if those recommendations were right. Industry promoted early use to both physicians and patients. And treatment activists, including myself, pushed hard to make this

all happen. Our community organizations taught their clients to start treatment early. We all fell short of our responsibility to get the research done, instead we let our sense of desperation and desire for success get the better of us.

Worst of all, most of those involved did not learn from the mistake but, instead, repeated it over and over again: first and most cynically with 3TC; then again, with saquinavir and the rest of the protease inhibitors.

The treatment guidelines that came out after protease approval once again pushed for early treatment. The researchers responsible for designing and conducting the clinical studies to learn when to start treatment were the most aggressive advocates for guidelines recommending early treatment. Those guidelines made the studies impossible to carry out. Now we know the recommendations were wrong.

I became a pain in the ass at FDA hearings, ACTG meetings, and, most vociferously, as a member of the panel that developed the HAART treatment guidelines. I bitched and moaned about the lack of data, the need for when to start studies, the potential problems with the new and untested therapies. Most of the researchers did not want to hear it. They belittled my concerns about adherence, about the possibility of unknown side effects, and the need for "when to start" studies. It was the people with HIV on the panel, mostly Mark and I, who were always calling for more conservative guidelines, facing pressure not only from the virologists, but also from other community advocates, who were concerned that our caution and call for guidelines that only recommended that people with AIDS (not HIV) start therapy, would interfere with their advocacy for more ADAP and Medicaid funds.

My colleagues and I were certainly in favor of more ADAP funds, but we had lived through the mistakes of the past and did not want to see them repeated. We did not want these promising, life-saving drugs to be wasted. I was labeled anti-treatment, even though I was on treatment. My position was never anti-drug, but for a more cautious use of the drugs. It is a position that is now, finally, reflected in the guidelines. But how many people are unnecessarily drug resistant today who never should have popped a pill? How many suffer from facial wasting or high cholesterol? How many will have no treatment options left for them after their T cells drop below 200? After we finally succeeded in getting the guidelines changed, I quit the panel in disgust.

I came home from Berlin demoralized and depressed. I knew that there was little hope to offer the clients pouring into GMHC. I left the GMHC policy department and turned my attention to developing treatment education programs for clients. I felt that for some time to come our best defense would be OI prophylaxis and treatment. And teaching people about these options, particularly Bactrim, just might be the most important thing I could do. So I started developing workshops, counseling programs, and treatment fact sheets, while continuing to advocate for better and more responsible clinical research and drug development. And just as I saw so many friends, colleagues, and clients get sick and die, I also saw my own T cells drop below 200, my energy wane, and my health begin to deteriorate. In 1995 I began to consider going on disability. I never imagined that, only three years after Berlin, there would be another revolution in AIDS care. We were very lucky -- or, at least, some of us were.

One night in Berlin, Mark Harrington, Gregg Gonsalves, Derek Link, Simon Watney and I went

to dinner at the revolving top of the telecommunications tower. Everyone was in a good mood. There was a photo taken of all of us that sat on Gregg's computer in our apartment for years.

Next month: Berlin's schaden yields to Vancouver's freude, but only after a fruitless tour of Japan and a decision to pare down by half the frequency of the international AIDS conference.

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Yin and Yang Yokohama, Vancouver, Twin Pacific Ports, Serve as Polar Opposites for Scientific Advances

By David Barr
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Everything About to Change

In a September 1996 report for the Washington Post, science writer Elizabeth Kastor observed, "Hope is a hungry thing, as easily fed by wishful thinking as by certainties" (WP 9/5/96). And so it was, in the fading light of one extraordinary summer, that hope grew fat gorging itself at the twin troughs of imprudent optimism and intoxicated scientific circumspection. While celebratory mobs stampeded aboard the Eradication Express, at least one curmudgeonly Cassandra denied himself a ticket to ride. Shouting obstreperously, "But where's the data?" at every turn, David Barr came perilously close to acquiring an Iris Long reputation as elocutionary broken record. Instead, he put his money where his (big) mouth was, up and left his comfortable post at Gay Men's Health Crisis, and devoted the next four years of his life to facilitating a joint effort of government and industry which promised to shed light on the prickly issues of long-term clinical care in HIV infection. And so, the curtain rises on that "Woodstock of AIDS conferences."

