The Great Doctor / Patient Face-Off

“You don’t listen to me! You don’t work with me! You don’t respect me! You’re not honest with me!” Lovers’ quarrel? More like HIVers and their MDs going at it. POZ sits both sides down for some heavy therapy. People, can we talk?

September 1, 2003 By Rebecca Minnich and Bob Lederer

Meet Chardelle Lassiter, the proud product of 20 years of PWA empowerment. Smart, savvy and assertive, this Brooklynite knows precisely what she wants from her doctor—and doesn’t stop squawking until she gets it. “My doctor is my connection to the best health I can have,” says the 56-year-old former social worker, diagnosed with HIV in 1988. “It’s simply a matter of life and death to have a good working relationship.” That’s why she fired three of her last four doctors for being, as she sees it, insensitive to her needs.

Now, meet the other Chardelle Lassiter, the one some HIV specialists would call not just impossible to please but oblivious to the pressures today’s embattled AIDS doctors face—rising caseloads, erratic patients, drug-resistant HIV (see “Switching Tracks”), tight-fisted HMOs and slashed government budgets. Add a Lassiter to their plate and even the mildest among them could start spouting tell-it-like-it-is tough love. “If you have to switch doctors two or three times, you should look at yourself,” says veteran San Francisco HIV specialist Donald Abrams, MD. “You might have to adjust your expectations.”

And on it goes, with HIVers on one side of the chasm, sitting in their support groups and bitching over earthy mugs of antioxidant-rich green tea about their disdainful, dismissive, disrespectful doctors—and doctors on the other, clucking over their advice-dissing, dose-missing patients as they jet from one fabulous AIDS conference to another. It’s almost like one giant, never-ending session of couples counseling, with no facilitator in sight—and little memory of AIDS’ Dark Ages, when, in the absence of a playbook or equipment, many PWAs and their doctors made up the rules together as they went along, forging an accidental revolution in patient care. If that level of communication and collaboration between HIVer and MD could be brought to the age of HAART, the results might be measured in longer, healthier, happier lives.

Hence, *POZ*’s attempt to bridge the gap. Note to patients and doctors: Think of the following as a safe space to work through mutual feelings of fear, anger and helplessness—and to mourn the loss of the traditional fee-for-service health care system. HIVers will vent first, followed by physicians. Oh, by the way—everybody’s HMO *does* cover therapy, right?

PEEVED PATIENTS

Lassiter’s self-empowerment follows a brave tradition in the collective case history of AIDS. In 1983, at a time of rampant bigotry and fear combined with a widespread doctor-knows-best mentality, a few courageous PWAs drafted a visionary manifesto. Dubbed “The Denver Principles” for its birthplace, it demanded patients’ rights “to full explanations of all medical procedures and risks, to choose or refuse their treatment modalities…and to make informed decisions about their lives.” The Principles spawned countless advocacy groups demanding that health-care heavies address HIVers’ needs—a cry that extended all the way up to the FDA, which accelerated its approval process for HIV therapies largely due to ACT UP, a grassroots coalition of (mostly) PWAs. And until those drugs arrived, it took a steely HIVer to look a doctor in the eye and refuse the toxic pall of high-dose AZT. But many did, and their rebellion was vindicated when the 1993 Concorde study confirmed that patients with decent CD4 counts were better off without AZT. The first decade of AIDS was dire indeed, but a complacent medical establishment, a dearth of effective conventional treatments and plain old desperation emboldened PWAs to take their survival into their own hands.

Even today, in a vastly better era for American HIVers, that spirit is alive and well in folks like Lassiter. Though she says she started talking back to doctors years before her HIV diagnosis, it was the Denver Principles, which she encountered at an HIV Leadership Training Institute program in 1998, that “validated me as a person with AIDS.” Committed to holistic healing and determined to make meds her last resort, she says the manifesto “helped me understand my medical rights and changed my attitude about dealing with professionals.”

But that didn’t jibe with her then-doctor—who, Lassiter recalls, “had a nice bedside manner, but always rushed through my appointments, at best spending 10 minutes. I felt he couldn’t give good care without taking some time to ask me questions and answer mine.” Out went Dr. Clockwatcher. Lassiter had already pink-slipped two other doctors who she felt dissed her choices—especially her reliance on supplements, yoga, meditation and massage. “‘I don’t believe in that mumbo-jumbo,’” she recalls her first doctor saying. “I was angry. I felt demeaned. I stopped seeing him immediately.”

