Hope Against Hope

We finally have effective treatments. It‘s time we did real prevention

November 1, 1997 By Walt Odets

If 1968 was the Summer of Love in Haight-Ashbury, 1996 was the Summer of Hope in Vancouver. As if overnight, the hope officially born at last year’s International Conference on AIDS transformed, for the first time since the epidemic began, the way many HIV positive gay men think about themselves. The gay press, popular media and, to some extent, professional literature seemed filled with the optimistic news that the epidemic was, if not over, clearly on its way out. The lives of the infected seemed reborn.

The Vancouver conference marked three years since the Concorde study had inspired widespread hopelessness by reporting that AZT monotherapy might be worse than no treatment at all. Research, medicine and treatment activism were all suddenly becalmed and drifting, and because prevention then seemed our only promise, it quickly became the priority on our communities’ agenda. But we still desperately needed something for that already infected—to penetrate HIV’s apparently seamless invulnerability and, once again, provide hope. A knockout antiviral would be a welcome miracle, but even a solid punch would do. Last summer, the three-drug protease cocktails seemed suddenly to offer a solution. Many already using them were showing dramatic improvements in health and quality of life, at least in the short term. The results were encouraging enough that many HIV positive gay men began to feel hope for a “normal” future, with all its opportunities, tribulations and uncertainties. Furthermore, the low—sometimes “undetectable”—viral loads achieved by the cocktails also promised (as yet undemonstrated) reduced transmissibility, which might help assuage the feelings of many infected men that they are “diseased and contaminated” and a danger to those they love. Those with HIV might join other survivors of the epidemic; united again, we might all hope that the suffering, loss and despair of the last 15 years were finally over. We might even someday make love again without the nagging fear that we are also killing or being killed.

For all the compelling hope we have attached to these new treatments, their promise has also raised the dogged, epidemic-long specter of false hope. Certainly our hopes for treatment have, to some extent, denied our doubts. But authentic hope exists only in the context of an examination of doubt. HIV negative gay men have always had much more skepticism about HIV treatment than they would ever communicate to positive men, and privately many have expressed doubt about the promise of Vancouver. As if to substantiate such doubt, the protease cocktails were hardly out of the laboratory before they gave birth to a new category of gay men: “Nonresponders.” These men—who do not tolerate or benefit from the new drugs—comprise as many as half of all infected

gay men who have access to the drugs. Straggling hopelessly behind the well-publicized, if elusive, “back to work” tidal wave, nonresponders often have a sense of personal failure, a feeling they are irredeemably lost, forgotten and abandoned. But even we they feel their lives eclipsed by our almost-exclusive focus on the success of the new treatments, nonresponders—living proof of the days of awful possibilities—bring up for all gay men nagging seeds of doubt about our optimism for a relatively untroubled future. Because of what they represent, we have abandoned the physical and human needs of nonresponders to an extent that none of us ever before dared to abandon positive men, even during the short-lived, post-Berlin days of prevention activism.

Among “responders” themselves there is much more doubt—and many more complex feelings—than is acknowledged in our public sentiments. Many question the drugs’ durability and live with extraordinary uncertainty about their futures. What will the positive man, who has forfeited disability benefits and returned to work, do if, once again, he becomes unable to work? If community, family and friends express such relief at even the possible end of the epidemic, how will they respond if it is not really over? Already much of the support for responders and nonresponders alike has been supplanted by the relatively unconcerned expectation of success. Others’ expectations have always shadowed infected men and threatened to dictate how they were to feel, and what they were to do, about their condition. When optimistic, these expectations often give rise to fear of failure in those with HIV—and to fear of abandonment by those who might be disappointed. Suddenly, in a year since Vancouver, the peculiar security, clarity and purpose of the HIV positive condition have been stirred and muddied by precisely the possibilities we had hoped for.