Yokohama 1995

In the words of Mark Harrington, "Never have so many traveled so far for so little." At the last minute, I decided to stay home. We had rented a house in up-state New York, and I spent my time there. Yokohama produced little progress -- either scientifically or politically. The ACTG 076 trial of AZT to prevent perinatal transmission was formally presented there, but everyone already knew the remarkable and unexpected results prior to flying half way around the world.

Vancouver 1996

Vancouver was lovely and the weather was great. Despite my reservations about the treatment hype, there was no question that this was big news -- not only the treatments but also the better understanding of how the virus affects the immune system, and the use of viral load testing in clinical practice. Everything was about to change.

The 1996 Vancouver conference was the Woodstock of AIDS conferences, the "eradication conference," the promise and the glory. But I acted as the curmudgeon. I was nervous that the hype was premature, that we would allow our desperation to guide us and not push for more rigorous studies. I was shouted down everywhere. Even my closest colleagues had jumped on the eradication train.

I had spent the weeks leading up to the conference involved in a series of meetings led by the Keystone Center to discuss how the new drugs, diagnostics and understanding of the virus would affect our clinical research infrastructure. The meetings consisted of treatment advocates, representatives from the National Institutes of Health, the Food and Drug Administration, the Centers for Disease Control, academic research centers, Congressional representatives, health care providers and insurers, and treating physicians.

We all seemed to agree that HIV clinical research would move into a new phase, requiring a more collaborative approach. Instead of focusing solely on drug development, we now had to conduct studies that tested the use of approved treatment strategies in large patient populations. The discussion was a good one, and in our final report we recommended creating a body that would continue the discussion to identify the emerging questions in optimizing HIV care and clinical research.

That body became the Forum for Collaborative HIV Research. And I left my job at GMHC after seven years and my home of 41 years to go to Washington, D.C. to start the project. The federal government and the pharmaceutical industry funded the project. It was started with the blessing of then Vice-President Al Gore, and was led by an Executive Committee that included representatives from industry, government, academia, health care provision, and the AIDS activist community. I ran the Forum for four years.

Once it was on its feet and had developed its agenda and a way of working, I felt it was time to turn it over to someone else. Also, I couldn't stand being away from New York. So I left. And it is now quite healthy and productive in the hands of Dr. Veronica Miller.

My concerns in Vancouver continued to drive my ideas for the Forum agenda. While the Forum was not successful in getting NIH and industry to conduct large studies examining when to start treatment and the effects of antiviral therapy over time, some progress in that area was made -- especially through cohort studies. Meanwhile, the Forum focused its attention on the emerging difficulties in using the treatment regimen.

The Forum held the first meeting ever on treatment adherence, which produced a research agenda that guided HIV research funding. It held the very first discussion about fat redistribution and lipid abnormalities, and produced recommendations that led to multiple studies. It outlined the need for, and ways to develop, treatment education programs for physicians and patients (about how to use the new drugs effectively). The Forum also developed a plan for the federal government to provide treatment education for patients (some of which was actually implemented). The Forum developed the first agenda for "outcomes" research in HIV treatment.

Stephen Gendin arrived in Vancouver with his dog in a bag and his hair dyed like a rainbow.

Laurie Garrett complained that he needed a shower, and she was not at all pleased to be seated directly in front of him on the British Columbia-bound 737. I spent a good amount of time with him there. I was lucky to have a really nice hotel room with a great view, and so we had a party there. I spent much of it talking with Stephen on the balcony. He was already pretty sick, and the drugs were coming along just in time.

Stephen firmly believed in "Hit early, hit hard," and by the time the protease inhibitors came along he was pretty much resistant to everything else. He was on multi-drug salvage therapy from day one of the HAART revolution.

Stephen created the phrase "barebacking," which means deliberately not using a condom for anal sex. The whole issue created quite a firestorm, and Stephen was in the middle of it all. He was not advocating unsafe sex between HIV-positive and HIV-negative men; but rather, arguing for the importance of allowing people to make their own choices about the conduct of their sexual lives.

The issue started with a reasonable (and I would say, useful) discussion about sexual behavior. But it quickly became sensationalized and Stephen bore the brunt of it. His documentation of his own personal struggles with safer sex and with his illness were published in painfully blunt and self-exposing articles in Poz magazine.

