My View: Shifting Gears

How ’80s-style AIDS activism fails us in the ’90s

December 1, 1994 By Niles A. Merton

Larry Kramer should shut up. His brashest child, ACT UP, would do well to GROW UP and calm down. They have pushed a permanent state of anger, desperation and selfishness as the most appropriate response to the AIDS crisis. While anger, desperation and selfishness are each utterly valid parts of our response to AIDS, they fall far short of what it takes to end the pandemic. Anger is indispensable as the bridge between despair and action, but it must remain a bridge and not a dwelling place.

The tactics of ACT UP have chalked up some notable successes -- creating public awareness of AIDS, watch-dogging drug companies and kick-starting the government and medicine in the 1980s -- but I believe those successes are outweighed by their failures in the ’90s.

Taken together, anger, desperation and selfishness are called a tantrum: The strategy of choice for three-year-olds of all ages. Tantrum-throwing is marvelous for gaining attention, and in the short term, well-played tantrums can shock or coerce targets into capitulation. But as a way of life, tantrums and their component emotions are slowly destructive. Tantrums destroy credibility, so in time few or none care what tantrum-throwers have to say. Tantrums also erode civility and compassion, so a target’s impulse to give way is lost in a growing disgust and impatience with the nastiness of the tantrums. By far, the worst drawbacks of indulging ourselves in these emotions are the victimhood in which they trap us and the blinders they put on our good sense.

The demand “make a cure for AIDS available now!” sets an example of the blindness of the tantrum-throwing mindset. Anger, desperation and selfishness have led many of us to call for a Manhattan Project to cure AIDS.

Upon further consideration, however, the Manhattan Project, which developed the atomic bomb in the 1940s, is not at all analogous to the study and cure of AIDS. Finding a cure for HIV and its destruction of the immune system is vastly more complex than the development of the atomic bomb.

The depth and breadth of our knowledge of atomic energy was relatively advanced as World War II raged on. Thus it was possible to assemble the best scientists in the field and focus their attentions on what they already knew was possible: Building an atomic bomb.

Before HIV, however, bio-scientists had barely scratched the surface of the immune system. Without such knowledge, it's unlikely there can be a cure for a disease as complex and multifactorial as AIDS. As with leprosy, physicians are becoming more adept at extending life and quality of life for people with AIDS through management of opportunistic infections. Nevertheless, science is hobbled in its search to cure the underlying process of HIV disease.

Why do we still know so little about the immune system after 12 years of intense study? Because researchers must compete for what little funding exists and, as one might expect, they tend to study whatever they can get funded. As angry activists and their allies have grown in political power to press the "instant cure" demand, scientists have increasingly structured their research proposals around various slim possibilities of finding a cure. This has gone on for more than a decade with little real progress. It's equivalent to a 17th-century patron offering a prize to the person who first invents a flying machine: Everyone immediately gets to work on random gizmos, but the guy who begins studying aeronautics will most likely eventually win the prize.

In 1994, we're left with a trashbag of failed "cures" and years of basic research on the immune system still to do. ACT UP's demand for a quick fix and the concomitant diversion of funds has led to bad science and, most cruel of all, a collapse of hope we've begun to see after the recent Yokohama International AIDS Conference. Anger and desperation blinded us, and the costs are counted in opportunities and lives lost.

Rage, selfishness and panic are all natural feelings that occur when the doctor looks one in the eye and says "You have AIDS, a terminal illness." We affluent Americans too often (and easily) have indulged ourselves in the vain hope that death, whatever its cause, can be diverted. But ACT UP and other tantrum-throwers such as Larry Kramer should take a deep breath, roll up their sleeves and face the fact that we're long overdue for a change of strategy.

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