All doubts aside, our communities are now publicly attaching an extraordinary amount of hope to the new drugs. The treatment of HIV disease—as opposed to the prevention of HIV infection—has quickly come to play a dominant, almost-exclusive role in our agenda for the epidemic, and thus for the future of gay male communities. It is the near-exclusivity of this hope—not the essential hope itself—which clarifies both some important feelings that we have about ourselves and some reasons that we have so poorly curbed new infections over the past 10 years. We are a shamed and stigmatized minority caught in an epidemic vectored by one of our most stigmatized activities—anal sex. While we know we do not get HIV because we are gay—for example, as retribution for our transgression—it is true most of us would not have HIV had we not been gay. The confusion of these two ideas—of cause versus circumstance—is not only deliberately promoted by homophobes but, unfortunately, also supported by our own, often-unconscious feelings—not thoughts—of shame about being gay, anal sex and having HIV. This synergy has led us to routinely defend HIV infection as if we were defending the very right to be gay: As one man recently signed a letter to me, “PWA and proud.

Almost from the beginning of the epidemic, we have felt and acted as if the “acceptability” of gay life depended on the acceptability of HIV infection. That fully half of us are HIV positive has come to feel like confirmation of our culpability, and because we need to deny culpability, and because we need to deny culpability for being gay, we also feel we must deny the undesirability of HIV itself. Thus we have always found it nearly impossible to assert the obvious: That even as HIV should have nothing to do with feelings of shame, guilt, failure or contamination, HIV is not an

asset, is nothing to be proud of and is no badge of honor. If some are able to live with AIDS, it is still better—much better—to live without it.

Even as we sustain every hope for effective treatments, it is critical that we help our uninfected stay uninfected by doing prevention that is allowed to clearly say that HIV is infection is undesirable. To date, our prevention efforts—which are, after all, exclusively for the benefit of uninfected men—have been almost completely compromised by our fears about how real prevention might hurt those already infected. Can we say that there are important benefits and possibilities in remaining uninfected—without simultaneously implying that the lives of infected men are deprived and hopeless? This is the problem we have never dealt with: How to assure the infected half of our communities that they need not feel shame or culpability, even as we say to the other half that is it very important that they not become like the infected?

Unable to face this dilemma, we have resorted to ambiguous, half-hearted prevention that tells all gay men—regardless of HIV status—to use condoms, with no regard to the very real differences in why infected and uninfected men might do that. We urge one another to “fight AIDS,” with the unconscious wish that no one will truly know what that means—whether to fight the disease within our own bodies or to stay uninfected—and no one will feel shamed or abandoned.

When hope that we might make HIV infection survivable and acceptable has been strongest, our will to do effective prevention has been the most compromised. It was during the Age of AZT—and now, once again, in the Age of Protease—that the desire to stay uninfected has apparently most threatened the hope of those already infected. Would not the insistent voice of prevention, right now, feel as it if implied that the lives of gay men with HIV are doomed, their hope futile? The most vulnerable in our communities—the young—have grown up learning of gay life and the epidemic in the same instant. They do not remember AZT, much less its crushing disappointment. For them, we must keep alive the hope that they might stay uninfected, express this hope in uncompromised prevention and, above all, stop infecting them. For these young men—a group we have usually both ignored and exploited—the promise of Vancouver has already added too much plausibility to HIV infection by providing yet another in a long list of reasons that being positive is, if not desirable or inevitable, at least “OK.” Our alternative is to learn how to feel “OK” about ourselves—but really OK—so we no longer need to say that we are “positive and proud,” or, for that matter, negative and guilty. If we could do just that, we would no longer get infected—at least not in such spectacular numbers—because we would no longer feel that we are fags, fags get fucked and AIDS is what we deserve. Even as we keep alive hope for effective of HIV, we must also keep hope alive for a shameless, guiltless age as free of HIV as possible, an age when we are truly loving of ourselves and one another.

© 2026 Smart + Strong All Rights Reserved.