Geneva 1998

The Geneva AIDS conference was the conference that felt more like a pharmaceutical trade show than any other. Part of this was the set up of the hall: You had to walk through the industry exhibition hall at least twice a day in order to get from the plenary lectures to the other auditoriums and poster exhibition spaces. I don't think the commercial displays have ever been more elaborate. The slogan of the meeting might have been "Bridging the Gap," but there was actually not much of a bridge. It was really "Selling the Pills."

Mark Harrington, Wafaa El Sadr and Eric Sawyer all made good pitches for broader treatment access, but the real push for global access was not to begin for another year when ACT UP Philly and Health Gap began to push hard on Al Gore, Bill Clinton, UNAIDS and industry.

Geneva did pay attention to some of the emerging problems associated with treatment -- particularly adherence. Treatment adherence was becoming a hot issue. Not only because it was causing large numbers of people to develop drug resistance, but also because the development of adherence services was a money maker for health care providers and community organizations -- many of whom were looking for new things to do since so many of their clients no longer required the kinds of late-stage AIDS services they were accustomed to providing.

Adherence was the new "program." Not that there is anything wrong with that, but it was a little odd to see so many community-based organizations jumping on the treatment education bandwagon with such a vengeance after being reluctant for so many years. We couldn't get them to push PCP prophylaxis, even though it probably saved more lives than ritonavir. But once they smelled a funding stream, they were all over it.

I had dinner with Stephen Gendin and his boyfriend, Hush, one night. Having moved to Washington, I hadn't seen Stephen in a while. He had been quite sick during that time. He was thin and gray. I knew he had had a hard a time. It was good to see him. During dinner, we spent a good amount of time talking about his health. Hush watched over Stephen, and it seemed like things were good between them, if difficult.

The next day, Mike Barr and I had a long talk on the grass outside the conference center, where he told me that Hush had recently seroconverted, that Stephen was the person who infected him, and that Hush was infected with a virus that was already resistant to every single drug -- as was Stephen. Later, I would spend much time talking with Stephen about all this. He and Hush both wrote long and personal articles in Poz magazine describing their experience, their unsafe sexual practices, and Hush's infection.

Next month: High-wire impostor Zulu drummers at Durban's Las Vegas style opening ceremony, scientists MIA in Barcelona, and a "growing sense of powerlessness."

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Tipping Point MSF, Oxfam Redefine the Possible, and Y2K Activist Trek to Durban Marks a Watershed

By David Barr

April 2003

Small Piece of History

DURBAN 2000

The buzz before Durban was all about security. The crime would be terrible. No one would be able to step outside their hotel rooms without being macheted to pieces. Also, there were no hotel rooms within 5,000 miles of the conference center. And, the conference would be terribly organized with little planning or coordination. The pharmaceutical industry, supposedly concerned about the security of their employees, drastically cut the number of attendees. Government did the same. Most shamelessly, many of the researchers stayed home. They complained that the conference would not be safe and would not have any important science anyway, so why bother. This from people who would normally fly ten hours a week to make a fifteen minute presentation where all they do is read from their slides. Yes, the crime in South Africa is a problem, but the white flight (or non-flight) was pretty shocking.

Is it possible that the security concern was a cover? Is it too cynical to think that many people involved in drug development and clinical research just did not want to attend a conference where their work was not all that important -- since there were no means (or will) to

deliver their miracle drugs to the over 5 million people infected with HIV in the host country? Where the latest research data on drug resistance or lipodystrophy is not terribly relevant? Where the exhibitionism of industry marketing is not only useless, but rubs salt in an ever-enlarging wound?

And yet Durban was a milestone conference, and anyone and everyone who attended left with a profound sense that they had witnessed a small piece of history and went home determined to make a difference in the lives of tens of millions of Africans. Indeed, most of the researchers who did attend the conference spoke of how incredibly moved they were by the experience. Some of them, like Charlie van der Horst, actually left jobs of many years to take on research and health care provision in Africa. David Barr carries us into the twenty-first century with the penultimate installment of his history of the international AIDS conference.

While many people came to Durban feeling that treatment access was just not a possibility in Africa, despite the urgent need; they left feeling that treatment access was possible and had to be pursued. Yes it would be difficult. But it was no longer a question of can it be done; but rather, how can it be done. Tony Fauci was incredibly moved by Edwin Cameron's opening speech, calling it the best speech he'd ever heard.

