Beyond Compassion

Remarks by Randy Shilts
National Correspondent, San Francisco Chronicle

V International Conference on AIDS
Montreal
June 9, 1989

It was eight years ago this week that I was at a cocktail party in San Francisco and somebody said that the Centers for Disease Control claimed there was a gay pneumonia. I remember saying it wasn’t bad enough that gay people were being blamed for the deterioration of the American family; now we were causing pneumonia too. It seemed patently absurd.

Needless to say, a lot has happened since then.

As a journalist, my general mandate is to report the news and to try to define that nebulous commodity known as the truth. Sometimes getting at the truth means focusing on failures as well as success, because within the failures of any group of people are the clues to the mistakes of tomorrow, mistakes you want to avoid. And there are mistakes we want to avoid as we leave here today for the next year in the battle against AIDS.

I’ve covered this story for a long time, back to the days when AIDS was called GRID, so I feel that I’ve got a pretty good handle on the general outlines of how this epidemic happened. What I find intriguing when I come here to the international AIDS conferences is how an Official Truth about this epidemic is emerging, one that often seems at odds with how I definitely recall things happening.
Let's start with central tenant in the catechism of the Official Truth about AIDS. We've heard it at this conference a number of times, as you hear it at every AIDS conference. This truth goes: "We found the virus that caused this disease faster than any other disease in the history of science."

There are elements of truth in this statement. We did find HIV faster than the microbes that cause, say, smallpox or polio. But let's get real here. It's the 1980s and I would hope that we would find viruses a helluva lot faster than we did when scientists were stumbling around with primitive microscopes a century ago, trying to figure out smallpox.

It's the 1980s, not the 1950s. With the billions of dollars going into scientific research, with recombinant DNA technology and electron microscopes and all, I would hope we'd do a better job of tracking down viruses now than we did decades ago with polio.

This gets to my point, that the Official Truth is not the whole truth.

In fact, anyone who worked in AIDS in those difficult early years of the epidemic knows the whole truth about the discovery of HIV is a bit more complex. The fact is we certainly could have found this virus much faster. The history of AIDS instructs us that it largely was not the fault of scientists that we didn't get this virus sooner. Serious, comprehensive lab research was delayed for as long as two years, largely by the political leaders in America who did not chose to devote the resources to
look for the virus or to study any aspect of AIDS in much depth. So this most essential research was delayed or, at best, tragically slowed.

That's the whole truth of the search for the virus. There was success and also failure.

There's another Official Truth of the epidemic that I find intriguing. We've heard it again this week with all the talk that AIDS has brought out unprecedented cooperation among scientists worldwide. Scientists are sharing their ideas and moving forward our understanding of this disease at record speed. AIDS, this Official Truth claims, represents science at its best.

Again, there are elements of truth in this. More scientists around the world have turned their studies to this one virus in a short period that is unprecedented in scientific history. We all know tales now of remarkable scientific brilliance and of selfless dedication of researchers.

But that's not the whole truth, because we also know in the history of this epidemic, we've sometimes seen science at its worst. We've seen researchers engaged in unseemly competition, prizing personal ambition and glory over the cooperative advancement of knowledge.

And what's more distressing, we've seen most of the AIDS establishment, including the scientific media, refuse to acknowledge this sad subplot to the epidemic, to act like it's never happened. This troubles me. To turn a blind eye to poor
ethics is to participate in the corruption of science.

Once again the Official Truth of the epidemic is not the whole truth. Like all people everywhere, it seems easier for the citizens of the AIDS world to recount achievements than to recall inadequacies.

I’m not bringing all this up just to be rude. Believe me: More than anything, I want you to succeed. The lives of many people I know...the lives of many people I love...depend on how well and how quickly success is able to meet this effort in which you are all engaged.

That’s why I don’t want you to repeat the failures of the past. The mountains of depressing epidemiological data we have heard this week has told us one thing. Whether we’re talking about drug users in southern Europe, housewives in Rio de Janeiro, children in Kinshasa or gay men in Montreal, we no longer have time for any more failures.

That gets us to the central challenge we have today. For years, the challenge we’ve talked about at these conferences is the challenge to achieve compassion...to make sure that society offers a decent and caring response to the people who suffer. That was a good and appropriate theme for the first stage of the epidemic. At this point we can agree: an international consensus has been achieved on the need for compassion.

But I think it’s also time for us to enter a new stage in
the psychology of the fight against AIDS, a stage that moves beyond compassion. It’s 1989 now. In the past week we’ve seen the challenges that the frightening epidemiology of AIDS has laid in front of us. If we are to truly face these challenges, compassion is no longer enough.

