

Alternatives 2000

April 1, 2000 By Staff

Blame it on the record economy, millennial fever or the stars, but a moment of spiritual chic is upon us. Anger's out, and inner peace is, er, in. Well, Hollywood may just be waking up and smelling the incense, but PWAs have marched in the advanced guard of the "alternatives" movement ever since HIV was named the cause of AIDS (we'll get to that controversy in a moment). For the seven HIVers profiled in our special Alternatives 2000 issue—each of whom has found health and happiness on an antiretroviral-free regimen—style is the least of it. Far from being warm-and-fuzzy New Agers, they're cold, hard skeptics who are waiting to call in the big guns of Western medicine in favor of waging a guerrilla war with their disease. What's in their amorphous arsenal of holistic options? Some as down home as a disciplined, delicious diet; vitamins, herbs and other supplements; meditation, massage, live-cell morphology (huh?) and much more. (Check their stats for results.)

Skepticism and hope are the poles around which PWA self-empowerment has always orbited. In 1990, the late Michael Callen did a study of long-term survivors, including himself, and found that the two things they all had in common were no AZT and an alternative approach to health and healing. This professional skeptic wrote in *Surviving AIDS* (HarperCollins) "As one survivor put it, 'Ultimately, the best indication of how you feel is how you feel. And if acupuncture reduces the side effects of chemo or a particular diet makes me feel like I have more energy, why not stick to it, without demanding how or why it works?' Since science and medicine have utterly failed to provide any certainty in the realm of treatments, it makes sense to remain open-minded about therapies for the immunodeficiency of AIDS."

What a difference a decade makes. Or does it? Callen didn't live to see science redeem itself with the protease revolution's un-detectable viral loads and deathbed recoveries. While HAART's anti-HIV punch might have surprised him, these drugs' many toxicities and side effects would strike him as very *déjà vu*. So, with a lifetime on HAART an increasingly dicey prospect and no pharmaceutical gushers currently in the pipeline, it seems like the right time to ask, à la Callen, What's the alternative?

What if, as our profilees profess, alternative treatments are not just "harmless add-ons" to HAART that make you feel a bit better but powerful tools for PWA survival? And while we're tweaking conventional wisdom, let's leave no theory unturned. What if HIV is only one of many cofactors causing an immune-system crisis? With the eradication boom gone bust and researchers refocusing on immune rebooting, these questions are as cogent as ever.

In this special issue, POZ presents you with a comprehensive user's guide to alternative theories and treatments. You'll find an account of one of the epidemic's great debates—HIV alone or with cofactors?—as well as tips on minimizing them as part of a treatment plan. There's an investigation into the high-on-promises, low-on-proof supplements market, plus advice for getting started (page 70) and getting the most bang for your buck. Our new media column, Meet the Press, kicks off with the nation's most controversial AIDS journalist, Celia Farber, who blasts what she views as the not-so-noble tradition of lemmings-to-the-HIV media coverage of the disease. And our Beyond Meds piece looks at the growing scientific evidence for the validity of spiritual healing.

In the pre-protease Dark Ages, dinosaurs like Michael Callen learned to question everything about AIDS. It's that ever-fresh perspective that we wish to recapture here. Of course, we're in no way suggesting that you hop off the protease express and jump on the bitter-melon bandwagon. We just don't want you to settle. Everyone has to find their own path, and many HIVers successfully mix and match modalities. Just as prevention pundits have learned to diversify their message, treatment activists must be willing to move beyond the one-size-fits-all, "it's the virus, stupid" approach to AIDS therapy.

But—and our science editor, Lark Lands, says it's a big but—certain approaches that our magnificent seven use may have little in the way of research support, and may even spell danger, especially if used inappropriately. For example, bitter melon—sorry, Stanley!—can point to only a single very small study showing benefit but waves a major red flag: It can cause mis-carriage, making it a no-no for pregnant women. Glycyrrhizin—a highly purified pharmaceutical extract, not the licorice product often promoted—has more support, but handle with care: In high doses, it can cause killer levels of water retention (making it particularly dangerous for those with high blood pressure, low blood potassium, or weakened hearts or kidneys), as well as headaches and vomiting. So, as always, dear reader, pack as much information as you can before heading out on the road less traveled. Bon voyage.

—The Editors

Donald Bliss

40, Mental health-care worker

Tested poz: 1995

Regimen: 23 pills with each meal and a few at bedtime, including acidophilus capsules (three per meal), DHEA 375 mg, melatonin 3 mg at night, multivitamins, vitamin C 3,000 mg per day, beta-carotene 75,000 IU per day, vitamin E 600 IU per day, selenium, flax seed oil, coenzyme Q-10, cat's claw, saw palmetto, kava kava, St. John's wort, valerian root combination, digestive enzymes, N-acetyl-cysteine (NAC) 3,000 mg per day, Dimethylglycine (DMG) and glutamine. Whew!

