Breathe Deeply and Hold

PWAs waiting for an alternative to Bactrim will just get blue in the face

May 1, 1996 By Amy Feehan

“I experimented with Chinese herbal prophylaxis for PCP -- and it didn’t work,” woefully admits HIV positive New Yorker Patrick Donnelly. Last November, Donnelly was hospitalized with *Pneumocystis carinii* pneumonia (PCP), one of the largest killers of people with AIDS. After two weeks of combined drug and alternative treatments, Donnelly was released and has been relatively healthy since. But his frightening experience followed a year of diligent adherence to a nontoxic regime he hoped would be an effective alternative to Bactrim -- the most widely used brand of TMP/SMX, an antibiotic considered first-line standard of care to prevent PCP in people with AIDS.

A long-time user and scholar of alternative medicine, Donnelly had previously been in pretty good health. He attributes that to a disciplined, holistic approach to managing HIV that includes exercise, meditation, extensive supplementation and a strict whole-foods vegetarian diet. So when his CD4 count dipped below 200 -- the point at which conventional wisdom said to start a prophylactic drug -- he decided to stick with his program and fortify it with herbs.

Donnelly was one of the growing numbers of PWAs with serious reservations about the effects of taking a potentially toxic drug for what could be years. He knew that studies found more than half of those on Bactrim have adverse reactions (almost all reversible by stopping the drug) -- most commonly itchy rash, fever, nausea and bone marrow suppression. Donnelly was concerned that Bactrim’s cumulative effects might include immune suppression and greater risk of other opportunistic infections.

So, under the care of Qingcai Zhang, M.D., an internationally recognized expert on Chinese herbs for HIV infection, Donnelly was prescribed a golden, oily liquid called Allicin, an extract of garlic. Allicin, the substance believed to give garlic its odor, has long been researched and used as an anti-infection agent, particularly in China. (In March, the AIDS Research Alliance of Los Angeles announced study results showing that Allicin greatly reduced diarrhea in 10 of 16 volunteers with hard-to-cure cryptosporidiosis, and -- unprecedented in a crypto study -- apparently cleared the pathogen from four of them.) Donnelly began taking Allicin twice weekly, both orally and through a nebulizer (a device which converts liquid into an inhalable aerosol spray).

Later Donnelly added a tablet form of an herb called qing hao (pronounced “ching how,” also known as artemisia or sweet wormwood); a derivative is used throughout Asia to treat malaria

because of its strong anti-protozoan properties. That made it a logical choice for PCP: Although the debate continues, the organism that causes PCP is considered either protozoan or fungal; either way, a New York University study found that the derivative inhibited *P. carinii* in the test tube. But while both qing hao and Allicin are inexpensive and have virtually no side effects, they remain completely unproven as PCP prophylactics. Donnelly's experience is testimony to that.

After his bout of PCP, he now takes Bactrim regularly. "I am not in love with taking an antibiotic all the time, but I am doing it," Donnelly says. "My feeling about antibiotics in general is they're not good for my body. That's why I was so reluctant for so long to take Bactrim. But having had PCP now, I don't feel I have any choice. It's very frightening not to be able to breathe."

Donnelly does have a choice about how often he takes Bactrim and what he takes along with it. He's opted to take Bactrim three days a week, which several studies show is equally effective and less toxic than the officially-recommended daily regimen. "On the days I'm taking Bactrim, my tongue gets very coated and sometimes the inside of my mouth is sore. My digestion seems different, too," he says. He takes acidophilus, hoping to counter the drug's side effects. And he continues the Allicin and qing hao along with the rest of his holistic program.

For many in the AIDS community, Donnelly's decision to supplement a standard PCP prophylactic agent is easier to stomach than his earlier practice of forgoing Bactrim all together. And for good reason. Without drug prophylaxis, more than 80 percent of PWAs eventually develop PCP. With it (whether TMP/SMX or the second- and third-line drugs, dapsone and aerosol pentamidine), not only has incidence greatly declined, but overall survival times have increased -- by six to 12 months, according to Dr. Neil Graham of Johns Hopkins University, who analyzed eight earlier studies.

