Dead Certain?

Despite the death of her daughter from what the Los Angeles County coroner determined was an AIDS-related infection, HIV positive Christine Maggiore stands by her views—including that HIV does not cause AIDS. Her position, labeled “denialist,” has been discredited by the majority of the scientific community. If her belief is widely disproved, why do others believe it too?

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“My husband was on the phone with the pediatrician, and I started screaming: ‘She stopped breathing!’ Then, she collapsed—right in front of my eyes. My baby! My baby!” That’s how Christine Maggiore, in tears on ABC’s *Primetime* last December, described the events that led to the death last May of her 3-year-old daughter, Eliza Jane Scovill. Dressed in black, her soft, maternal voice cracking, Maggiore, a prominent HIV positive AIDS denialist, tried to convince an interviewer that her controversial beliefs about AIDS—chiefly, that HIV doesn’t cause it—hadn’t killed her child. The program was a return to the spotlight for Maggiore, the Los Angeles–based founder of Alive and Well AIDS Alternatives who first garnered press in 2000 for her self-published booklet *What If Everything You Thought You Knew About AIDS Was Wrong?*

When she brought Eliza Jane to the emergency room that May night, Maggiore, now 49 and positive for 13 years, didn’t tell the doctors that she’d never had her daughter tested for HIV, nor did she mention her own HIV status, which could have alerted them to potential causes of her daughter’s respiratory distress.

Her explanation? “I wanted an unprejudiced evaluation of my daughter,” she says. Maggiore believes that if the emergency room physicians had known Maggiore was positive, they would have looked for AIDS-related causes at the expense of other possible reasons for her daughter’s illness.

Several months after Eliza Jane died, James K. Ribe, MD, senior deputy medical examiner at the Los Angeles County coroner’s office, pronounced that her death had been caused by Pneumocystis carinii pneumonia (PCP), one of the most common—and fatal—opportunistic infections associated with HIV, and her death was declared to be AIDS-related. Slides of cells from Eliza Jane’s lung showed large colonies of Pneumocystis carinii. The autopsy report also described the presence of HIV core proteins in the brain and confirmed a diagnosis of HIV encephalitis. Because of an ongoing criminal investigation into Eliza Jane’s death, the coroner’s office would not confirm to *POZ* whether it had actually tested her blood for HIV infection or HIV antibodies.

Maggiore challenged the findings, claiming that they were driven by the medical establishment’s

desire to discredit and demonize her. Mohammed Ali al-Bayati, PhD, a toxicologist who serves on the board of Alive and Well, approached Maggiore and offered to review the autopsy report. His analysis: “Eliza Jane did not die as a result of AIDS but as a result of adverse reaction to the antibiotic amoxicillin—which she had been given to treat an ear infection.”

Eliza Jane’s pediatrician, Jay Gordon, MD, says he knew that Christine Maggiore had HIV and that she had breast-fed Eliza Jane (breast-feeding is one of the ways a mother can transmit HIV to a child). He and Maggiore discussed her controversial views on several occasions, yet she was adamant about not testing Eliza Jane for HIV. Gordon says that he never saw any clinical evidence that Eliza Jane had immune suppression or other signs of HIV infection.

Gordon regrets how he handled the situation. “My feelings are at odds with Christine’s,” he says. “I do feel HIV causes AIDS. Many people in her life feel they should have done something different. I am one of those people.” This raises a difficult set of questions. What should he have done differently? Refuse to see Eliza Jane as a patient? Report her mother to some authority? Does a parent have the right to control his or her child’s health care, or should the state step in and mandate testing and antiretroviral treatment for children who have HIV?

The incident dusted off a debate that many in the AIDS medical establishment have long dismissed as ludicrous. Besides asserting that HIV does not cause AIDS, denialists contend that the HIV antibody test is meaningless, that safer sex cannot prevent AIDS, that HIV antiretroviral therapy (HIV meds) are useless toxins peddled by greedy drug companies and doctors and that nutritional supplements and holistic healing are the only effective AIDS remedies.

Throughout the epidemic, there have been skeptics who challenged or dissented from the most widely accepted conventional wisdoms. This group, generally known as “AIDS dissidents,” included at various times many of the brightest AIDS researchers, clinicians and activists. Even Robert Gallo, the codiscoverer of HIV, and other serious scientists called into question the silver bullet, single-cause theory that AIDS is caused solely by HIV. The questions they posed yielded insights that are now part of the conventional wisdom and that changed treatment protocols. Many of the most important advances in prevention and treatment have come from the grassroots AIDS movement, led by people with the disease and their doctors. Often, these advancements were initially opposed or ignored by the government, pharmaceutical companies and the health care establishment.