Looking for “some bonding,” she found in 1998 a female doc with HIV chops. “I told her I was terrified of meds,” Lassiter says. “At first she was fine. But with my CD4s at 400 and falling and my viral load at 80,000 and climbing, we started having a running argument—she was ‘HAART or nothing.’ It became a standoff, gunfight at the OK Corral. I wanted some respect, recognition—there was none.” Again, she issued walking papers.

Echoing her angst is Nate Klarfeld, 52, of Ft. Lauderdale, Florida, who tested positive in 1996. A former dentist and the cofacilitator of a support group for the newly diagnosed, Klarfeld knew the importance of MD matchmaking. “I researched my doctor very carefully,” he says. “He was highly recommended.” But Klarfeld immediately felt uneasy. “He seemed to talk over me, or at me, instead of with me.” The clinic staff resisted giving him copies of his lab results. “They acted like it was this huge inconvenience,” Klarfeld says.

But in this case, the deal-breaker was the doctor’s insistence on *not* treating—specifically, weight loss after a stressful period. A few years before, steroid therapy had helped Klarfeld beef up after pneumonia had left him emaciated—but this new doctor refused to prescribe them. “He actually laughed at me, saying, ‘That stuff is for body-builders,’” Klarfeld recalls. Even after a bioelectric impedence analysis (BIA) confirmed he was wasting, the doctor held out, saying that wasting sometimes reverses itself. Klarfeld finally snagged a prescription from his old doctor—and, shortly after that, a new MD.

It’s a familiar gripe from HIVers: doctors who brush off complaints of side effects, body-shape changes—anything not confimed by the standard labs. One Canadian survey of HIVers ranked “physicians’ minimization, or frank disregard, of [lipodystrophy’s] impact” high among their grievances. “My doctor acted as if my numbers were more important than my quality of life,” one HIVer in the study remarked, while another said, “I heard a very prominent HIV doctor say flippantly at a conference, ‘It’s better than being dead’—this doctor just didn’t get it.”

And to hear patients tell it, doctors *just don’t get it* in so many ways. Tania Hernandez, who counsels other HIV positive women at Los Angeles’ Women Alive, says many of her clients “feel like their male doctors don’t understand or care about gynecological problems, or problems with their kids.” And don’t get Lassiter started on the white doctor who kept telling her he didn’t take Medicaid. “I repeatedly told him I’m on Medicare,” she says, but “when he saw me, a black woman, he saw Medicaid.” Naturally, she fired him.

DEFENSIVE DOCTORS

OK, HIVers, you’ve had your turn—let your MDs say what they please. And—surprise!—most say they wish *all* their patients were as engaged as Chardelle Lassiter, because as HIV spreads in communities ravaged by poverty, homelessness, drug abuse and mental illness, their biggest headaches are patients who can’t or won’t take care of themselves. “It’s easy to get frustrated,” says David Wohl, MD, who treats hundreds of low-income HIVers at the University of North Carolina at Chapel Hill. “When the twelfth person comes in not taking meds, doing crack, fighting, you want to shake them and say, ‘I’m trying my hardest, where’s *your* effort?’” Likewise, Drew Kovach, MD, of Honolulu, says that his nightmare patient “has so many crises in their life you don’t know which to address first. If they’re depressed they won’t take their meds. If they’re substance-addicted, they don’t show up for appointments—just one thing after another.”

Not to mention know-it-all patients who have a “Why?” for every doctor’s order, right? Wrong. Contrary to our worst stereotypes of doctors as God-playing control freaks, many say they most dread, according to Donald Abrams, “the patients who are passive, who say whatever I think is right. I find they’re not taking responsibility for their own health, so when things go wrong they’re more likely to blame me.” The University of Cincinnati’s Judith Feinberg, MD, recounts a common scenario: “A lot of patients walk into the room and say, ‘You’re gonna yell at me,’ because they didn’t do whatever—take their pills, quit smoking, cut fat intake.” The result, she says, is that “they tell you what they think you want to hear—in other words, they lie. That, of course, totally undermines [my] ability to figure out what’s going on medically.” What’s more, she says, women patients often “are moms and grandmoms...putting children or a partner first, and taking care of themselves last.” She says her job is “talking to people over and over, commiserating with them, finding out what they need—sometimes counseling, sometimes antidepressant therapy, sometimes both.”