Finding Bliss: A San Franciscan from way back, Bliss was up-to-speed on all the HIV treatments when he tested positive. "I was advised to take AZT, but I understood it to be very toxic," Bliss says. "But I came to the table with an alternative orientation—I did yoga as a teenager!" After researching, Bliss decided to focus his treatment on symptom management, developing an ambitious vitamin-herb regimen to combat the bloating, diarrhea and other problems that he says prevent his body from absorbing nutrients.

Stop the clock: “My doctor thinks I’m a rapid progressor who’s not progressing rapidly because of my focus on overall well-being.”

Support staff: “My father will clip articles on alternative treatments and send them to me.”

Stats: His CD4 cell count remains stable between 250 and 350; viral load 25,000 to 55,000.

Drawbacks: Cost! About \$300 a month not covered by insurance or supplemented by any other health care programs.

—Sandra Hernandez

Mark Kuebel

39; graphic designer, medical writer, full-time student of Chinese Medicine

Tested Poz: 1989

Regimen: Acupuncture twice monthly, especially for his peripheral neuropathy and digestive problems; antioxidants such as vitamins C, E, beta-carotene, alpha-lipoic acid, NAC (N-acetylcysteine) and selenium; DHEA; olive leaf extract, ginseng, glycyrrhizin (pharmaceutical extract of licorice root), acidophilus, L-carnitine; Chinese herbs, as needed—for example, shuganwan (smooth liver pill) for bloating and to help ease digestion.

Class notes: With an undergrad degree in molecular biology, Kuebel put this regimen together just a year after testing positive. “I didn’t go through some dark night of the soul where I felt betrayed by Western medicine and said, ‘Screw it.’ It was more a matter of learning what was important.”

Get To The point: “No, the needles don’t hurt. They part—not tear—the skin. And you rarely bleed. I normally wouldn’t have this many needles in my face. Each one is at a specific energy point. It’s a wonderful feeling. But needles in your feet—arrgh!” Relief pitch: “I don’t have to worry about side effects, and I don’t have panic attacks about ‘I didn’t take my meds and now the virus is mutating in my body and...’”

Sleep therapy: “I think of my treatment as anesthetizing the virus—not eradicating it, but keeping it dormant.” Stats: CD4s are 425; viral load, 2,500.

—Sandra Hernandez

Stanley Rebultan

48, Respiratory therapist

Tested poz: 1988

Regimen: Bitter melon, a vegetable cooked in stews throughout East and Southeast Asia, used as rectal infusions or tea five times a week.

Recipe: Wash, cut and juice equal parts bitter melon leaves and fruit. Apply each 16-ounce dose using a rectal syringe and hold in body 30 minutes; then clean out system with warm water. Rebultan recommends at least 30 minutes’ rest afterward.

Household hints: “You can use an enema bag or a rectal syringe. You must keep the fluid in as long as possible so that your colon absorbs it. I prefer to do it early in the morning after a bowel movement. And don’t do it at night because it may give you insomnia. You’ll be wide awake.”

The Seed Of The Idea: Growing up in a Filipino family, Rebultan was often offered bitter melon at dinner but turned his nose up at it. He was later turned on to the medicinal use of the plant by a

Filipino friend. “Then I remembered how my grandparents always said it helped to improve your health.” After his CD4 cell count dropped to 400, a skeptical Rebultan gave it a try, first chopping the vine and juicing the fruit to leave a higher protein level than if it was boiled.

Protein power: Rebultan thinks it’s the so-called MAP-30 protein compound that juices him—he’s never taken antiretrovirals. He says his confidence was boosted by a small study that concluded the plant had a positive effect. “I understand that it inhibits the formation of infected CD4 cells into clumps, which causes their death. Something like that.”

Stats: Soon after he began his regimen, Rebultan’s CD4 cell count began to climb and is now steady at 920; viral load is 8,000

—Sandra Hernandez

Chardelle Lassiter

53; Peer educator, former social worker

Tested poz: 1988

Regimen: In addition to a mainly vegetarian diet including whole grains, beans, juiced fruits and vegetables, Lassiter has embarked on a course of spiritual exploration. Meditation and prayer play leading roles in her daily routine. “I practice daily rites and do positive affirmations. I just follow my instincts—practice Reiki [an energy therapy], vitamin therapy, aromatherapy—and I dancercise.”

Believing is seeing: “During meditation I breathe out all the stresses and toxins in life. I imagine myself stronger than the virus—the light within me overpowering it.”