But it took a struggle by activists and community physicians to make drug prophylaxis the official standard of care. (See Breathe Easy Now) Dr. Joseph Sonnabend was a key researcher and advocate, along with his famous patient, the late AIDS activist Michael Callen, in that battle. "In the larger picture, there is no controversy over the use of PCP prophylaxis. There just isn't," Sonnabend says, his British accent adding to his air of authority. "Back in the '80s, researchers simply looked for some magic bullet against HIV. Time has taught us a lesson which common sense could have taught us earlier: If you can prevent the opportunistic infections that people die from, you do a lot to keep them alive. There's no question Bactrim has had an impact on all the suffering and horrors of this disease."

Although Sonnabend plainly states that the small number of his patients who refused prophylaxis "just got PCP and almost died," he understands that decisions come down to risks versus benefits. "If you only have a one percent risk, then of course you wouldn't do it. But if you've got a 60 percent chance of getting something, then you might say it's worth preventing. It's like being a policeman and wearing a bulletproof vest. If there are proven ways to reduce your hazard, you'd be a damn fool not to do it."

But PWAs who want to balance the risks of drug prophylaxis with carefully-selected supplements,

much less alternative agents, find little evidence to go on. Rare is the research on either the long-term risks of drugs (and especially combinations) or the potential benefits of unpatentable alternatives such as nutritional supplements.

So those seeking to maximize their options find themselves caught in the middle of a crossfire by rigid thinkers on both sides. A few just-say-no-to-drugs advocates fiercely insist that pharmaceuticals have no place in the preventive arsenal. But the very discussion of “alternative” PCP prophylaxis sends chills down the spines of conventional AIDS treatment educators, who fear giving license to what they consider dangerous denial by poorly informed PWAs. Lost amidst the clatter are the quiet voices offering hope with a judicious combination of both conventional and alternative medicines.

Loudest among the dissident forces is Health Education AIDS Liaison (HEAL), a self-proclaimed counter to drug orthodoxy that was founded in 1982 in New York City and now boasts chapters in seven U.S. cities and five countries. In public lectures, literature and cable-TV shows, HEAL spreads a gospel labeling the entire official line on AIDS as false: HIV is not the cause, HIV antibody tests are useless, all antiretroviral drugs are harmful. And although HEAL’s director, hypnotherapist Michael Ellner, supports using antibiotics to treat an established PCP infection, he says, “The prophylactic use of antibiotics is dangerous to your health and may cause AIDS-like illness. A person prophylaxing against PCP is far more likely to develop CMV, cryptosporidiosis, MAC, TB or wasting syndrome.”

The Los Angeles-based Project AIDS International (PAI) differs with HEAL’s “Fire Your Doctor!” slogan, but also uses public outreach -- including a syndicated radio show -- to spread its anti-prophylaxis message. PAI has gone further, filing lawsuits -- 30 of which it claims to have won, either in or out of court -- charging doctors who have prescribed Bactrim or Septra (another brand of TMP/SMX) with making HIV positive people sick. (Despite repeated requests by *POZ*, PAI provided no evidence for this assertion.)

But Martin Delaney, founding director of Project Inform, says these groups blow the side effects way out of proportion. “Years of studies offer an overwhelmingly opposite conclusion. People who use preventive treatments live far longer than those who don’t.” Furthermore, he notes that a procedure called desensitization allows most of those allergic to these drugs to tolerate them. Delaney complains, “I think it’s really sad that any of us would have to debate this issue. There’s a major educational effort underway nationwide trying to help minority communities and others catch up to the advantages of PCP prophylaxis that the better informed and wealthier gay populations have had since the 1980s.”

David Barr is part of that educational effort as the director of treatment and advocacy at Gay Men’s Health Crisis in New York City. “How can a magazine that promotes living well with HIV even consider an article discussing anything other than the standard protocol?” he asks. “Bactrim is the single most important AIDS prevention treatment. It’s 90-plus percent effective.”

