Curb Your Dogma

Replacing one form of arrogance with another is just not the solution

June 1, 1995 By Bob Lederer

Perhaps inevitably, the question of how to treat a disease which has killed as many as AIDS arouses the worst dogmatic and fanatic behaviors. Of course, no dogma or fanaticism is as powerful or destructive as that of the medical/pharmaceutical/insurance/research complex: Promiscuous promotion of toxic, marginal drugs and arrogant dismissal of alternative co-factor theories and treatments. But as a longtime activist for the latter, I must speak out against the increasingly irresponsible positions and tactics of some community organizations that promote alternative approaches.

Recent practices of two groups -- New York City?based HEAL (Health Education AIDS Liaison) and San Francisco?based DNCB Now! (named after the photo chemical DNCB) -- best exemplify the problem. HEAL was founded in 1982 to share information on alternative treatments. For its first several years, HEAL's work was exemplary, if uneven, offering weekly discussion groups, lectures and reprinted material on myriad non-sanctioned treatments. Thousands of people gained hope and options as they took control of their health care; many surely extended their lives.

In the late 1980s, HEAL expanded its presentations to critique the dogma that HIV is the sole cause of AIDS, and AZT the treatment of choice. These critiques were an important antidote to the widely accepted simple-minded one-bug/one-drug line.

But as time went on, shrillness, distortion and fanaticism crept into, and now pervade, HEAL's message. In its public forums, agitating flyers and weekly cable television shows, HEAL now aggressively promotes some irresponsible claims of noted virologist Peter Duesberg. Among them: HIV cannot possibly cause AIDS; AIDS is not sexually transmissible (thus safer sex campaigns are absurd); and AZT is not only useless but deadly to even the briefest user.

To this list, HEAL adds two more: CD4 counts and other standard blood tests mean nothing, provoke needless stress, and should be avoided; and antibiotics and prophylactic drugs are so immune-suppressive that PWAs should never use them. A new HEAL slogan is "Fire Your Doctor!"

For many communities traumatized and decimated by the medical establishment's monstrously profit-obsessed mismanagement of AIDS, these simplistic messages offer an understandable but dangerous allure.

Gene Fedorko, a nine-year HEAL veteran and former president, offers an insider's reflections: "HEAL's message that all Western medicine is bad -- and particularly not to take antibiotics -- is horribly oversimplified. Sure, there are toxicities to consider and counteract. But the big killer infections like Pneumocystis carinii pneumonia [PCP] can't be treated with less than antibiotics [at this point] or the person will die."

Fedorko has personally met many PWAs who, after following the no-antibiotics advice of HEAL or others, had to be rushed to emergency rooms with "raging cases of PCP." Some died of what, when caught early, is a treatable infection.

As to blood work, Fedorko grants the pitfalls of fixating on every rise or fall in CD4 counts. But he emphasizes that for PWAs with low counts, regular doctor visits can save lives. "Studies have shown a vastly greater chance of developing OIs below 100 CD4 cells. Monitoring blood values can indicate possible interventions (both Western and nutritional/herbal)."

Then there are the outrageous recent tactics of HEAL's leaders. I have seen them loudly insist that they have all the answers, that any community member who disagrees is corrupt or sold-out and that all doctors who prescribe AZT and even antibiotics are murderers.

But HEAL does not have a monopoly on such tactics. The DNCB Now! group is convinced that the photo chemical DNCB, applied to the skin by many PWAs as an immune stimulator, is the definitive HIV treatment. To be sure, some group members have, like HEAL's in the earlier days, made useful (if sometimes dogmatic) contributions to the AIDS discourse, including pointing out the value of antioxidants. But DNCB Now!'s vitriolic attacks on all who disagree and their mindlessly disruptive, even abusive, behavior at public meetings chagrined even some would-be allies and, unforgivably, provoked last year's implosion of ACT UP/San Francisco by hyper-polarizing members.

The bottom line is this: While hard-hitting critiques and militant activism are crucial to expose and fight the AIDS establishment's crimes, it is no solution to replace one form of dogma and arrogance with another. Such behavior can shorten lives. It's time to demand an end to promotion of half-truths and intolerance. What the AIDS community urgently needs from alternative health advocates -- and what growing numbers are providing -- is well-documented information about theories and treatments, awareness that they don't have all the answers and, most of all, respect for the self-empowerment of people struggling in various ways to improve and extend their lives.

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