Dose of Reality

A former holistic hardhead finds the best in East and West

March 1, 1997 By Bob Lederer

I'll never forget my reaction when I saw a poster announcing ACT UP's first demonstration in March 1987. It called for an early morning Wall Street march whose primary demands were speeding drug approval by the Food and Drug Administration (FDA) and cutting outrageous prices. "But it's so *drug* focused," I whined. "Where's the call for access to holistic health care? Plus, 7 am is so damn early." I didn't show.

It's been a long journey from that knee-jerk response from my humbler appreciation today of the diversity of medical paths PWAs need to traverse. In 1987 I was an AIDS rookie-an HIV negative gay-lib activist who'd lost only one acquaintance and was just beginning AIDS journalism. Meanwhile, chronic intestinal problems had led me to read up on-and benefit from-Chinese medicine, nutritional supplements, healthy diet and meditation.

Everything seemed so simple then, before the deaths of 31 people I cared about. All a PWA needed for survival, I believe, was a thorough holistic health program, a positive attitude and an absolute avoidance of antiretroviral drugs-which I considered poison. Prescription drugs, I grudgingly allowed, should be used only for life-threatening infections and as a prophylaxis against *Pneumocystis carinii* pneumonia (PCP). Unlike most of ACT UP, I considered the FDA an enemy of PWAs not because it held up drug approval, but because it undermined consumer access to alternative medicines-while licensing all manner of dangerous drugs.

Soon after joining ACT UP in 1988, I cofounded the Alternative and Holistic Treatment Committee (A&H), a collection of experienced activists, holistic healers and PWAs new to politics. In the four years I was involved, our focus was battling the "quack-busters," the self-appointed guardians of the health care marketplace-whether the FDA, American Medical Association or insurance industry-that persecute alternative medicine manufacturers and practitioners.

But gradually, the misfortunes of a success of holistic-minded PWAs I came to know-and lose-opened my mind to the complexity of healing this disease. For some who were already seriously ill, alternative treatments made matters worse: Aldyn had to stop megadose vitamin C after developing kidney stones; Vince died a few days after starting self-infused ozone therapy; Tony was allowed to develop severe PCP by an herbal-retreat manager who saw serious illness as "healing crisis" to be waited out.

These and other bitter experiences caused me to re-examine the painful criticisms of A&H cofounder Jon Greenberg, a feisty PWA who argued that demands for social responsibilty among alternative practitioners should take priority over fighting persecution against them. In 1991 he led a group that left A&H to form the Treatment Alternatives Project. TAP published fact sheets and pressured practitioners to organize clinical trials of non-drugs. The project died along with Jon in 1993, but his work impressed on me the urgent need for PWAs and their doctors to have reliable information on the efficacy and safety of alternative treatments.

Compiling and simplifying already-existing information was one of the missions of a local buyers club, Direct AIDS Alternative Information Resources (DAAIR), started in 1992 by long-term survivor Fred Bingham. I gladly accepted his invitation to join the founding board. Fred is one of the growing ranks of PWAs who are doing well by combining alternative therapies and judiciously chosen pharmaceuticals. But not all have done well. Some died, lacking the social and psychological suppor to stick to the holistic regimen they so fervently believed in: Tommy, who had trouble adhering to his daily herbal teas and vitamin pills; and Dean, who got much worse after a long-term sugar binge.

Watching these difficult struggles chastened me and pushed me further toward a realistic philosophy. Last year, when we entered the era of protease-inhibitor cocktails, my conversion to an eclectic approach became complete. My friends John and Patrick, after adding these drugs to their holistic protocols, made remarkable recoveries from downward slides in weight, energy and CD4 cells. I was impressed-more so after hearing a cascade of similar reports. So today I accept not only the value, but sometimes the necessity, of combining the best of East and West.

No, I’m not a sellout. I’m still appalled by the rush to “early intervention” with toxic, hard-to-stick-to drug combos. And I’m still committed to the tough, uphill battle to transform the dangerous Western medical monopoly. But as long as the U.S. medical system remains so skewed against alternative approaches, many holistic-minded PWAs may have to crank drugs into their healing equation. So today when I ACT Up, I fight like hell for research on and access to the full gamut of treatment options.

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http://beta.docker.poz.com/article/alternative-medicine-HIV-12541-1610