Matthew Sharp, a treatment activist with ACT UP/Golden Gate, has stayed PCP-free for six years

while on both Bactrim and aerosol pentamidine. He shudders at the thought of going without. “It’s simple. If you don’t take PCP prophylaxis, you will get PCP and probably die.”

Certainly there is reason for concern about the dangerous impact of campaigns by HEAL and PAI. Gene Fedorko was Ellner’s predecessor as HEAL president; he resigned in protest of Ellner’s pronouncements. “I see more and more new cases of PCP that likely could have been prevented with prophylactic measures. These are people uneducated about AIDS, many from susceptible minority populations. They listen to HEAL’s messages and just end up getting PCP.”

Although HEAL claims its mission is to empower people to make good medical decisions, Project Inform’s Delaney isn’t buying it. “This isn’t a question of dueling scientific data. The data are overwhelming on the side of PCP prophylaxis. I can’t think of another word except pure sophistry, which is gambling with people’s lives.”

But a middle ground has begun to emerge. For more than a decade, nutrition educator Lark Lands, author of *Positively Well: Living With HIV as a Chronic, Manageable, Survivable Disease* (Arbor Vitae/Chicago), has been forging a new path while advising hundreds of PWAs. “People need to use the best of Western medicine, but with the support of everything else that makes Western medicine not so toxic. You’re crazy not to prophylax if you need to,” Lark cautions. “But be aware of the consequences.”

One of the most important consequences, she says, is the destruction of the aerobic portion of the good bacteria which normally inhabit the intestinal tract, mouth and vagina. William Crook, M.D., author of *The Yeast Connection* (Vintage Books/New York City), explains the concern: “Broad-spectrum antibiotics resemble machine gun-shooting terrorists in a crowded airport. While they’re killing enemies, they also kill friendly and innocent bystanders. In a similar manner, antibiotics knock out friendly bacteria on the inner membranes of a person’s body while eradicating enemies.”

Good bacteria are important for manufacturing B vitamins, aiding digestion and keeping yeasts in check. Dr. Jon Kaiser, a longtime AIDS practitioner in San Francisco and author of *Immune Power: A Comprehensive Treatment Program for HIV* (St. Martin’s Press/New York City), warns that long-term use of Bactrim “alters the normal population of bacteria present in the body and this may pave the way for the occurrence of viral, fungal and other diseases that might otherwise not have occurred.” In fact, Graham of John Hopkins found a higher rate of such opportunistic infections among PCP prophylaxis users (though he links it to the natural progression of HIV disease). Graham says those infections explain why the drugs extend survival by no more than a year.

But Kaiser, like Lands, does not reject the use of Bactrim. One suggestion both offer is to consider taking supplements of good bacteria such as acidophilus. This is the path Patrick Donnelly has embarked upon since starting Bactrim, on the four days a week when he is not taking the drug. For years, gynecologists have advised women on antibiotics for bacterial infections to consume a daily cup of yogurt with live acidophilus cultures. That advice has now been confirmed by a study finding that this intake leads to less yeast infections.

But is acidophilus necessary for Bactrim users? Tom Navin, chief of epidemiology for the parasitic disease division at the Centers for Disease Control and Prevention (CDC), says, “As far as we know it’s perfectly OK to take those supplements. They should not interfere with the effectiveness of PCP prophylaxis.” But he adds, “Bactrim has no effect on the more important anerobic bacteria.” Lands says this statement disregards “the delicate balance of normal flora in both the intestines and the vagina.” She contends, “Even though a particular antibiotic may not destroy the predominant bacteria in a given location, it might disrupt the overall balance in a way that could result in the overgrowth of unwanted organisms.”

Since aerosol pentamidine (AP) does not affect intestinal bacteria (and generally has less side effects than Bactrim), Kaiser encourages his patients to consider it in certain circumstances. “Since my overall philosophy is to avoid the use of chronic systemic medications as long as possible, I often recommend AP for prophylaxis as long as the T-helper cell number is above 100...and the patient can afford it.” For those below that count, he feels “more comfortable” with Bactrim, because studies find it much more effective.