In earshot: “A voice deep inside me 11 years ago told me not to take antiretroviral drugs—that they were toxic and wouldn’t work for me. I have learned to respect that voice. I attribute my success to that spiritual strength—not to be confused with religion, which to me is just a business.

Her Attitude: “‘Just Do It.’ Since I tested positive, I’ve given up a lot of things, but first on the list is fear. I’ve also had to remove myself from negative people, toxic thinking. To me, AIDS is a war. I have friends who have been killed. It’s partly for them that I’ve made a choice to survive.”

Still a drag: “Sometimes I miss the things I’ve had to give up: fatty fried food, sugar and alcohol. I still smoke an occasional cigarette. It’s something from the old life.”

Doctor without orders: “We have the same conversation at every appointment. She says, ‘Go on the drugs,’ and I say, ‘No, I’m not ready.’ It’s our little ritual.”

Stats: “My CD4 count fluctuates between 260 and 300, and my viral load is at 30,000—down from 100,000.”

This means you: Lassiter, who calls her outreach work “protease for the soul,” advises a reader at the end of her rope to look to herself: “Find out what makes you afraid and confront it.”

—Becky Minnich

Matthew Carmody

33; AIDS legal-services advocate, former modern dancer

Tested poz: 1991

Regimen: A whole-foods veggie diet, daily workout and an alternative buffet including SPV 30, curcumin, bitter melon, glycyrrhizin, antioxidants, intestinal-flora (acidophilus/lactobacillus) supplements and spirulina. “The supplements brought my T cells up, but I still had intestinal troubles. Three months of acupuncture took care of that, but for maintenance I started on a

regular course of Shiatsu massage.” Bingo!

Skin Graph: “Like acupuncture, Shiatsu works on a meridian system. My therapist stretches out my limbs and then works certain pressure points along the meridians. Afterward, I feel like I’ve been cleared out physically and emotionally. Whatever tension I’ve been holding on to has been released—I return to myself.” **body of evidence:** Carmody says his twice-monthly sessions bring the digestive relief he needs to maintain the rest of his regimen. “One problem I’ve had is I can never tell if the supplements are working or not, so it’s a big leap of faith. It makes such a difference to be doing something like Shiatsu massage where I feel immediate results.”

Stats: “My T cells nearly doubled after starting—from 350 to 600. Now they’re stable at just under 500, and my viral load is 8,000.”

Bedside Manner: His doctor, AIDS specialist Robert Friedman, “is a doll. He supports my program because it seems to be working. But he says, ‘If your T cells drop below 200, we’re gonna have a talk!’”

Five-Finger Discount: Carmody lucked out with a Shiatsu therapist-in-training pal who practices on him for free. “She gives nutritional and lifestyle counseling as well. She got me to give up caffeine. It was rough, but I have more energy now. Coffee was sapping my chi.” We see.

—Becky Minnich

Marie Naveaux

48; Systems consultant in the public schools, counselor

Tested poz: 1992

Regimen: Lysine 500 mg, pantothenic acid 500 mg, L-carnitine 500 mg, digestive enzymes, vitamin C, brewer’s yeast, thymic factor, fiber, grapefruit seed extract, wild oregano oil, melatonin, vitamin E 400 IU, multivitamins, flaxseed and other essential oils. Naveaux also cooks up high-protein meals from soy products, vegetables, raw nuts and seeds, as well as lemon and kelp. And she skips the flour and processed foods.

HAART NaveAux: After testing positive, the New Mexico resident test-drove numerous alternative treatments. But in 1998, when diagnosed with viral pneumonia and 8 CD4 cells, a bed-ridden Naveaux started a year of antiretrovirals. “My T cells had risen to 90, but by the end I basically felt so tired and sick that it wasn’t working for me. I had to make a decision to live or die.”

Blood simple: That’s when Naveaux hit upon live-cell morphology—regular blood tests examined by an herbalist for imbalances that can be treated through diet and vitamin supplements. (She estimates costs to top \$300.) “I just feel so much better. I have energy and didn’t even get that winter flu everyone else had.”

Stats: CD4 count is 10; viral load count dropped to 74,000 last December, down from 200,000 in June.

No doormat: “I focus my thoughts, energies and money on the positive. So I am becoming an ‘unwelcome host’ and killing the virus.” And naysayers? “I shun them. I say, ‘Each to her own, and this is my way,’ and then I never speak to them again. They are bad for my health too.”

Family practice: “My mother only wants my happiness—she’s on my side. My dad, too. My sisters are among those I shun. My husband backs my approach and has switched his diet to mine.”

Drawbacks: “It’s a constant battle not to be overwhelmed by the mainstream view that HIV is about death. My advice? Ask! Ask! Ask! Read! Read! Read! Don’t put your life in the hands of your doctor. Do what you feel is right.”

—*Sandra Hernandez*

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