What makes Feinberg “stark raving mad,” she says, is that “morons who know nothing about what you’re doing are making decisions.” By that she doesn’t mean her patients, but the middle-men in their managed-care plans, who demand that doctors bend over backward to justify expensive tests and treatments. “It’s a waste of my time. I could take care of more people if I wasn’t constantly filling out forms. This is why managed care is a fallacy,” Feinberg says. “You try to get to the bottom of what’s upsetting patients—they may need to cry their hearts out. You can’t do that in 15 minutes.” (For more on what docs think about patients, see “MDConfidential”.)

MEETING HALFWAY

Doctors, did you hear your patients say they just want to be heard? Patients, did you hear your doctors say they just want to help you help yourselves? Good. Soooo...how can y’all work together? On both sides, it all comes down to three little words: *communication, communication, communication*. “The common denominator in the most miraculous survival stories is a patient who’s very involved in treatment decisions, yet nondogmatic and willing to dialogue with me,” says Paul Sax, MD, HIV honcho at Boston’s Brigham and Women’s Hospital. Likewise, Wohl says, “When your viral load is undetectable and your CD4 count is high, it’s you who should get the congrats, not me. Physicians who are punitive, patronizing or impatient are inexcusable. Patients need someone on their side.”

How can docs prove they are? “I show patients upfront that I’m a nice guy,” Wohl offers. “I smile. I’m not gonna give them a hard time.” Abrams favors a nonjudgmental tack: “If they’re practicing an unhelpful behavior—smoking, drug use, poor diet—I suggest little projects we can do to improve their health.” He likes to focus on nutrition, because it “gives patients something they can control and starts setting the stage for getting control of their overall health.” (Patients then also see that doctors care about more than just their lab numbers.) Sax says he builds trust by telling patients “that if [their] insurance says they won’t cover a test or treatment with proven merit, I’ll try hard to get it.”

Perhaps doctors can best earn trust by conveying that they’re on the cutting edge of HIV research and care. How? By staying there. “I don’t think a nonspecialist should take care of HIV patients,” says pioneering AIDS doc Joseph Sonnabend, MD. Indeed, several studies have correlated HIVers’ longevity to both their doctors’ years of experience treating HIV and number of HIV positive patients. Such findings have led to a specialist-accreditation movement (see “Name Recognition”). Sonnabend also urges colleagues to “get information from as many sources as you can”—not just from the routine conference circuit and accepted medical journals, but from community research and treatment activist publications, plus constant canoodling with a wide array of HIV-treating colleagues. Fellow Gotham doc Antonio Urbina, MD, wows patients with his knowledge of complementary therapies. His bible? “The German PDR [*Physician’s Desk Reference*],” he says proudly, “the most extensive listing of herbal and other alternative treatments, especially regarding drug-drug interactions.” Docs can also bring patients into the loop by sharing bits of key research; Abrams says he’s constantly printing out info for his patients.

So how can patients pump up the partnership? For one thing, before visiting doc, make sure you’re thoroughly prepared (see “Work That Visit!”). And speak up! “If you feel your doctor isn’t giving you enough time or isn’t explaining things fully, tell them,” GMHC health-care-access guru Howard Schwartz says. “Don’t bottle up your feelings—that just creates stress, not good for your T-cell count.” On the flip side, he adds, “if you feel gratitude to your doc, tell them. They like to hear that they’re appreciated.” Tip No. 2? Patient, educate thyself—through reading (like, duh, POZ), Web-surfing (www.aidsmeds.com gives great HIV 101), hitting community treatment forums and chatting up other HIVers, for starters. Lassiter likes to do her homework in the GMHC library, “where, in case I get an anxiety attack or wave of depression, I have someone to turn to.”

Yet despite efforts on both sides, some doc-patient duos, like some couples, just aren’t meant to be. But whereas born-again singles can fly free as long as they like, doctorless HIVers need a new MD marriage ASAP. Matchmaking services exist (again, see “Work That Visit!”). One good weeder-outer: Be honest with prospective new docs about why you left your last one. (They cut you off? Rushed you out? Resented your second-guessing?) A *Yeah, well, that might happen here, too* should be a sign to keep cruising; an *I’ll do my best to keep that from happening* at least hints at a two-way street—not to mention humility, an indispensable trait among Those Who Treat.