I’m a newspaper reporter, so when I think of the history of this epidemic, I think of the headlines that have told this story; when I think of the future, I think of the headlines that I one day may write.

The rapid progress we’ve seen in AIDS treatments over the past year ... and that is the major scientific story in the AIDS world today ... have allowed me to think of the day when I’ll write a headline that will be both my dream and my nightmare.

The headline will be that we’ve finally whipped AIDS.

I’ll be at the press conference with a lot of you. And at that press conference, eminent scientists will unveil that armamentarium of treatments that will make HIV disease into a manageable chronic infection. We’ll have the antivirals, the immune boosters and the other drugs that might be needed to ameliorate whatever toxic side-effects these drugs create. And people with HIV will be able to look ahead not to some miserably excruciating death, but to a reasonably normal span of productive life.

That’s my dream. And I believe you scientists and experts
when you tell me that this day will come, that it is virtually inevitable.

And then there’s my nightmare: That this press conference will be held in 1996 by which time the great share of HIV-infected people alive today will have long been dead and buried.

One of the most momentous days in science will come and it will be utterly irrelevant.

As a journalist covering this conference, I’ve seen much evidence that my dream will come true one day.

As a journalist covering the science, the bureaucracy and the politics of AIDS, I’ve also seen copious evidence that my nightmare will come true as well.

This gets to the central challenge I think faces the world of AIDS today. If I go on to write another history of the AIDS epidemic, I have no doubt that its central theme would revolve on how well this challenge is met and where we have failed. Because we are failing that challenge, the challenge that can be summed up in one word: Urgency.

Of course we’ve heard lots of talk about urgency from this podium this week. In fact, the most often-articulated phrase from the new Official Truth of the epidemic is that never has science moved with such urgency against any disease.

Again, there are elements of truth to this. The urgency is unprecedented, but that doesn’t address the more crucial issue of whether the level of urgency we’re now seeing is enough.

Take, for example, the most dramatic treatment breakthrough
to emerge in the last year, aerosolized pentamidine. This is a treatment that has saved thousands of lives. It is nearing licensure in the United States now, but, again, the history of this drug amply illustrates that the process could have been moved much faster. Years faster. In fact, it seems that the government agencies that are supposed to be speeding the development of such drugs -- either through testing them or through their regulatory approval -- did less to help than to obstruct the testing and release of this treatment.

For all the talk of increased urgency, I must say that in my reporting, I have not been able to see action commensurate with the scope of the problem. Studies that should take months to conduct, now take years. Not because of scientific demands but because of ponderous paperwork and sluggish bureaucracies.

When called to task, scientists and government officials seem content to tinker with this or that specific problem within the system rather understand that an entirely different thought process is needed to conceive of the challenge AIDS presents us: All the work in AIDS must be judged by how well it will meet this cruel deadline that AIDS imposes. Business as usual cannot continue.

Both as a reporter and as a person who knows so many people stricken with HIV disease, I'm always disappointed when the elite scientists of the AIDS world say, almost with one voice, that good science cannot move rapidly. There's a tendency to characterize the conflict today as one between the defenders of
good science, holding off the charges of barbarians who would want quick, and by inference, bad science.

The facts at this stage of the history of AIDS, however, suggest a different analysis. We’re not talking about good science versus bad science. We’re talking about relevant science versus irrelevant science. Any solution to the problem of HIV infection that comes after most of the HIV-infected are already dead will not be relevant science. All of you are working against this deadline.

Good science may not always be fast but neither must it always be slow. I am profoundly troubled that so many researchers and leading voices in the AIDS establishment seem to think that good science does not need to be relevant science.

Frankly, I sometimes imagine I can hear their voices, at that 1996 nightmare-press conference. I can hear the talk, outlining the future Official Truth of AIDS, when researchers congratulate each other on the scientific breakthrough of controlling a viral disease. And they’ll tell each other how the treatments came faster for AIDS than with any other infection in the history of science.

Elements of such statements would certainly be true.

But the whole truth would be read in the agonized faces of the dying in Dar es Salaam and Copenhagen, in Barbados and The Bronx.

Those dying faces will be all around us, the world over, if we do not ensure that the Official Truth we hear today about the
urgency to fight AIDS does also not become the whole truth.

This gets to a second challenge that scientists will face in the year ahead and increasingly through the future history of this disease -- the challenge of accountability.

My background is as a political reporter in a world in which the people I wrote about were accountable to voters. Most institutions everywhere have comparable means of accountability.

