

contents

- 3 *Walking Away*
- 4 *Positively Isolated*
- 5 *Partnership in Care*
- 7 *Do As You're Told?*
- 8 *The Road to Empowerment*
- 9 *Both Sides of the Pill Bottle*
- 13 *Avoiding the Power Struggle*
- 14 *Person First/ Patient Second*
- 15 *What if God Was One of Us?*
- 17 *Learning to Trust*
- 18 *What Do All Those Letters Mean?*
- 19 *ACRIA News*

winter
2004/05

Working With Healthcare Providers

For many people with HIV, their relationship with their healthcare provider is as intimate as any relationship in their lives. Mutually respectful, honest, and thoughtful communication between a patient and his or her healthcare provider is one of the most important keys to success in dealing with HIV. Beside yourself, your provider is often your best ally in your struggle with HIV. Numerous studies have shown that many of those individuals with HIV living particularly healthy lives have excellent relationships with healthcare providers who they trust.

Learning how to interact productively with your provider is an important but not necessarily easy skill to master. In the past, doctors generally told their patients what to do, and the patients

usually followed directions without question. Today, thanks to the efforts of people with HIV over the years and the work of the women's health movement before that, many patients are more actively involved in their medical care – and staying healthier than ever as a result.

This issue of *ACRIA Update* focuses on the relationships between individuals and their healthcare providers. We thank the writers who have shared their personal experiences – the good, the bad, and ugly – as well as the healthcare providers who have been willing to offer their perspectives. We hope that some of the tips included in these pieces will help you to develop a more productive relationship with your provider or, if necessary, help you move on and find a provider with whom you connect.

The following is adapted from the curriculum that ACRIA uses in workshops to discuss the often complicated relationship between individuals and their healthcare providers:

So – What's the First Step?

- *Get involved with your care!*

Educate Yourself

- It's pretty easy to find information about HIV and basic treatment options:
 - Through treatment newsletters.
 - Through the Internet. Learn how to use the Internet and find places where you can go online – your AIDS service organization, the library, etc. (See the Spring 2004 issue of *ACRIA Update* for a list of organizations, newsletters, and websites that provide HIV treatment information – it's available online at www.acria.org.)
- In today's world of healthcare cuts and managed care, doctors rarely have the time to properly educate their patients on the complexities of combination therapy.
- Do your homework – know as much as you can about HIV and your treatment options.
- Get subscriptions to treatment magazines and newsletters – most are free!
- Go to your local AIDS service organization and talk to the treatment specialist or enroll in a treatment education program.
- Talk to other HIV-positive people who are experiencing some of the same things that you are.

(continued on page 10)

Editor in Chief
J Daniel Stricker

Editor
James Learned

Medical Editor
Jerome A. Ernst, MD

Publications Manager
Mark Milano

ACRIABoard of Directors
Ross Bleckner, *President*
Donald Kotler, MD, *Vice President*
Vincent Wm. Gagliostro, *Secretary*
Charles Franchino, DC, *Treasurer*
Marisa Cardinale
Bob Colacello
Douglas Dieterich, MD
Deborah Hughes
Kevin Krier
Adam Lippes
Mark J. Montgomery
Martha Nelson
Maer Roshan

In Memoriam
Gary Bonasorte
Kiki Mason
David Seidner
George N. Stathakis

Medical Director
Jerome A. Ernst, MD

Executive Director
J Daniel Stricker

ACRIA is an independent, non-profit, community-based AIDS medical research and treatment education organization dedicated to rapidly improving the length and quality of life for people living with HIV/AIDS. Bulk copies of *ACRIA Update* are available free to agencies that provide services to people living with HIV/AIDS. For more information, call 212-924-3934 ext. 120.

Copyright © 2005
AIDSCommunity Research Initiative of America. All rights reserved. Non-commercial reproduction is encouraged provided appropriate credit is given.