WE CAN WORK IT OUT

Aren’t there *any* happy, in-it-for-the-long-haul doctor-patient dyads in HIV Land? Actually, more than you might think. Take the Houston twosome of Sharon Wagner and Shannon Schrader, MD. Diagnosed with AIDS in 1994, Wagner, 41, approached Schrader five years later with heavy drug resistance and CD4s hovering just under 200. “I researched him very carefully before I came in,” Wagner recalls. “[But then] he looked like a little boy—I figured he was too young to know what he’s doing.” Not so, she found: “He was up on all the latest research, answered all my questions and really took the time to understand my history.” It didn’t hurt that Wagner brought along her “war book”—med lists, bad reactions, infections and conditions, lab tests and office notes. “He was very impressed,” she says.

Four years and several combos later, the duo are still going strong, even as they struggle to boost Wagner’s T cells and suppress her viral load (Schrader has enrolled her in a clinical trial for the experimental protease inhibitor tipranavir). “Whenever he suggests a new medication, he gives me all his information, then lets me make up my mind,” Wagner says. But to hear Schrader tell it, she wouldn’t have it any other way. “Sharon is not the kind of person you can tell what to do,” Schrader says. “She has opinions, but is also seriously committed to her care. Those kinds of patients not only do better; they’re more fun.”

And what of serial terminator Chardelle Lassiter, whom we left in 2000 with no doctor and falling T cells, not to mention severe fatigue and weight loss? Just as she was reconciling herself to starting HAART, a fellow drug-naive friend from the PWA Health Group raved about his doc, Paul Bellman, MD—a longtime HIV specialist in Manhattan—calling him a “brilliant” melder of standard and alternative medicine, and eager for patient input.

Skeptical Lassiter visited Bellman, who suggested a regimen of Combivir and Kaletra. “She was appropriately concerned about the toxicity of the meds, the optimal time to start and the lack of full information on specific risks for women and people of color,” Bellman recalls. “By acknowledging her legitimate concerns, I’ve been able to work with her and start medication at a point where she was comfortable.”

Three years later and in excellent health, Lassiter says she’s never regretted it—and that she and Bellman are still going steady. “I consider us a team,” she says. “Recently, *he* suggested substituting Ziagen for the Combivir to reduce toxicity. I thought, ‘Somebody is *seeing* me.’ I felt safe.” Bellman returns the compliment. “Chardelle, like many HIV patients, maintains her sense of self and goes ahead with life in a positive way,” he says. “She’s taken the challenges of HIV and used them for her poetry, her performance art and her work as an AIDS volunteer, which is inspiring to me.”

Lassiter hopes her happily-ever-after will motivate other doc-patient partners to work toward a better back-and-forth. But of course she directs her strongest advice to those on her side of the scenario: “Don’t hesitate to bring up your concerns to your doctor. And for major decisions—especially whether to start meds—don’t be intimidated by your own fear. Get a second, even third, opinion.” After all, she notes, it’s not *just* a relationship. “It’s your life.”

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WORK THAT VISIT

Perturbed that Doc sometimes seems a bit, uh, hurried? Well, did you check out that crowd in the waiting room? “We want to be thorough,” top Boston HIV doc Cal Cohen, MD, insists. “But people do get pissed off when we’re running late. So please do what you can to make the most of the visit.” Like trying on these tips for full-throttle face time with Doc:

BEFORE your visit: Buy a “Doc Log”—simply a notebook with pockets for loose forms. Record: Your pre-HIV medical history Year of HIV diagnosis and your first CD4 count/viral load Subsequent meds (with doses and times per day), lab numbers, illnesses and supplements Copies of your labs All symptoms and concerns to address at your next visit. Also: *Have your labs done early so they’re on Doc’s desk to discuss*.

DURING your visit: Show Doc your symptoms list right away. “Sometimes #12 on the list is a big deal to us,” Cohen says. Ask if you can e-mail queries between visits. Find a pharmacy that will let Doc renew all your ’scripts on one fax form.

AFTER your visit: Ask yourself: Does Doc cut you off? Dismiss your concerns? Talk over your head? Say so—nicely. No change? Find a new doctor! Get referrals from HIVers or your nearest

AIDS organization. Go to www.aahivm.org; click “Resources,” then “Find a Provider.” E-mail your location and health plan to hivma@idsociety.org for a custom list of prospects. No insurance? Call 800.734.7104 to get hooked up to ADAP or Medicaid. P.S. Your new Doc will love you for your Log.