I should admit at the outset that I came to Durban skeptical. Not about whether treatment access was just and necessary, but conflicted about whether or not it really was possible to do. I worried that Western activists were pushing an agenda based on their experience and not based on the experience, needs and capabilities of the people and countries there. I still worry about that, but I no longer question whether treatment access is and should be a high priority. I now believe that unless we -- and here I mean all of us -- commit to making treatment access a high priority in any and every response to HIV, then all efforts to address HIV will fail. I do not see how a prevention program can succeed without providing the promise and hope of treatment to those who are infected. How can a prevention program succeed if overwhelming death and illness surround it? How can you expect people to value life if their governments and medical establishments do not?

I arrived in Durban and checked into the Holiday Inn. I had a room overlooking the ocean and could watch the surfers in the annual night surfing competition from my window. The conference center was a few blocks away and was gleaming and new. Despite the concerns about poor organization, the conference was flawless. The center was comfortable, easy to navigate, and the sessions were well planned. It was the most diverse group of attendees ever and people were excited to be there.

The opening day was the high point for me. The day began with forum organized by Médecins Sans Frontières and the Treatment Action Campaign (TAC), the South African AIDS activist group. The meeting was packed with hundreds of people, mostly black South Africans. We heard reports on the need for and attempts to provide treatment access. The high point was Justice Edwin Cameron, who gave us a preview of his opening plenary speech. A white South African with AIDS, Justice Cameron spoke of his illness and his recovery since starting antiviral drugs. He talked about the injustice of his good fortune compared with the sickness and death facing most of his countrymen and women because of their inability to obtain treatment. It is not possible to write about this speech and do it justice. It needs to be seen. Get the tape.

After the meeting, there was a large rally outside the City Hall, organized by TAC. Union leaders, church leaders, activists, and even Winnie Mandela addressed the crowd. Thousands of people were wearing T-shirts that had "HIV POSITIVE" in large letters on the front. This alone was a chilling piece of activism as we were only 30 miles from where a woman was stoned to death for publicly declaring her HIV status. After the rally, we marched through the streets of Durban, yelling for treatment access. People were singing songs and dancing in the streets in a scene that was so reminiscent of all the anti-apartheid demonstrations I had seen on television. It was thrilling to be surrounded by South Africans demanding access to treatment and demanding that their government and all the governments of the world address the AIDS crisis in Africa and worldwide. The march was peaceful, but very exhilarating.

There was one scary moment. At some point, a guy driving a car got stuck in the march. He could not move forward or backward. Had he been patient and waited, he could have easily left the scene. No one was interested in him or was trying to keep him there. But instead of being patient, he started honking and then yelling at the marchers to get out of the way. When they did not listen, he began driving a bit faster, threatening to run down the marchers in front of him. Then the demonstrators did pay attention to him. They surrounded the car, telling him to stop. This only made him more agitated. He started yelling. He sped up again. The demonstrators surrounded his car, trying to stop him. My boyfriend Sam was one of those. The guy then pulled out a gun and pointed it right at Sam. Others intervened, and I think some police finally showed up. The guy turned the corner, and the crisis was quickly over. But it was scary for a moment. We marched to the soccer stadium, where the conference opening ceremonies would take place.

The soccer stadium was packed. Finally the show began. (And that is what it was.) Broadcast nationwide, the opening ceremonies were complete with musical numbers, hundreds of fake Zulu drummers (some were white) descending from the air on wires, dancing girls, you name it. It was a huge Las Vegas-style production, and it didn't have much to do with AIDS. After the extravaganza and a few introductory speeches, the South African President, Thabo Mbeki, came out for his speech. Here was a perfect moment for the President to shame the pharmaceutical industry and the western/northern governments into committing the resources needed to address the worst AIDS epidemic on the planet. Instead, he let them off the hook.

Much of what he said was true: that AIDS is a disease born and spread by poverty, and that the many conference attendees speaking about how South Africa should or should not respond to its AIDS crisis had little knowledge or understanding of the country and would leave in a week not having seen how people really live. But rather than say what should be done, he stopped there. He did not discuss treatment. He did not lay out a prevention strategy. He basically said to leave him alone. People were furious and started leaving the stadium in droves. Also, we were hungry and it was time for us to have dinner and complain about the President. Most of us missed the boy with AIDS who spoke after the President, myself included. My friends and I went back to the Holiday Inn for a big Japanese dinner -- a meal that cost more than most people make in a month in South Africa. This contradiction was continual and ever-present: I was a tourist, a tourist who cares, but a tourist nonetheless. But after the conference was over, I would leave with my friends for a vacation of a lifetime, touring the game parks and visiting Capetown.