ACRIA
230 West 38th St., 17th Floor
New York, NY 10018
Phone: (212) 924-3934
FAX: (212) 924-3936
Internet address: www.acria.org

ACRIA STUDIES IN PROGRESS

UK-427,857 for Drug-Resistant HIV

People who have taken anti-HIV drugs from three of the four classes of drugs will take either UK-427 (an experimental HIV CCR5 attachment inhibitor) with an optimized regimen of anti-HIV drugs, or take a placebo (dummy pill) with the optimized regimen, for 11 months. Participants must be 16 or older and have a viral load of at least 5,000.

The Effect of Reyataz on Cholesterol Levels

People who have high cholesterol levels and a viral load below 50 while taking Kaletra will either switch to Reyataz or continue taking Kaletra. The study will last 12 months. Study participants will be reimbursed \$25 for each visit.

Reyataz Compared to Kaletra

People whose viral load has risen to over 1,000 while taking an NNRTI as part of their first HAART regimen will switch to either Kaletra, or to Reyataz / Norvir. Everyone will also take Viread and either Videx EC or Zerit XR. The study will last for 22 months. Study participants will be reimbursed \$25 for each visit.

One-day study of Reyataz Resistance

People whose viral load has risen to over 1,000 while taking Reyataz will have blood tests for resistance, CD4 and viral load. Study participants will be reimbursed \$25.

For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at ext. 124.

Standard of Care Treatment vs. ZEST Once-Daily Regimen

(Closed to Enrollment) This trial is studying whether people on their first HAART regimen who take their drugs two or more times a day can switch to a once-daily regimen. People in the trial either remain on their current medications, or switch to Zerit XR, Epivir and Sustiva (ZEST) taken once daily.

Editor's Notes

- All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
- *ACRIA Update* refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

Personal Perspective: Walking Away

by Carlos H. Arboleda

I have the best doctor on earth – caring, compassionate, knowledgeable, funny, and, possibly, a liberal. But this hasn't always been the case. Having spent several years as a health educator, talking to both patients and healthcare providers, I thought of myself as confident and savvy enough to choose and have a relationship with a good, new doctor when the time came. Was I wrong. I had moved to a new city in 2000 and, being new in town and having a rather small pool of doctors in my health plan to choose from, I just went down the list and randomly selected a doctor for an annual physical and to check a minor pain I had.

Things started off badly from the moment my new doctor and I met. As I had always told clients, talking to your doctor should always be as frank and informed a conversation as possible regarding one's health history – especially with a new provider. I informed my doctor that I was gay, single, sexually active, approaching my forties (okay, this was a while ago), and offered many other details that I considered pertinent. This should have triggered a series of questions from her regarding my health, such as HIV status, hepatitis A, B, and C (including vaccinations), and STDs. But no such questions were asked. Given my age, I also should have been asked about and checked for testicular cancer, and a conversation regarding colon and rectal cancers should have taken place. No such luck. During our brief – very brief – “conversation” we did talk about my occupation. “HIV health educator,” I said. “Ah!” she exclaimed. “In that case, we need to do a TB test.” I asked whether she suggested the test because I'm from a third world country. “No, ‘those’ people you work with are at higher risk for TB than the rest of the population,” she explained. I should have walked away at this point. But I didn't, partly because I was caught off guard and partly because, in the ten minutes of our interaction, I had been reduced to a semi-naked dummy sitting on a cold chair answering questions as if I were back in the principal's office.

I explained that I was there for my annual physical, a minor itch, and chronic back

pain. I requested a basic lab work up and a referral to a specialist for my back. I was informed that I was too demanding and possibly a difficult patient, too, which I suspect was noted on my chart. The doctor left the room and I waited for about ten minutes, which seems like an hour when you're sitting on a cold chair wearing nothing but a thin hospital gown. Finally, a nurse came into the room, ordered me to dress, gave me several prescription forms and the referral for the lab work, and then left. I waited some more and then decided to investigate. I left the examination room and asked at the front desk about my doctor. I was told that she was with a patient. But she was with me, I explained. No, I was told. She's finished with you.

“She impatiently explained that she was the doctor... and that I should be more cooperative and trusting.”

