



ACT UP = LOVE

April 18, 2012 By [Peter Staley](#)

For those that only watched ACT UP from a distance or via TV news reports in the late '80s and early '90s, you probably only remember the anger and determination the group was famous for. But being part of it was so much more. The emotional cauldron that ignited and stoked ACT UP in those early years brought out the best in all of us, creating a potent sense of brotherhood and sisterhood I doubt I'll ever feel to that extent again.

As the 25th anniversary demonstration fast approaches (Wednesday, April 25th, 11am, starting at NYC's City Hall, then marching to Wall Street), many of us have been remembering those early years. We've been watching new documentaries that will keep this history alive. We've been creating sad lists of those we lost, while posting happy memories we have of them in a remarkable Facebook thread now filled with 741 comments. We rushed to see Gran Fury's iconic graphics from our protest signs at the gallery show that closed last month.

And now this, from Jim Eigo. If Larry Kramer was ACT UP's father, Mark Harrington its boy genius, and Maxine Wolfe, Ann Northrop, and Iris Long its professors, then Jim Eigo was its moral compass. I have never met a more selfless activist, one who was both gentle with his comrades and a force that all others had to reckon with.

Last week, Jim spoke on a panel at the LGBT Community Center in New York that was convened to discuss the current state of AIDS activism "and its history." He graciously agreed to let me post his comments here. They are worth your time reading (click "continue reading"):

Jim Eigo's Remarks for the panel: AIDS Activism NOW, the LGBT Center, New York City, April 11, 2012

I would like to thank Gran Fury for inviting me here tonight and Jill Harris for moderating. In the early days of ACT UP the Center was our home, not just for Monday night general meetings but to most of our various committees, subcommittees, task forces, affinity groups, trainings and teach-ins. In those pre-renovation days, the Coordinating Committee would meet in a room on the top floor of some distant wing. Encounters with rats on the long trek up were not infrequent. When it rained outside, it rained in on us as well, and with nearly equal force. In addition to thanking the Center for hosting, I would like to encourage the Center to return to its roots and become once again a second home to all queers, including those groups that are now excluded because of their political views on the Middle East.

In the summer of 2010, in a kind of warm-up for the recent Gran Fury show at the 80 Washington Square East, the ACT UP Oral History Project curated a show at White Columns. Sarah Schulman, a Project cofounder, asked me to read there one evening. Here are the first few sentences of the introduction I wrote for that occasion: "ACT UP came into being when a critical mass of people with AIDS recognized: my body, the site of a devastating disease, has become the site of a social struggle as well. So they took those bodies down to Wall Street, that conduit for international capital, and they sat down, gummed up the works, and said in effect, 'This is my body, disease and all. Now deal with it.' In this disembodied age, it's good to remember that bodies-on-the-line has always been ACT UP's most elemental story."

I wrote those sentences because, as evocative as the exhibition was for me, I sorely missed those bodies, those we lost and those that have gone on to other things, and I was trying my best to conjure them, bring them back if only in spirit. But maybe I was asking too much of art. In January when I saw David France's powerful new film on AIDS activism, I was in equal parts exhilarated and devastated. I had never seen most of that archival footage. To see Vito Russo, the man responsible for my working on AIDS treatment issues, sitting next to me on a dais in Montreal, the scene where ACT UP became an international force in experimental AIDS drugs, was like seeing a ghost. I saw many a ghost in the movie, but still, no body. This is not a brief against the film. Art can feed activism, but it can't replace it, or the life that feeds it.

I say this as someone who earned two degrees from art schools and has lived steeped in the downtown art world for nearly three and a half decades. In early 1988 when two Gran Fury members came to ACT UP's coordinating committee asking for a small start-up grant--Todd Haynes, I think, and I don't remember who else--I was the only committee member that spoke strongly in favor of it. I argued that this was an important cultural moment for AIDS, in the wake of such art world events as the AIDS issue of October Magazine and the New Museum's AIDS show--which brought the oversized, neonized SILENCE=DEATH logo to lower Broadway. I was able to convince the Coordinating Committee to make the small grant--in hindsight a very wise investment--but Bob Rafsky, in the days before he mellowed out a bit, a hardcore advertising man with limited tolerance for capital-A art, abstained rather than vote yea. More personally, I wrote two articles for the legendary issue of New York Crimes that Gran Fury published and distributed for ACT UP's 2nd anniversary.

The treatment work I did within ACT UP required huge amounts of writing that I always approached not like essays or even logical arguments but as narratives, pieces of the most important story of our time. Those art school degrees that I mentioned are in Theater, playwriting. Just about everything I did publicly for ACT UP I staged. Never did I go into a meeting or hearing with a federal healthcare official or congressional subcommittee or drug company representative or member of the media without a *mise-en-scene* running in my head. It's surprising how often the other guy--especially if the other guy underestimates your smarts and your expertise-- will let you direct the proceedings if you just take the initiative. But I also learned to always be prepared to improvise on the spot, just as ACT UP became virtuoso improvisers in the incomparable street theater that for many years our major demos achieved. All those bodies on the line.

Had I instead been making the movie on ACT UP's record of AIDS treatment activism, it would show this explicitly. The regulatory and procedural reform that ACT UP secured within the federal and private AIDS drug establishment from 1988 through 1990 got us two things. First, it got us a lot of mediocre AIDS drugs, but it got them very quick, so do not underestimate this accomplishment. These modestly effective drugs of similar action but different toxicities enabled a lot of people with AIDS to juggle their drug regimens, managing side effects, avoiding total failure and staying alive until the better drugs came. And guess what? The regulatory framework that we totally remade became the perfect funnel for the good drugs when those good drugs finally came. My movie would also remind everybody that ACT UP scored significant achievements in at least half a dozen areas beyond AIDS treatments, such as needle exchange, housing, immigration, insurance, women and AIDS...the list goes on.

