Alternative Scene

How this Californian resolved to master her treatment—naturally

January 1, 2006 By Lucile Scott

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60, San Diego
Diagnosed 1991

Before I was diagnosed with HIV, I took my health for granted. But when I started taking AZT monotherapy, I developed extreme anemia, a common side effect. My T cells plummeted. I was hospitalized, and a young medical intern held my hand, crying and saying, “If you die, ma’am, we killed you.” I decided then that if I’m going to stay healthy, it’s up to me. My doctor halved my AZT dose, but I took myself off. I decided I would rather treat myself naturally with supplements as much as possible and avoid the bad side effects of pharmaceuticals. I started researching alternative therapies to treat HIV and side effects like diarrhea and consulted expert AIDS nutritionists. For three years, my T cells were below 200, but I was taking over 100 nutritional supplements a day and never had an opportunistic infection. You name it—I did it. I went to Mexico and tried ozone therapy. I ate bitter melon, a fruit from the Philippines with antiviral properties. Still, I realize you need to balance the supplements with antiretrovirals (HAART) now that they’re available. Antiretrovirals get viral loads down—they are often the only hope. I take Ziagen, Viread and 3TC for one week, off for three. Meanwhile, the supplements help keep my blood work excellent. Learning which to take requires research, time and expert advice. Here’s how I did it.

—As told to Lucile Scott

3 steps to supplemental knowledge

1. Talk to doc
It’s crucial to find a doc who will work with you and tell you if what you are doing is dangerous. My doc and I don’t always agree, but I say just tell me if it will kill me. There are many excellent, progressive docs who are self-educated and very knowledgeable about supplements. Post an inquiry on a site like AIDSMeds to locate one. But such docs aren’t everywhere or covered by all health insurance. I’m on Medicare and can’t go to the best doc in my area.
Post questions and find info at AIDSMeds, www.aidsmeds.com.

2. Do the research

I started going to seminars and medical conferences and talking to experts like Lark Lands and Michael Mooney, two of the nation's best experts on AIDS and nutrition. I discovered excellent treatments, including the herbal supplement CM4, which suppresses cells' HIV receptors. Then I started volunteering at the Houston Buyer's Club, a nonprofit that sells and provides information about treatments, and continued discussing and researching treatment options. The hardest part is making the time for research and sorting through conflicting information. Always consult an expert or a reputable website.
Find experts, products and tips at the Houston Buyer's Club, www.houstonbuyersclub.com, 800.350.2392. Find info and consult Lark Lands at www.larrylands.com/lark and Michael Mooney at www.michaelmooney.net.

3. Be skeptical
There will always be someone out there hawking snake-oil cures. I remember one product called T Up, as in T cells going up. It cost $12,000 for two weeks, which seemed way too much for a natural herb, so I skipped it. A few months later, the guy involved went to jail. High cost is always a red flag: Ask others who have tried it. And I never buy discount supplements—studies show they can have less of the active ingredients. Look at who is sponsoring information, like pharma or a vitamin producer, and what they have to gain or lose from it. I believe in positive thinking about health and that the healthiest people are the most proactive. I'm 60 and have the energy of most 30-year-olds.
For more info on supplements, check out the National Center for Complementary and Alternate Medicine, www.nccam.nih.gov, 888.644.6226.

Additional resources:
AIDS Treatment News, a newsletter on traditional and alternative therapies, www.aidsnews.org.

Medibolics, an e-zine about anabolic steroids and alternative HIV therapies, www.medi bolics.com.

Project Inform offers a treatment information website and hot line, www.projectinform.org, 800.822.7422.

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