At this point, many things had gone wrong, but I was still dumbstruck by the events that had taken place in less than 20 minutes. I dropped off the prescriptions at the pharmacy, made the appointments for the specialist, lab tests, and follow-up visit, and went home. Once at home, I realized that I had left the doctor's office with a year's worth of pain killers (the doctor had prescribed 11 refills), sleeping pills, and antidepressants. I decided to wait until my next visit to ask some questions regarding this course of treatment.

In the meantime, I concluded that this was probably not the best choice of healthcare provider. For starters, she didn't seem very sensitive to my sexual orientation, which I consider paramount to my health.

I should have been offered HIV, STD, and hepatitis screening. I should have been asked about my sexual behaviors and/or partners. I should have been checked for testicular cancer. Attention should have been paid to my family's disease history, which I had written down. I should have been told what tests I was getting and, more importantly, we – the doctor and I – should have discussed the drugs she was prescribing, the side effects I might expect, and any interactions I should be aware of. Since there wasn't a single sentence devoted to my mental health, I should have been told the reasons for prescribing antidepressants. And since we talked very little about my back pain, there was no clear explanation as to why I was given a year's worth of refills of a very addictive pain killer. And the itch? I forgot about the whole thing.

My next and last visit to my new doctor was better for me. I had prepared myself to be assertive and firm, and I was. My doctor, on the other hand, did not find this amusing. When I asked about the course of treatment she had prescribed, she impatiently explained that she was *the doctor*, that's what doctors do, and that I, the patient, should be more cooperative and trusting. I agreed with her on this one – patients should be cooperative and trusting. But this doesn't mean giving up the right to know and understand, the right to ask and question. Cooperation and trust must go both ways.

The lesson? I should have shopped around more; I should have asked my friends and colleagues for referrals; I should have researched my health plan better; and I should have left the office the minute I got a hint that this doctor and I were incompatible from the beginning. Now I'm back with my old doctor and I couldn't be happier.

Carlos H. Arboleda is a freelance consultant who has done HIV treatment education and advocacy work for over ten years for organizations such as Gay Men's Health Crisis, the National Minority AIDS Council, and, yes, Abbott Laboratories.

Personal Perspective:

Positively Isolated

by Name Withheld

Prior to ending up living in the sparsely populated area of Michigan's Upper Peninsula, I had resided in Portland, Oregon. That metropolis is also where I tested positive in 1987. It was in Portland that I encountered a few phobias of healthcare workers on the occasions that I did seek consultation at the county medical clinic. One incident in particular stands out in my mind. One doctor had an aversion to making any kind of physical contact. He didn't mind chatting up a storm, though. On that one occasion, an anal swab was required – I don't recall for what – but he took the swab, handed it to me, and said, "Here, stick this up your ass and hand it back to me." How professional.

In 1992, I found myself moving to the Iron Mountain area of Michigan. The need for dental attention came up, and I was very fortunate to be referred to a local dentist who had no problem whatsoever in treating an HIV-positive patient, nor did any of his staff. I have been a patient there since and have never had a problem.

It was my choice not to pursue any of the treatments being offered when I tested positive, as I felt they were ineffective and more time was needed to research them. I continued to resist any of the available medications up until 1996 when I read about Crixivan and decided it looked promising. An infectious disease specialist out of Marquette, Michigan saw me and prescribed a combination that included Crixivan. I have been on various combinations since then and continue to do well. I am extremely pleased with the services of that doctor, his medical staff, and the two other doctors that have since joined his practice, all of whom are extremely knowledgeable, friendly, and caring.

While I had doubts at first about the quality of care in any area – especially one so isolated – I immediately realized that this thinly-populated area is quite fortunate to have doctors of such high caliber and who don't in any way, shape, or form discriminate on account of HIV status. The past couple of years I have chosen to deal with one particular doctor in that clinic even though any of the others would be perfectly acceptable. I just feel more comfortable dealing with one person each and every time. When

I come for my appointment, the doctor spends a minimum of 30 or 45 minutes with me. This doctor even calls me at home with test results. And when I call the office with questions from time to time, he calls me back. He's a peach, and I feel so fortunate to have quality medical care in this middle-of-nowhere area.

It has been my observation that I receive better care and that more funds are available per person here because it is so isolated and because the area is not overwhelmed with HIV cases as many metropolitan areas are.