IN BETWEEN visits: Hit these sites for more HIV/MD insights:

www.hiv-dialogues.com
www.projinf.org/fs/dr-patie.html
www.thebody.com (search “doctor patient relationship”)

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NAME RECOGNITION

Meet the movement to make every HIV doc a pro

OK, you need to find an HIV specialist—but there’s no section in your HMO book listing them just like internists, OB-GYNs or other specialists. Hmmm...

That’s because there’s no board for accrediting HIV doctors, most of whom are either infectious-disease specialists or internists who ended up with lots of HIV positive patients. But genuine accreditation of HIV care would vastly benefit both HIVers and their doctors because it would help separate the wheat from the chaff—and make health plans take HIV-related reimbursements more seriously.

The movement to make it happen is already underway. In California, a new law requires HMOs to refer HIVers to HIV specialists, who must earn that title by meeting such criteria as passing a bi-yearly exam developed by the American Academy of HIV Medicine (www.aahivm.org). The AAHIVM has also created an HIV care curriculum and its own credentialing exam for providers nationwide.

“It’s a major breakthrough,” says Scott Hitt, MD, the group’s interim executive director, of the California law. “There was enormous resistance from insurers [because] they lose big money on HIV patients.” That’s not stopping the AAHIVM from trying to create what Hitt calls “a level playing field” for HIV care. “Last year we credentialed 1,300 people,” he says—a number the group hopes to double this year.

But not everyone’s rooting for them. “We don’t think it’s appropriate that an advocacy group credential its own members,” says Christine Lubinsky, executive director of the HIV Medicine Association (www.hivma.org), AAHIVM’s rival of sorts, which represents 2,500 HIV providers. Instead, the HIVMA is working with The American Board of Internal Medicine and the American Board of Family Practice to develop an HIV-care curriculum that’ll pass muster with the American College of Graduate Medical Education, a major accrediting body.

One thing both groups agree on: research finding that the more HIVers a doctor sees, the better those patients do. Hitt hopes other states soon follow California. But first things first:“Now we have to get the HMOs to actually list the HIV specialists in their books under their own heading.” Nobody said it would be easy.

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DYNAMIC DUOS

Chicago

Ida Bythersmith, 53 (diagnosed 1991)
Wanda Elliott-Pearson, MD

Working together since: 1998

Wanda on Ida: What makes Ida special is her faith and her positive outlook. She has a strong belief in God and she is determined not to give in. She waited years before going on HIV meds, but now that she’s on them, she takes them on schedule, even when that’s very difficult.

Ida on Wanda: When I first tested positive, the hospital didn’t have anything to offer me but AZT and no hope. So I went back to Dr. Elliott, my family doctor. I said, “They told me I have five years.” She said, “Don’t you let anybody tell you how long you’re going to live.” Since then we’ve been learning about HIV together. She keeps in touch with all my viral doctors, keeps track of my bloodwork, my diet, my stress level. We’ve been together longer than husbands and wives.”

New York City

Maria Ortiz, 47 (diagnosed 1994)
Antonio Urbina, MD,
St. Vincent’s Hospital

Working together since: 2000

Tony on Maria: She’s triumphed over hardships and remains hopeful and optimistic. She knows I’ll work diligently to address her health issues. I don’t take anything for granted.

Maria on Tony: He asks questions about everything—not just the HIV. He makes sure I understand every number on the lab test before I go home. He returns my phone calls right away, and he’s a great listener. Once I told him he was starting to dress a little sloppy, and the next appointment he was in a shiny new lab coat and nice ironed shirt. He said, “Is this better?”

San Francisco

Vince Gaither, 37 (diagnosed 1990)
Virginia Cafaro, MD,
Wellspring Medical group

Working together since: 1997

Virginia on Vince: He first came to me in search of an equal partnership. He’s intelligent, articulate and doesn’t want to be dictated to. With his resistance and allergies to so many HIV meds, we’ve had to try a lot of treatments, but he hasn’t lost patience. It helps that we both have a good sense of humor—we laugh a lot.

Vince on Virginia: She treats me like an individual. I’m a former heroin addict with 15 years in recovery and I have a lot of problems with HIV meds, but she’s been very persistent about finding appropriate treatments, including alternative ones. She’s always attending conferences, staying up to date. When I had crypto, she could tell before it showed up on the tests. I really trust her.

-RM