

AIDS SCAMS CON THE UNWARY

by Sarah Henry
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Untested Treatments Prove a Bonanza for Unscrupulous Marketers

After learning that he had contracted the AIDS virus, Los Angeles resident Jim Looney was determined to do whatever it took to stay healthy. In mid-1989, Looney's T-cell count, a key measure of the immune system, started to plummet. Looney became desperate and panicky, fearing that he was going to die.

That October, the 40-year-old aerospace company employee heard about Viroxan, an underground treatment that, he says, a doctor was heralding as a cure for AIDS. Looney decided to start injecting the drug, a plant extract that his lawyer describes as having the consistency of refrigerated honey.

Later, according to Looney, his physician convinced him to have a catheter surgically inserted into a vein in his chest so that the Viroxan, an unsterile substance, could flow directly into his bloodstream.

Jim Looney is one of as many as 100 people with the virus that causes AIDS who were convinced that the Viroxan concocted in a doctor's home could keep them alive, even cure them of AIDS. And Looney, who spent about \$20,000 on the treatment, which he took for nine months, is angry and embittered by his experience. He has lumps of dead tissue on his buttocks and hips from the painful Viroxan injections and potentially serious blood clots from the catheter; and the drug leaked under his skin, he said, so that at one point he felt like a freak of nature.

"My arms were blown up, and I could barely bend my fingers," said Looney. He said he was forced to take six weeks off work to recover.

Looney, along with eight other patients, has filed a civil lawsuit alleging medical negligence and malpractice, fraud, conspiracy and emotional distress against the physicians, radiologist, pharmacist and Los Angeles hospital where he had his surgery. The case is expected to go to trial soon.

His doctors argue that they are innocent of any wrongdoing, saying the drug has merit and will soon be tested in a hospital. They argue that they were motivated to help find a cure for AIDS and were looking beyond the mainstream drug options.

The case highlights a difficult issue for the entire AIDS community. Many people who are infected with the human immunodeficiency virus (HIV) that causes AIDS are willing to try unproven treatments, some of which appear effective in maintaining health.

"This is such a desperate time, such a desperate illness and people are still so uneducated. And it's 11 years into the epidemic," said Mark Roh, an FDA official in San Francisco and a member of the California AIDS Fraud Task Force.

Larry Tate, who formerly ran the information hotline for Project Inform, a San Francisco-based clearinghouse on HIV treatment, added that all the drugs that provide some help in treating HIV have serious side effects. "It gives legitimacy to those who come by and say, 'None of those work, try this,' " he said. "For the foreseeable future, it's a very rich field for scams."

Indeed, AIDS scams have fast become one of the most common kinds of health fraud the FDA encounters. One reason, said Randolph Wykoff, the U.S. Food and Drug Administration's AIDS coordinator in Rockville, is that when a person is facing a disease such as AIDS, sometimes the only good news comes from a charlatan waiting to make a buck.

Many scams have involved ozone therapy. In different guises, ozone therapy at one time was pushed as a cure for AIDS by con artists. The treatment involves pumping ozone gas through the rectum in an attempt to kill the AIDS virus. It can cost hundreds of dollars and is potentially harmful.

In another example, attorneys for the Federal Trade Commission in San Francisco and officials at the Department of Consumer Affairs in New York City last year cracked down on companies selling a \$300 immune-boosting supplement as a cure. The supplement, "Immune + Plus," turned out to contain little more than what a multi-vitamin pill has to offer. According to court records, there were only four or five sales of the treatment, including two to undercover government investigators. But officials point to the case as a rare occasion in which they were able to quickly halt the sale of a treatment that promised a cure for AIDS.

Officials of the New York City Department of Consumer Affairs also moved quickly this fall to bring charges against a Brooklyn real estate agent for his role in advertising an allegedly fraudulent AIDS cure. In one case, a flier distributed for several weeks in Greenwich Village boasted "HIV (+) to HIV (-) in 30 Days - All Expenses Paid." The cure turned out to be a regimen of diet, exercise and ozone therapy at a naturopathic clinic in Mexico. It also wasn't free; some people were charged \$20,000.

Some claims made by con artists are patently absurd, said the FDA's Roh. He points to such items as "Anxifree" herbal body shampoo, which the manufacturer claims can prevent infection with HIV. "Anxifree," according to a mail flyer, prevents AIDS - as well as hepatitis, hemorrhoids and pimples. "Love Solution," a spray-on "sterilizing detergent" available by mail from China, prevents AIDS, too - if users spray their genitals "2-3 times" before intercourse, boasts an advertisement for the product.

Some of the patients using these treatments and drugs vouch for them even after doubts about a treatment surface. Jim Templeton, a former Los Angeles resident, took Viroxan off and on for almost four years. Templeton said before he died last month that he believed "the powers that be" are trying to discredit the drug because they don't care about helping people with AIDS who are gay.

Wykoff of the FDA points out a major problem with buying underground AIDS treatments. "Sometimes, people with serious diseases want to have their cake and eat it too," he said. "They want protection from fraud, and they want community access. You can't have it both ways."

Officials say it is difficult to determine the magnitude of the problem. According to those who have been scammed, many people who try secret or experimental treatments realize later that they have been defrauded but are reluctant to come forward because they feel foolish. Some remain convinced that a treatment is helpful despite mounting evidence to the contrary. Others simply become too sick or die before letting it be known that they were conned.

The majority of AIDS activists don't look to the government for help in exposing charlatans; they look within their own community. Therein lies a quandary: as people with AIDS readily acknowledge, it is only after somebody gets hurt - or dies - that officials are called in. Community monitoring works "miserably, appallingly, badly," conceded Larry Tate. "There isn't any scam central."

There is another dilemma. Although opposed to exploitation, activists worry that an overzealous government investigation could jeopardize potentially legitimate treatments available through the underground. They are quick to point out that a drug such as DDC, which is of benefit in treating AIDS, was first made widely available through buyers clubs.

The best protection against quack cures, said both community activists and federal regulators, is an informed consumer.

"You've got to educate yourself on a basic level," said Lewin Usilton, a board member of the Healing Alternatives Foundation, a San Francisco buyers club and information center. He suggested that patients should be wary of any treatments that are advertised as a cure or said to render patients HIV negative. They should also be suspicious of any remedy called "secret" or if the promoters claim that the product also works for other diseases, such as cancer. Consumers should also ask for scientific studies from reputable journals, rather than just personal testimonies of success.

A basic rule of thumb, said Usilton, is "as soon as they make a claim, they've got to be able to back it up - and it can't just be anecdotal."

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