While I realize my experiences in this area have been exceptional,

I am pleased that I have nothing to complain about, and would urge any person experiencing difficulties in other areas to move up here to take advantage of the fine care available. Of course, there is one drawback – it tends to be lonely with not much going on socially!

Name Withheld is a baby boomer gay man living near Iron Mountain, Michigan. He works as a caregiver and enjoys traveling to populated areas to enjoy the flavor of the urban jungle.

"He took the swab, handed it to me, and said, 'Here, stick this up your ass and hand it back to me.' How professional."

Personal Perspective: Partnership In Care

by L. Jeannine Bookhardt-Murray, MD

Medical providers or primary care providers include physicians (MDs or DOs), Nurse Practitioners (NPs), and Physician Assistants (PAs). Primary care providers who care for people with HIV include those with special training in Infectious Diseases, Family Practice, Internal Medicine (Adult Medicine), or Pediatrics.

Over the past 20 years of caring for people with HIV/AIDS, there have been challenges and rewards. The rewards outweigh the challenges. I like to focus on the rewarding parts of my practice. The greatest reward for me is getting to know each of my patients and to see them stay healthy. If you're struggling with your health, with adherence to medication, to understand what your provider is talking about, or to keep up with your medical appointments, then please read on.

Human relationships cannot be underestimated, and the partnership you have with your provider can help you stay healthy. Like any partnership, the one between a medical provider and a patient takes time to build. And, as with all relationships, there must be regular contact, mutual trust, honesty, understanding, and kindness. Relationships don't always start out great, but they can get there with work. It may take several visits for a provider and patient to adjust to one another and to build trust.

One thing is for sure – the course of care goes much more smoothly when a provider and patient finally click. I call it the "click thing." I encourage patients to stick it out and give a new relationship time. It may take four or five visits with a new provider in order to find out if it will work. Personalities sometimes need time to adjust to one another in order for the relationship to take shape. The staff is an extension of the provider and is part of the bigger relationship. Your relationship with the staff and your comfort level when you see your provider are all important aspects of your well-being and care.

During medical visits, both your concerns and your provider's concerns about you and your care must be addressed. Knowing how much time your provider has to spend with you will guide you in your discussions. Medical visits in this day usually range between 15 and 30 minutes. A lot of information must be shared in those minutes, and time seems to move too quickly. If you're knowledgeable about your health, your medicines, and the results of your tests, it will help to build a true partnership with shared goals.

“I have told my patients that if I seem not to hear a particular point they are making to stand up and walk to the middle of the room.”

Some partnerships do not work. For some reason, some people just do not get along. That is true with providers and patients. This is a part of being human. If you have given the relationship a chance but the "click thing" just doesn't happen, try talking to trusted friends. Finding out where friends go, if they are receiving quality care, and if they are happy with their provider and the environment in which they receive care can be helpful in finding the type of provider you want and need.

Some people believe that they don't need to know their test results because their

provider already knows them. Have you ever noticed that your provider wants your medical record when seeing you or when speaking to you on the phone? That is because she may have over a thousand patients and cannot possibly remember all the details about your care without looking at your medical record. You, on the other hand, are one person and can remember your own information easier than your provider can. Other patients are afraid to know their T-cell and viral load levels. Unfortunately, not having that information can do more harm than good. I have found that these are often the patients who are struggling the most to accept their HIV diagnosis and to understand the importance of adherence. I strongly feel that if patients know and understand their results, they are more likely to own their health and are empowered to stay as healthy as possible. Knowledge is power. And knowledge about your condition can help you stay healthier.

Sometimes patients are uncomfortable with medication side effects. I encourage my patients to tell me about them, even when the side effects seem minor. If a patient who gets side effects doesn't return to tell me about them, then we've both lost the opportunity to work together to find the best treatment. What works for one person may not work for another. Finding the right medication is best done in partnership with the same provider over time.