As an outsider, what I find fascinating about the world of science is how little it seems to understand this language of accountability. Mechanisms such as the peer review process make scientists accountable to each other, in an extremely imperfect system, but there have traditionally been few mechanisms to make science accountable to outsiders.

In the history of AIDS, we've seen one institution that should be an accountability mechanism...scientific journalism...often being much more interested in acting as a cheerleader than in bringing accountability to the science of AIDS. I frankly don't any evidence that this will change, but without any doubt, other dynamics will force a new era of accountability to the science of AIDS and you should be prepared.

For the first time in the history of medicine, we've seen a political coalition form around a health issue. It's absolutely unprecedented. In North America, where the most of the organizing has been done by the lesbian and gay community, this has meant a health coalition created by people who are very politically
sophisticated.

In the past, this coalition has proven the most crucial ally of AIDS science. Let's face it, virtually every penny that comes from the United States government for AIDS research...and that means the majority of the money going for AIDS research in the world...can be credited to this political constituency. But in the past year, we've also seen this constituency begin to turn to science and ask, quite reasonably, "What are you giving back?"

The answer of scientists has largely been, "You have to understand how we work -- it's slow."

That answer will no longer be good enough. It is no longer the job of the world to understand science. It is the job of science to understand the world and what the world expects of science.

What the new health constituency wants from you is results. Remember: You're not getting hundreds of millions of dollars in government research grants simply because you look fabulous in white coats. You're getting that money because you're supposed to produce and you're supposed to produce under the tight deadline pressure which this horrible epidemic presents.

Increasingly, you will be held accountable. The people affected by this disease, particularly in the gay communities of the western world, have already demonstrated they will not be passive patients and stand idly by while business dawdles on as usual. Concerns about turf wars and bureaucratic niceties will no longer be tolerated from government agencies. They will be
held accountable. Private companies that appear to put concerns of patents and profits ahead of the need to quickly save lives will find themselves held accountable. Political leaders who deny scientists the funds and staff they need to do their job...they too will be held accountable.

You don't need a crystal ball to see this is the trend. You have been able to hear the shouts of those who will hold you accountable all week, echoing through the streets of Montreal.

Keep in mind, too: History will also hold you accountable.

Today, as I’ve talked about the epidemic’s history, I’ve outlined some of the mistakes of the past and the problems of the present. Still, I’d be dishonest if I didn’t also note that this history also has many heros and heroines. These heros have been in the research labs of Bethesda and Paris, and among doctors and nurses who have tended the sick and the dying in Kampala and Canberra. They have worked in AIDS prevention...former prostitutes in Mombasa, recovering drug addicts in Madrid and lesbians and gay men volunteering in Los Angeles. Many of these heros are here in this room.

The challenge that faces us all before we see each other next June in San Francisco is one that will again demand heroic efforts. You will be writing the future history of this epidemic, in every day of your work. It will be up to all of you to ensure that the future history does not continue to be written like the past...in warnings unheeded and in opportunities lost.
I’ve talked to hundreds of you in my years of reporting and I know one truth about your ability to confront this challenge: You’re up to the job.

Remember you are all part of history in this struggle. And historians will note how well you take up the challenge of urgency. How well you do, more than anything else, will measure our degree of civilization.
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Of course we've heard lots of talk about urgency from this podium this week. In fact, the most often-articulated phrase from
the new Official Truth of the epidemic is that never has science moved with such urgency against any disease.

Again, there are elements of truth to this. The urgency is unprecedented, but that doesn’t address the more crucial issue of whether the level of urgency we’re now seeing is enough.

Take, for example, the most dramatic treatment breakthrough to emerge in the last year, aerosolized pentamidine. This is a treatment that has saved thousands of lives. It is nearing licensure in the United States now, but, again, the history of this drug amply illustrates that the process could have been moved much faster. Years faster. In fact, it seems that the government agencies that are supposed to be speeding the development of such drugs -- either through testing them or through their regulatory approval -- did less to help than to obstruct the testing and release of this treatment.

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When called to task, scientists and government officials seem content to tinker with this or that specific problem within the system rather understand that an entirely different thought process is needed to conceive of the challenge AIDS presents us: All the work in AIDS must be judged by how well it will meet this cruel deadline that AIDS imposes. Business as usual cannot continue.

Both as a reporter and as a person who knows so many people stricken with HIV disease, I’m always disappointed when the elite scientists of the AIDS world say, almost with one voice, that good science cannot move rapidly. There’s a tendency to characterize the conflict today as one between the defenders of good science, holding off the charges of barbarians who would want quick, and by inference, bad science.

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