The term “AIDS dissident” is not used as often anymore, although there remain varying degrees of skepticism among activists, people living with HIV and the medical community. Nevertheless, the beliefs of those who have been labeled “AIDS denialists” are far more extreme than the challenging skepticism of AIDS dissidents. Denialists contend that there is no link between HIV and AIDS.

Their opponents argue that overwhelming, scientific data prove the link between HIV and AIDS and support the efficacy of HIV treatments. They charge the denialists and their activism with the deaths of thousands, for having

discouraged those who need treatment from getting it.

Matt Levine is an HIV Positive San Fransican who was formerly president of the board of Quan Yin Healing Arts Center, one of the largest alternative/complementary care HIV clinics in the country. “I refused antiretroviral treatment, against my doctor’s advice, for seven or eight years,” says Levine, who believes he was infected in the mid-’80s and was diagnosed in the mid-’90s. “I went on treatment when my T cells dropped below 100. I made the right decision to refuse treatment for the period I did, and I made the right decision to go on treatment when I did.”

He summarizes what he believes to be part of the denialist movement’s attraction: “There is some truth in the claims made by AIDS denialists. Not everyone with HIV has gotten AIDS. HIV testing is not a perfect science, and there have been many documented cases of testing errors. Safer sex is highly effective at preventing transmission, but not 100% effective. Thousands of people were put on AZT monotherapy to treat their HIV who should not have been and died from it, even though it was considered a ‘best practice’ at the time. Nutritional supplements and holistic healing are an integral part of survival for many of us, and much of the medical establishment’s wholesale dismissal of these strategies is disheartening.”

There is also a history of the health care establishment and the government disregarding the specific needs of people of color and sexual minorities. In the ’80s, there was confusion and mistrust on the part of the gay community. Feeling like the government and the medical establishment didn’t care whether they lived or died made it difficult at the time for gay men and now people of color (including many women) to believe what the medical establishment said about AIDS.

Indeed, conventional wisdoms in the AIDS epidemic that turned out later to be big lies, big mistakes or remain highly controversial, even among mainstream experts, are legion. They include: that treatment of HIV with high-dose AZT monotherapy is effective (AZT, given at a much lower dose than it was in the ’80s, is today a common component of combination therapy); that protease inhibitors can “eradicate” the virus; that all people with HIV should “hit early, hit hard” with meds; that oral sex is high risk; and that women give HIV to men as easily as men give it to women.

A major factor fueling the denialists’ arguments is the distrust the medical establishment engenders by repeatedly—and not just in the case of AIDS care—overhyping (and overcharging for) drugs, underplaying side effects and being insensitive to patients’ needs.

Studies show that many HIV med takers eventually develop elevated LDL cholesterol and triglycerides, fat clumps and facial atrophy. Cases of HIV-meds-related heart disease and diabetes are rising. And many have battled diarrhea, degenerated bones, peripheral neuropathy (painful sensations in limbs) and more. Reports are slowly trickling in of deaths from conditions such as lactic acidosis and liver failure. Not all of these conditions can be attributed solely to HIV meds. Some are the result of accelerated aging in people with HIV, others of normal aging in a group of people who had not been expected to live through middle age.

Some AIDS educators report that many people with HIV—especially those influenced by denialists—are fixated on old information. “People who saw friends die of toxic doses of AZT monotherapy in the ’80s are stuck back there,” says Hank Wilson, a manager at Tenderloin AIDS Resource Center in San Francisco. “They still think all drugs are poison. They don’t understand there are more than 20 HIV med options now—many of them brand new—all with different side-effect profiles.” Many positive people with higher CD4 counts have had monitored treatment interruptions, which physician Joseph Sonnabend calls “important for toxicity management.”

Another source of suspicion is the corrupting influence of pharmaceutical funding, says Alan Berkman, MD, an AIDS specialist at Columbia University’s School of Public Health, cofounder of Health GAP (Global Access Project) and an ardent foe of denialism. He says, “We’ve turned over the direction of biomedical research to drug companies—that’s deplorable.” Berkman adds, “They lie about the results of their trials. There needs to be enormous skepticism about their claims and more oversight. Doctors get bought off consciously or unconsciously and do the companies’ bidding.”

But Berkman and Sonnabend both believe these various concerns don’t excuse the distortions of denialist zealots. “The issues are not black-and-white. Drugs that can save your life can also under different circumstances kill you. This is a distinction that denialists do not seem to understand. The fact that drugs are sometimes used badly does not mean that they are always ‘poison,’ ” says Sonnabend.

Until the late ’90s, Sonnabend was outspoken against the notion that HIV had been proved to cause the disease. Today, he says, “The evidence now strongly supports a role for HIV,” citing particularly “the effects of potent HIV meds.”

