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How HIV treatment advocacy can heal you, your community and the world.

In the early 1980s a medical revolution took place. It started with HIV-positive people and their allies demanding that their health care providers include their thoughts and wishes in all aspects of their HIV treatment. When it became clear that doctors often had little knowledge of how to treat the deadly new disease, and that research on HIV and the immune system was moving at a snail’s pace, the revolution quickly developed into another kind of advocacy—to change how HIV research was prioritized, funded and conducted. Thus, the patient empowerment and treatment advocacy movements were born.

Tearing Down the Ivory Tower
At the beginning of the epidemic, in the 1980s, researchers sat in the equivalent of an ivory tower, deciding how much money to put into HIV research and how to conduct that process—all without consulting people with HIV or the doctors who were treating them. Moreover, the standard drug approval procedure—whereby a drug could take 10 to 15 years to make it from the test tube, through human testing and onto pharmacy shelves—was never designed to move at the quick pace necessary to fight a deadly viral disease. When people with HIV questioned the slow-going business of drug approval, they were told that this was simply how the system worked, and to accept it.

Fortunately, AIDS advocates were not quieted by such status quo responses. A new mantra—perhaps the defining war call of the earliest and bravest activists—was born: SILENCE=DEATH.

Advocates quickly realized, however, that if they wanted to revolutionize AIDS research, and become informed decision makers in their own care, they would have to do their homework. This meant learning about immunology and biology, drug chemistry and details on research and funding. Fortunately, sympathetic doctors and researchers joined their cause and helped with the education process, thereby becoming AIDS advocates as well.

Ultimately, this diverse bunch of self-educated people with HIV and their allies threw down the gauntlet to challenge the heads of the National Institutes of Health (NIH), which funds most of the country’s biomedical research, and the U.S. Food and Drug Administration (FDA), which oversees new drug approval. Not to mention, they had to face the U.S. Congress. These newborn activists demanded that the agencies involve people with HIV at every aspect of the research process—from funding appropriations for HIV/AIDS research to deciding about whether to approve a new drug.

Research Revolution

Though it took a gargantuan effort, and plenty of public demonstrations, the activists were largely successful. Today there are community advisory boards for most types of HIV research conducted, not just in the United States, but all over the globe. What's more, Congress passed a law in the early 1990s that gave people with HIV early access to potentially lifesaving drugs and shaved months and sometimes years off the FDA drug approval process.

These successes transformed not only HIV research, but virtually every aspect of HIV care in the United States. Activists work alongside medical experts to draft federal treatment guidelines and constantly engage legislators about the need for increased funding to support the AIDS Drug Assistance Program (ADAP) as well as housing and social services.

HIV activists have also changed doctor-patient relationships. Now, people with HIV take center stage in the treatment decision process—and many doctors like it that way.

Advocating for the Future

Today, activists have begun to meet new challenges: how to train and raise the next generation of treatment advocates—not only to influence research, but also to fight for access to HIV prevention and care services. Another challenge is how to engage and involve HIV-positive African Americans, Latinos and other people of color in this process. For people with HIV there are also opportunities to learn more about the virus and get involved in advocacy efforts. Here are a few:

Learn

Danielle Houston, the director of Project LEAP—a 17-week training program based at the Center for AIDS in Houston—stresses that good advocacy relies on understanding HIV treatment and barriers to care in the United States. She's working with the Black Treatment Advocates Network (BTAN) to develop similar types of training programs in cities across the country, in order "to build a class of informed advocates" who will take up the work that remains to be done.

If you don't have access to these kinds of trainings, there are a number of great sources available on the Internet or by telephone, including POZ.com. Look there for links to helpful resources.

Represent

Another way to give voice to the needs of people living with HIV is to get more involved with local service organizations. Most need volunteers. This can be an excellent way to learn about issues while contributing to the quality of services provided.

Local HIV service planning bodies—Ryan White Planning Councils are a good example—are another way to contribute. A great first step is to simply attend a meeting. Most HIV funding at the local level is controlled by planning bodies, which require input from the communities affected by the epidemic.

Educate
To ensure people in your community have accurate information about HIV treatments and that AIDS research considers their needs, attend free local HIV treatment educational forums at AIDS service organizations (ASOs) or universities. Also apply for scholarships to conferences and trainings run by the National Minority AIDS Council and the Black AIDS Institute, or join local advisory boards at clinics where AIDS research takes place.

Go Digital
For Justin B. Terry-Smith, activism meant starting a blog (justinshivjournal.blogspot.com). Terry-Smith says his blog is as much therapy as it is activism. “It has definitely helped me get a lot of stuff off my chest and open up to the world about HIV and how I have to deal with it,” he says.

At its core, advocacy is about one simple thing—speaking truth to power. June Jordan, a black poet and activist, frequently talked about the healing effect of good advocacy. This is particularly poignant for people with HIV. In a 2000 interview with *Essence* magazine, she summed it up this way: “To tell the truth is to become beautiful, to begin to love yourself, value yourself. And that’s political, in its most profound way.”

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