I am unbelievably lucky to have been born when and where I was [well okay, until George 43]. There I was in South Africa, being inspired by the treatment activists, arguing with people about what to do and how to do it. But my role in the both the crisis there and how to address it was increasingly confusing to me. I was surrounded by activists from the U.S. who were rapidly abandoning their AIDS agenda at home to concentrate on an epidemic in a country very foreign to them.

I became suspicious -- not of their motives, but of their missionary zeal. It is too easy for us Americans to impose our ideas and solutions on others. I found myself making assumptions about everything without wanting or trying to. I knew that there was work I could do that would help, but I did not want to make assumptions about what that should be. Instead, I wanted to be guided by the activists there. They should determine how we in the U.S. should assist them. In the years since, they have shown that, while they appreciate our assistance, they do just fine on their own. I decided that when I went home I would raise money for TAC. That seemed like something they would need -- and I could do. Gregg Bordowitz made a videotape based on TAC's work during the conference. Sam Avrett and I mailed it out along with a letter also signed by Gregg Gonsalves, Peter Staley and Mark Harrington. The letter and tape made the rounds and we ended up raising over \$75,000 for TAC.

I arrived home from South Africa and my phone was ringing as I opened the door. It was Gregg Gonsalves, who had arrived home a few minutes before me. Stephen Gendin was dead. He had been diagnosed with lymphoma just before the conference started and had to cancel his trip. I had met his former boyfriend, Mark Aurigemma, in the airport on the way over and he told me that news. The chemo was very hard on Stephen and apparently caused a heart attack. Everyone was away when it happened, except Hush. The memorial two weeks later was packed. Mark Aurigemma, Hush, Moisés Agosto and others spoke beautifully about Stephen. Larry Kramer talked of forming terrorist cells and new Irgun tactics.

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End of an Era Can a Conference (and an Activist) Outlive Its Utility? A Moment of Unabashed Navel Gazing

By David Barr

May 2003

Life Without AIDS, Nearly

ACT UP/Paris founder Didier Lestrade put away his Doc Marten black high-top boots back in the Mitterand years. His "no more AIDS conferences" policy has been in effect since the Yokohama snoozer nearly 10 years back. He doesn't "do" drug company meetings any more and has limited his activist involvement to an occasional treatment column for Têtu, the gay

Paris-based magazine he co-founded. And these days, he does it all from his sister's country house where he has taken up full-time residence, nearly two hours outside of Paris.

Likewise veteran activist Moisés Agosto made the Vancouver conference (where he was awarded his gold watch and prematurely memorialized) his last AIDS junket. They both spend more time cooking, writing -- and in Didier's case, gardening -- than juggling conference calls or booking flights to remarkable (and some, decidedly unremarkable) cities. More and more, aging HIV-positive activists are questioning the use of their time -- and just how big a part of their lives they want "the virus" to be. More and more that answer is "less and less." TAG alum David Barr returns from the last big international confab with nothing but questions -- an enduring gratefulness -- and a touch of despair.

I have been to many international AIDS conferences, probably too many. While I could and do wonder whether all those trips to all those places made any difference in anyone's life other than my own, I also know that I worked hard at all those meetings. So, while I can wonder if the impact has been worth the expense, I know that I did what I could to make those experiences worthwhile. And while doing so, I saw some great places and spent some really good time with people I care about dearly. And that makes me feel extremely fortunate.

Barcelona 2002

In Barcelona it was a bit different because I had no role to play. I was not working for an organization. I did not have anything to present or accomplish. Frankly, I was going to Europe on vacation. Mark Harrington suggested I go to Barcelona and write this series of retrospectives for TAGline. It seemed like a good way for me to reconnect with my AIDS work and the people in it. So I went. My attitude going in was not great. It seemed as if there had been so little progress since Durban. Gregg Gonsalves disagreed. He argued that while Barcelona would not represent a milestone, it would be full of evidence of progress. He said that Durban had been the turning point and that Barcelona would reinforce that fact with updates on the creation of infrastructure -- both micro and macro -- that would make treatment access a reality. As usual, he was right.