But he has not changed his view that developing AIDS, like other infectious diseases, requires cofactors such as other viruses and bacteria. Another prominent AIDS dissident, Robert Root-Bernstein, PhD, professor of physiology at Michigan State University in East Lansing, has shared Sonnabend’s evolution. “Both the camp that says HIV is a pussycat and the people who claim AIDS is all HIV are wrong,” says Root-Bernstein. He argues that mainstream researchers should be investigating leads on cofactors, as he has been. But, he adds, “The denialists make claims that are clearly inconsistent with existing studies. When I check the existing studies, I don’t agree with the interpretation of the data, or, worse, I can’t find the studies [at all].”

Meanwhile, the medical establishment’s latest findings, published in The Lancet in July 2005 and based on a large observational study, found that HIV combo therapy cut the rate of full-blown AIDS and death by 86% over several years compared with those not receiving treatment. Despite this, some people with advanced disease—particularly purist followers of holistic healing—continue to risk the consequences of refusing HIV meds in late-stage illness.

For Richard Berkowitz, a long-term survivor and an AIDS activist integral to the launch of the PWA (People With AIDS) empowerment movement, the turning point came in 1995 when, with only five CD4 cells, he “came down with rapidly proliferating Kaposi’s sarcoma. Berkowitz, who at one time

insisted that HIV could not cause AIDS, says, “I was dying.” He started an HIV meds combo. “In less than two months,” he says, “all of my lesions were gone, and my CD4 counts were jumping.” The lesson: “I really needed to reexamine my beliefs.” A decade later, he remains on HIV meds, with a CD4 count of 605 and an undetectable viral load and is “feeling fine.”

Berkowitz, activist Michael Callen and Joseph Sonnabend coined the phrase “safe sex,” wrote and published the first prevention materials and were vocal in their opposition to putting everyone with HIV on AZT.

“The reason I’m alive and well is because I didn’t jump on the AZT bandwagon, which killed most of my friends, who started when they were only HIV positive,” Berkowitz says. Sonnabend concurs, “Sadly, the orthodox AIDS medical leadership has made mistake after mistake,” he says. “1,200 mg a day of AZT [the first approved dose in the ’80s] killed thousands,” as did so-called early intervention.

As for handling the toxic side effects, HIV nutrition expert Lark Lands, PhD, founder of the site larklands.net, says immune-damaging nutrient deficiencies, shown to be present even in early HIV disease, help explain a groundbreaking eight-year study of 1,078 Tanzanian women in July 2004, that showed that PWAs on a high-dose, three-vitamin combo (without HIV meds) experienced 30% less disease and death than a group on placebos. But Harvard nutrition-and-AIDS researcher Wafaie Fawzi, MD, who led the study, cautions, “Vitamins are by no means a cure or substitute for HIV meds therapy, but nutrients could greatly delay the start of meds.” Lands adds, “You can gain all the benefits of HIV meds while using nutrients, enzymes, herbs and, where appropriate, other drugs to counter the meds’ side effects. It’s medical malpractice not to pass this information on to those who are suffering.”

The opponents of denialism often point to South Africa, the country with the world’s highest per capita AIDS rate, for evidence of what they consider the movement’s deadly impact. Khayelitsha, one of many sprawling townships outside of Cape Town, teems with people impoverished by generations of apartheid and is overwhelmed by the daily drumbeat of AIDS deaths. A woman named Ntombekhaya (last name withheld by her family’s request) went to the public clinic there in October 2004. By the time she decided to get help, she had a CD4 count of 45, was wasting and had tuberculosis, according to an account from the Health-e news service. Ntombekhaya began a course of TB treatment, which she planned to follow with combination HIV meds therapy.

In early 2005, Ntombekhaya visited a new natural health clinic in her town set up by German vitamin entrepreneur Matthias Rath, MD. A researcher of antioxidants, Rath claimed his patented vitamins could cure heart disease and cancer. Local newspaper ads and pamphlets from Rath’s foundation proclaimed that HIV meds “severely damage all cells in the body, worsening immune deficiencies and expanding the AIDS epidemic” and that his nutritional supplements alone could reverse AIDS. “The Rath people have launched an aggressive door-to-door campaign, pushing their vitamins on the sick and vulnerable,” said a local clinic nurse who asked that her name, too, be withheld.

As a result of her visit to Rath’s clinic, Ntombekhaya stopped taking her TB meds and her health

quickly deteriorated. In March of 2005, she died.

Ntombekhaya wasn't the only South African influenced by Rath's denialist group. After her death, Health-e investigated more of Rath's patients and uncovered at least 12 more deaths of local PWAs who were told that the Rath supplements could stop AIDS.