But I could never make this movie. We no longer have the bodies and there is no surviving footage for most of it. As I wrote recently on the ACT UP alumni Facebook page, I sometimes worry that the history of ACT UP will devolve into a string of its most photogenic moments, whereas, so much of what we did involved daily, grinding work by dozens or hundreds of ACT UP members that no camera ever captured. The greatest AIDS literature yet produced was the ACT UP contact sheet, a new chapter arriving every Monday night. By early 1990 it was two full sheets, every line indicating a meeting or activity scheduled for the week ahead. When I think of all these people doing all this fine, demanding work and with no remuneration--all these years later I still get the shivers.

A big part of my phantom movie would find some way to show what ACT UP failed to accomplish. While our needle exchange showed how effective we could be when we turned to HIV prevention among injection drug users, ACT UP never got seriously involved in working to prevent the sexual transmission of HIV among men who had sex with men--the very mode of transmission that the majority of us was intimate with. I regret that ACT UP had no internal mechanism--something like an Inreach Committee, maybe a panel of ACT UP veterans--that would try to mitigate the internal strife that was a predictable product of doing hard work under difficult conditions in a time of plague, strife that eventually tore ACT UP apart.

This is perhaps my greatest regret. By 1992 it seemed that the gravity of the AIDS crisis and all the flaws that it exposed in America's healthcare delivery system would force the nation to begin to confront the need for a major healthcare overhaul. Believing that ACT UP could play a significant role in the coming healthcare debate, Peter Staley, Jay Lipner and I began work toward drawing up an ACT UP campaign for universal healthcare. But because ACT UP was falling down around our ears, our efforts never went beyond the planning stage. And the next year, the Clintons botched it all.

Which cues us to a potential future. If, instead of that movie about ACT UP's early years that I won't be directing, I were directing instead the 25th anniversary celebrations, I probably would not have tied us to a tax and to the very fine occupy wall street movement. This is no criticism of the people that have done terrific work on the big birthday celebration, which I will be attending. What are the few general points that I would have wanted our birthday to focus us on? 25 years

later and we still have no cure. 25 years later and we still have no vaccine. 25 years later and the major means we have to curtail the sexual transmission of HIV is the same old highly flawed means that most insertive partners dislike--oh, and we have still have no means for receptive partners, be they women or men, to protect themselves. Finally, I would stress that without Universal Healthcare all the treatment advances we have made and will make mean nothing to a significant number of people that need them.

Were I still an active AIDS activist, here is a smaller project I would be working on. For two and a half years pre-ceding March of this year, I slept on my father's couch in Park Slope. He will be 92 next month. Though he remains in good basic health, at this point he can only do a few basic tasks unaided, reading, writing in a journal, eating a meal someone sets before him. He requires round the clock homecare. I provided that care for 16 hours a day, until on March 1, after a struggle of 13 months, at a time of insane budget slashing for healthcare at every level of government, I finally secured for this World War 2 veteran the right to Medicaid-reimbursed homecare. (I still have to care for him 5 hours a day.) I myself turned 60 last September, so aging is much on my mind. I now am pretty expert in the difficulties the infirm elderly face under our woefully inadequate system of healthcare. I would like to see a concentrated focus on the special needs that a whole generation of seniors with HIV will be facing, in fact are facing now.

But I want the activists of today and tomorrow to know that ACT UP in the beginning was so much more than the campaigns we engaged in. We were just as much how we did it. Here are a few life lessons that a current generation of AIDS activists might profit from. Always remember that direct democracy is the best democracy and ACT UP is the best example of direct democracy that most of us have seen in our lifetimes. You are activists and not a service organization or a non-profit: don't become a mouthpiece of the non-profits you sometimes might align yourselves with. "The AIDS Crisis isn't over," means differently if an activist or non-profit organization says it. When a non-profit says it, it might be a call for adding a little more gravy to an already profitable status quo. ACT UP achieved great things not because it shook money from government coffers but because it secured real, fundamental, lasting change in the way things worked. Because we were a true grassroots organization, we understood by our nature the devastation AIDS was causing in a way the federal healthcare bureaucracy could not. We were a full-blown community of our own. Our authentic voice came from the fact we worked from the bottom up and not the top down.

At our best we learned to listen to everyone among us, because untapped talent and breakthrough insight come from the least likely places. Every one of us was forced to discover within ourselves reservoirs of intelligence and courage and beauty and love that we never knew we had. There I said it, love. ACT UP was ACT UP not just because we were angry and smart and media savvy and goodlooking and brave in the face of government officials and cops and mounting death, and managed to change in a very short time the worst of so many of the conditions we faced. ACT UP was ACT UP because we were good, we were the righteous, we answered the call. ACT UP remained ACT UP for as long as--amid the living hell that was the AIDS epidemic at its raging height and in a society that tries to put a pricetag on everything--we dared to love one another when there was little hope that we would get anything in return. We were so much more together

than we could ever be alone. My parting advice to all who would be AIDS activists now or in the future: work to attain the love we achieved, and do even better. It won't be easy. You live in a society in which Big Money has colonized just about every nook and cranny of what, back in our time, we quaintly called our "personal" lives. And oh, yeah: if you come to the party, please remember to bring your queer bodies along. You will need them, because the revolution, contrary to current opinion, when it finally comes, will not be tweeted.

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