From time to time I hear people complain that their providers don't listen to them. In all partnerships, it is important for each person to be heard and understood. You may notice that, during visits, your provider is doing a number of things at one time – listening to you, going through your medical record, and writing. Your provider is checking to make sure that you have had all of the elements of care that are necessary to keep you healthy. Sometimes a provider may be focused on a particular aspect of your care while you are focused on something else. That can result in miscommunication and misun-

Partnership In Care *(continued from previous page)*

derstandings. Over the years, I have told my patients that if I seem not to hear a particular point they are making to stand up and walk to the middle of the room. It sounds funny, but it works for my patients and for me. Whatever you do, ask your provider for a way to get her attention when you need it most.

It can be helpful to have a family member, friend, or case manager accompany you to medical visits to reduce the stress of the visit. Sometimes there seems to be just too much information to understand, and your advocate can help get the information you need and later discuss it with you in a more comfortable environment.

I encourage my patients to focus on the **quality of care** they receive. The following are tips that may help you to understand what your provider will find helpful in order to give you the best care:

- q Keep a notebook with dates and results of tests you have had.
- q Know your current medications by name as well as the ones you have been on in the past (keep a list).
- q Write down any problems or questions to discuss with your provider at your next visit. You may not be able to get through the entire list, so focus on one or two of your most important concerns.
- q Arrive at least a half-hour early for your appointments and try not to miss appointments.
- q Ask the staff to explain any delays. Your doctor may be running behind because she is seeing a lot of sick people, so try to be patient. Make a decision about whether you can wait that day or have to reschedule.
- q Tell your provider whenever you are not sure about instructions. If you do not ask questions, your provider will think you understand.
- q Have a family member, friend, case manager, or other advocate accompany you to appointments.
- q If you think your provider is not listening to you, find a nice way to tell her and ask how you can best get her attention in the future.
- q Write down dates and where you went for specialty care and try to get business cards of specialists to give to your provider for your health record. Remind the specialist to send a report to your primary care doctor.

Your provider is focused on giving you the best care possible, and giving the best care includes following "standard of care" guidelines. The following care should occur at least once a year and more often if determined by your provider:

- q Physical and mental health examinations
- q PPD (tuberculosis test) if your PPD was previously negative

- q Women's health exam, including Pap smear, chlamydia and gonorrhea screening
- q Blood test for syphilis screening
- q Blood test for Hepatitis A, B, and C screening (as determined by your provider)
- q Eye/vision examinations
- q Mouth and dental examinations
- q Blood tests for cholesterol and sugar levels

The following are usually performed every two to three months or more often as determined by your provider:

- q T-cells (CD4) and viral load (level of virus in the bloodstream)

Immunizations are important to prevent sickness:

- q Flu vaccines once a year (flu shots are usually available by mid-September)
- q Pneumonia vaccines every 6 years
- q Tetanus diphtheria every 10 years
- q Hepatitis A immunizations if you have a negative blood test (2 shots 6 months apart)
- q Hepatitis B immunizations if you have a negative blood test (3 shots over 6 months)

Be proactive and work with your provider to stay on top of the routine care that you need in order to stay as healthy as possible. Cancer prevention and screening is also important, so do not forget to ask your provider about:

- q Colon cancer screening (for men and women 50 years old and older)
- q Breast cancer screening with mammograms for women and for male to female transgendered (age 40 years old and older)
- q Prostate cancer screening (for men 40 years old and older)

As you can see, there's a lot of work that goes into caring for each and every person. At first, it may seem a little overwhelming when you try to keep up with everything. However, just as with everything else in life, the more you learn and do to keep yourself healthy, the more comfortable you will be with your own health, your provider, and the healthcare system. Every step forward counts, so "just keep putting one foot in front of the other." Before you know it, you will be working in partnership with your provider in order to stay on top of *your* health.

L. Jeannine Bookhardt-Murray, MD, is Medical Director at Harlem United in New York City and Medical Consultant to the Office of the Medical Director at the New York State Department of Health AIDS Institute.

Personal Perspective: Do As You're Told?

by Patricia Storey

I remember growing up as a child in the 60's and 70's when life was oh so much easier and less complicated – at least in my mind.

There was only one thing that was required of me at all times and that was to “Do as you're told.” It was a golden rule understood by parents and grandparents alike, repeated to me so often that it became a part of my schema. And I learned to act accordingly.