The seeds of denialism were planted in South Africa in 1996 when local attorney Anthony Brink discovered the websites of U.S. denialists and wrote a book lambasting AZT as a useless poison. Three years later, Brink wrote to the newly elected South African president, Thabo Mbeki, sharing his views. In July of 2000, at the International AIDS Conference in Durban, South Africa, Mbeki's opening speech shocked the world; he suggested that poverty—not HIV—was the root cause of AIDS.

Since then, a small but relentless group has backed Mbeki and his like-minded health minister, Manto Tshabalala-Msimang. Opposing them has been a growing array of civic groups, labor unions, religious groups, medical and AIDS
organizations. Leading the charge has been the Treatment Action Campaign (TAC), formed in 1998 to demand maximum access to quality medical care for those with HIV. As a testament to their efforts, in July of 2002, the South African cabinet declared that "HIV causes AIDS," silencing Mbeki; in August of 2003, they agreed to offer HIV meds in public clinics. But implementation has been slow—at press time, UN statistics say, 85%, or almost 900,000 people with HIV who need antiretroviral drugs (defined there as those with symptoms or CD4s count below 200), aren't getting them.

TAC also went after Rath's group. "At first, we thought his ads were too insane to bother with," says Nathan Geffen, TAC's treatment and policy coordinator. "Then, people started calling in saying they'd stopped taking their HIV meds because of Rath." Health Ministry spokesperson Sibani Mngadi declined to give an opinion on Rath's activities, responding via e-mail: "We give people options on the variety of services available for management of HIV and AIDS. We explain to them the advantages and limitations of each intervention, make recommendations. But at the end, it is an individual decision."

TAC grants that the vitamins are given out free to South Africans, but adds, "Rath's goal is to use [results from using his products on] the African people as part of marketing his high-priced products overseas on the Internet," a claim that Rath denies.

There is a residual issue arising from the notion of wealthy whites and first-world corporations using impoverished communities of color and poor countries as "test sites," whether it is for pharmaceutical or nutritional treatments. Denialism and skepticism have a strong foothold in communities of color in the U.S. "There's a long \history of medical experiments using—and not benefiting—black people," says Robert Fullilove, MD, an African-American professor of sociomedical sciences at Columbia University. "There is a common belief among black people that HIV was invented in a government lab as a conspiracy to eliminate them," he says. "Incidents like these contribute to the belief, on the part of black people, that the government and corporate

sectors don’t take their interests to heart.”

Attitudes are similar in the Latino community. Dennis deLeon, an HIV positive man who directs the Latino Commission on AIDS in New York City, says, “Many Latinos believe the drug companies have the cure but are holding it back because they want to promote their meds.”

Already alienated, then, from the medical establishment, these communities are all the more open to those with different, even radically different, views about the disease.

At press time, Los Angeles police were determining whether there are grounds for charging Maggiore and her husband, Robin, with criminal neglect and would not comment on the investigation. Meanwhile, she has had her other child, Charlie, age 8, whom she also breast-fed, tested for HIV. He was found to be negative.

Does Maggiore regret any of her decisions regarding Eliza Jane’s upbringing and medical care? She tells POZ, “I am devastated over the loss of my daughter. I did everything I could to help [Eliza Jane] grow to be healthy and strong. None of what has happened to me and to my family has shaken what I know to be correct and true about science, medicine and my experiences.”

Nor does she believe the larger movement will suffer from the publicity around Eliza Jane’s death or any potential criminal proceedings. “But do I want any good to come out of this increased attention for the cause? No. I lost my daughter. It’s very difficult to find any upside. It’s like winning some sick, twisted Lotto. I can’t look at it like that,” she says.

How the global community of people living with HIV/AIDS can, do and even should look at Eliza Jane’s death is, of course, an intensely personal matter, as the clinicians and people with HIV/AIDS interviewed for this article have revealed. On the tenth anniversary of the protease “revolution,” do Maggiore and the denialist movement offer an extreme prism through which to view and critique the medical establishment? Only one thing is certain: There are those who believe HIV is the primary cause of AIDS (including the vast majority of the medical establishment) and those who do not (including Christine Maggiore, Matthias Rath and a small but vocal group of scientists and their followers).

Whatever one’s opinion about Christine Maggiore and the claims of the denialists, to demonize the very act of their questioning, to cede it as the exclusive property of a fringe group, may be a mistake. It may be helpful to remember that in the early ’80s, many people living with AIDS were dissidents—considered radical for believing that they could actually fight a “death sentence” disease. To be a dissident was all about being open-minded, asking questions, railing against establishment wisdom.

Where does one draw the line between the healthy skepticism of dissidents and the dogma of denialists? To keep challenging and keep asking questions is not always comfortable. But as AIDS has taught us, it’s the only way to survive.

Additional reporting by Lucile Scott and Scott Wald