In Barcelona, politics had overtaken the conference. What was missing was the science. It seemed that most of the scientists had flown instead to the first of a new series of bi-annual meetings of the International AIDS Society: Argentina in 2001. Later this year, the same gang of refuseniks will be found scouring the plush hotels and three-star Michelin restaurants of Paris. Yes, the IAS and that stalwart team that runs the Retrovirus conference have finally succeeded in their efforts to shield the scientists from having to mingle with all those tedious people who run prevention programs, provide support services and health care. Of course there were scientific presentations at Barcelona, but they felt few and far between. There were certainly fewer Track A and B presentations (Basic Science and Clinical Science, respectively) than there used to be. Instead of an emphasis on science, the Barcelona organizers gave us a show complete with Bill Clinton (a few years late), clowns, and flying dancers (although not as many dancers as in Durban). Let's just say it now and get it out of the way: no more dancers, no more clowns, no more drummers! I like a good ritual as much as the next guy but, please, a little respect. A little dignity.

Despite the tidbits of progress -- most notably the treatment and prevention successes in

Brazil, the work of TAC in South Africa, and the excruciatingly slow progress of the Global Fund -- there was really nothing but bad news in Barcelona. The epidemic rages out of control in most of the world. The news from Asia, India, the Caribbean and Eastern Europe was devastating. In many of these places, the epidemic does not have to turn into "Africa." Needle exchange, condom distribution, education, treatment and care could stop the epidemic from reaching massive proportions in Russia. Terje Anderson, in a beautiful speech at the closing ceremonies, said it best when he noted that, more and more, the AIDS crisis is about political will. The work in science has come far enough that there are many things we can do today to stop AIDS (or at least slow it down), but the political will to make this happen is lacking. That seemed to be the message of Barcelona. And as with most of the world situations today, I find myself feeling more powerless than ever.

Perhaps that is why the demonstration against Secretary of Health Tommy Thompson was so important for so many of the activists, advocates and service providers. The demonstration came out of nowhere (well, it came out of Gregg Gonsalves' head and heart). It was organized in a matter of hours. There was so little discussion about whether to do it or how to do it or on what it should focus. There was a senior official from the Bush Administration and we had a chance to express our displeasure towards them.

But back to that feeling of powerlessness... AIDS is bad enough, and yet there now seem to be a bunch of other world crises that will take precedence over AIDS. I want Israel and Palestine to stop fighting. I want Muslim kids to play with my Jewish nephews. I want people to eat -- in both Zimbabwe and in Alabama. I want to feel safe in my city. I want everyone who needs it to get the medicine that is keeping me alive. But at the same time, I have absolutely no idea how to have any impact on any of these things. And the Tommy Thompson demonstration didn't really help. It felt like going through the motions. It felt good to yell (as it always does), but it didn't feel like it did any good. If it sounds like I am depressed, maybe I am. But to return to the confusion I experienced in Durban -- I am also not depressed.

I am healthy. I am enjoying my family and my friends. I am feeling good about the way I am living my life. I love my boyfriend madly, and we are making a good life for and with each other. It is a life I didn't think I was going to get to have. I was diagnosed with HIV in 1989, and I thought I would be dead by now. I want to enjoy this time and use it well for many purposes -- but not just to fight AIDS. AIDS can't take up all my time anymore. I won't allow it. Some days when I think about this, I feel that I am abandoning "the cause," and that I have no right to do so because I am so lucky to be alive when so many are not. Other days, though, I think that people like Stephen Gendin would be happy to hear that I am doing things other than going to Bethesda for interminable meetings, sitting in conference centers looking at endless slide presentations and having the same unresolved arguments about when to start antiviral therapy. I wish Stephen and Hush had had the chance to enjoy each other the way Sam and I are today.

I see many people doing really good and important work -- work that is making and will make a difference. I don't want to stop working on AIDS entirely. I have a good amount of experience and feel that it is important to put this experience to use. I know that I have to find things to work on and remember that each piece of work that one does can make things better -- and that no one piece of work will make it all better. I know that you do what you can until you can't do any more, and then someone else does what he or she can.

Perhaps it is time to let someone else go to Thailand in 2004.

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