Another approach favored by middle-roaders is supplementing Bactrim with antioxidants to counter depletion of glutathione -- a vital nutrient for immune function -- and reduce side effects. Both lab tests and human studies of sulfa drugs suggest this may be useful. Lands notes that several nutrients can help restore glutathione levels.

People with AIDS trod many paths to their prophylaxis decisions. Jorge Rodriguez contracted PCP four years after testing HIV positive -- all the while taking no prophylaxis. The first time he took Bactrim he developed terrible fevers and rashes. He went on a desensitization program, which made the drug more tolerable, but he was still weak from the lung damage caused by the PCP. “Even on Bactrim, I still had trouble walking across the room. I was constantly out of breath.”

After a year of suffering fatigue and diarrhea from an unknown cause, Rodriguez went to New York acupuncturist, herbalist and R.N. Susan Paul. Paul, who was informally studying qing hao, recommended it for Rodriguez’s diarrhea and as a prophylactic agent for PCP. He was comfortable going off Bactrim because “it scared the daylights out of me to take it,” but went back on it along with the qing hao when his CD4 cells leveled off at 40. Cutting out dairy and wheat products and drinking cranberry juice to flush out his kidneys makes Rodriguez feel better about taking Bactrim. “I do as much as I can prophylactically. I take multiple vitamins, I drink a lot of water, I cut down on sweets and I rest a lot.”

Eran Deran, an Oakland, California PWA, was diagnosed with HIV -- and AIDS -- a year and a half ago, when his CD4 count was measured at 100 and dropping. He tried both Bactrim and dapsone before settling on AP. Deran knew he was allergic to sulfa drugs, but hoped desensitization would work. It didn’t. “The second time through the process I did better. I probably could have put up with the drugs, but I decided not to because the quality of my life was severely hampered.” He’s not thrilled with the bitter, metallic taste AP leaves behind, but he’s sticking with the drug.

Since adding a Chinese herb, Clear Air, Deran feels more energetic. “As frightened as I was in the

beginning, somewhere in the back of my mind I kept saying, 'Doctors don't have all the answers, so I'm going to look elsewhere for something to make me at least feel better.'" He visits a homeopath to help rebuild his immune system, takes vitamins and avoids dairy and wheat, two food allergens for him. "I realize that maybe some of the things I do are not doing anything, but at least I'm in control. And it puts my head in a much better space than totally turning my fate over to a doctor." But like Donnelly, he understands the need to let go of his biases. "I don't totally dismiss Western medicine. I'm picking and choosing what works for me. Because conventional medicine has been pretty successful in preventing PCP, I'll go along with that."

But how long will that success last? Scientists fret that *P. Carinii* may some day develop resistant strains that will outwit antibiotics. Dr. Henry Masur, chief of critical care medicine at the National Institutes of Health (NIH), observes, "If you look at any other microorganism -- virus, fungus or bacteria -- exposed to antibiotic pressure, resistance has developed. There's no reason to think resistance will never develop to *Pneumocystis*." But no test yet exists to tell whether a given "breakthrough" infection -- one occurring despite prophylaxis -- is caused by a resistant strain, noncompliance or something else. The CDC's Navin says, "In preparation for possible resistance, we need to have as many alternative agents as possible."

But the list of alternatives being researched excludes non-pharmaceuticals, whether as possible prophylaxes or supplements to current drugs. Herbalists have yet to release data on their patients using herbs as prophylaxis -- including "SEES-2000," a Mexican root derivative marketed as "100 percent effective." These practitioners lack the funds to do formal trials. And while NIH has funded a general study of alternative AIDS treatments that includes alternative prophylaxes, it is not designed to produce definitive data on their effectiveness.

While everyone either waits for research that may never be done or argues the pros and cons of various drugs, Patrick Donnelly feels philosophical about his hair-raising experience off the beaten track. "I don't regret anything I did. I knew there was a risk involved. But taking risks is how most medical discoveries have been made. Conventional medicine often presents its treatments as more simple and effective than they really are. Alternative medicine does as well. No one has ever told me, 'You will absolutely not get PCP again from doing this.' I guess we may each have to make our own discoveries."

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