Why Not a Cure?

ACT UP's AIDS Cure Project will work

May 12, 1995 By Mark Milano

There will be no cure for AIDS in our lifetime. That's what everyone tells us. "We will all be dead before this virus is dead," says Peter Piot, head of the United Nations' AIDS efforts. C. Everett Koop, the former U.S. surgeon general, foresees no cure in the next century. National Institutes of Health (NIH) researchers and even some AIDS activist paint an equally gloomy picture, citing science's failed attempts to cure the common cold, let alone HIV. Major AIDS organizations urge us to focus our efforts on caring for the ill rather than fighting for the type of radical reform necessary to find a cure within years rather than decades.

Niles A. Merton joins the pack in his My View column headlined "Shifting Gears" (*POZ* No. 5). Merton accuses ACT UP of a "tantrum-throwing mindset" that he feels is not effective in the '90s. He also claims ACT UP's call for a coordinated all-out effort to cure AIDS—similar to the Apollo Project of the 1960s space race—is fueled by "anger, desperation and selfishness."

A cure for AIDS selfish? What a strange viewpoint. Many would see a vision of a cure as far more benevolent than developing the atom bomb or putting a man on the moon. Both goals were considered highly unlikely when these projects began, but fear and national pride overrode the naysayers.

The AIDS Cure Project, introduced in Congress as HR 761, is a map for what this country could do if it wanted a cure for AIDS as strongly as President Kennedy wanted a an on the moon. The basic approach is: Gather the best minds from a variety of disciplines, encourage them to pursue a wide range or hypotheses, give them access to all needed materials and data, give them the power to remove scientific and bureaucratic roadblocks and give them a clearly defined goal—in this case, to find a cure for AIDS. No, the Project would not sequester scientists in the middle of a desert. It would not replace all AIDS research with one facility. It would not discourage drug companies from pursuing a cure. And it would not slight basic research in favor of finding new drugs, as Merton mistakenly stated. It would, however, address the chronic problems of the NIH, where innovative ideas are discouraged by a grant process that weeds out any non-mainstream approaches, where research agendas are determined by scientists who receive payments from drug companies, where there is no power to prevent a drug company from slowing or stopping research into a promising therapy and where people with HIV have only advisory input when decisions are made.

The AIDS Cure Project would aggressively pursue basic research and study both traditional and alternative approaches to a cure. It would require Project researchers to suspend all financial conflicts of interest with drug companies, and it would have the power of “eminent domain” to ensure that no therapy is shelved due to corporate agendas. We estimate its cost at $1.84 billion over a five-year period.

Some say that the call for such a Project is foolish in light of the new Congress. But did the 1994 elections have any effect on the need for a cure? Do we abandon the fight because of some self-fulfilling prophecy?

ACT UP says no. We refuse to accept decades of continued death because the “experts” tell us to accept a hopeless reality. They told us we couldn’t reform the FDA. We did. They said we couldn’t revise the CDC’s AIDS definition or change the NIH. We have. Now they tell us to stop fighting for a cure? Never.

It was our “tantrums” that enabled us to influence these stubborn bureaucracies. If Mr. Merton believes that we continue to have input into the decision-making process due to respect for our expertise, he’s kidding himself. We are able to wield influence precisely because the threat of our bodies in the street still frightens those in power. It is this combination of visceral street activism and cogent analysis such as the AIDS Cure Project that continues to effect change. When we are fooled into thinking we are “insiders” we lose touch with the community, as evidenced by Peter Staley’s shocking attempts to silence ACT UP at the January meeting of the AIDS Drug Development Task Force. Staley owes his seat on the Task Force to ACT UP’s demands that such panels include people with HIV. Yet he actually argued against FDA head David Kessler’s proposal to include ACT UP members’ input in the discussion. Staley’s act was a striking reminder that it is the nature of the establishment to co-opt critics.

Finally, ACT UP has not attempted to steer research toward “instant cures,” as Merton claims. Indeed, the one real accomplishment ACT UP can take credit for is the expansion of research into opportunistic infections. The frantic search for more marketable drugs is a profit-driven, not activist-driven, mistake. If Mr. Merton and anyone with HIV would like to know what ACT UP is really fighting for, I would urge them to actually read the prospectus for the AIDS Cure Project. Call ___ for a copy. They will see that it is not some childish “demand for a quick fix,” but rather a sober detailing of the deep problems at the NIH, and a visionary blueprint for a project that would do the basic research necessary to shave decades off this plague’s duration.

If it’s childish to work for a cure, I guess I’ll never grow up.

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http://beta.docker.poz.com/article/cure-HIV-1995-20773-4914