What I didn't understand, however, was that the rule applied to all relationships across the board and it didn't matter who was doing the telling. As a child, grandma always said, “A child should stay in a child's place.” After stepping out of place one too many times and not being able to sit more often than I can remember, I finally learned not to question any adult no matter how ridiculous they sounded at times.

Going with the flow worked for many years, but then something happened that I had no control over. I grew up, and it isn't as simple as our parents would have us believe. Life is very complicated and, in order to survive the journey, one of the skills you must acquire is learning to advocate for yourself. The “Do as you're told” mentality instilled in me as a child may have been sufficient in childhood but, as an adult, I found out the hard way that it didn't get me very far maneuvering through the challenges of life.

After learning that I was HIV-positive in March of 1998, I began to look at life in a totally different way. I question everything and everybody and no longer take anything at face value. I'm learning to live each day as if it were my last, and my values, priorities, and relationships have changed drastically. These relationships include those with each one of my healthcare providers.

Before I was HIV-positive, I would go to any doctor; it really didn't matter what initials followed his name as long as he had an office, a nurse, and a prescription pad ready to write what I thought was the cure-all for whatever ailed me.

Today, all of that has changed. The doctor/patient relationship has taken on a whole new meaning, and I can no longer afford to compromise my health by trusting my care to doctors who aren't knowledgeable about the illnesses that are specific to me. The way that I took great care in choosing the dealer with the best drugs when I was using is the same care I take in finding the right healthcare provider.

A positive doctor/patient relationship is a crucial component of the healing process. There must be mutual respect, open communication, and a willingness to listen and respond to each other with nothing less than positive vibes. It's important that we feel comfortable enough in our relationships with our providers to be able to agree to disagree with each other. After all, they're human and, therefore, capable of mistakes, just as I am.

One factor that has greatly improved my interaction with my doctors is that they know I'm my own best advocate and strive daily to keep abreast of the HIV/AIDS pandemic.

Someone who is self-empowered has the ability to unlock doors and create communication opportunities that someone who isn't empowered cannot.

I no longer take on the role of a spectator when it comes to my healthcare. I am an active participant with expectations that far exceed any other relationship in my life.

Living with any chronic illness can be a challenge physically, emotionally, and financially, and the last thing you need is to be locked into a doctor/patient relationship that isn't working. The goal is to promote healing, not to hinder it.

When my friends come to me complaining that they aren't satisfied with their doctor or the healthcare they're receiving, I leave them with these words: “What are you going to do about it?”

Patricia Storey is a member of ACRIA's Community Advisory Board and a student at the Black AIDS Institute.

“I question everything and everybody and no longer take anything at face value.”

Personal Perspective: The Road to Empowerment

By Kath Webster

Although I no longer subscribe to the traditional roles of the doctor leading and the patient following, I have often asked myself, “what would I do without my HIV doctor?” Shortly after my diagnosis, I became very sick and considered my doctor to be a lifeline. I depended on him to be knowledgeable and up-to-date, to recommend the best course of treatment, to listen to my concerns, to reassure me and give me hope...a tall order!

Before my HIV diagnosis, my relationship with my family doctor was more traditional. I didn't realize I might need to question her professional opinion. Unfortunately, she completely missed my diagnosis after I went to her repeatedly with some of the classic symptoms of HIV – skin rashes, recurring vaginal yeast infections, and bacterial pneumonia. I was finally diagnosed by the Red Cross after donating blood and by then my CD4 count was below ten. I know everyone makes mistakes – including doctors – but it really caused me to question my doctor's competency and I lost trust in her.

I see my relationship with my current doctor as a partnership, which may be considered somewhat untraditional. He advises me, but I am central in the decision-making process. I consider myself to be an empowered patient. I do my own treatment research and I am prepared to question my doctor when needed. He is always open, respectful, and ready to listen. I am very grateful to say that he has come through for me and has exceeded my expectations.

I trust my doctor and feel very comfortable and at ease with him. He has supported me with sensitivity and compassion through some of my most vulnerable times. My appointments are never rushed, and there is always time for me to raise questions and concerns. I admit that the healthcare system in Canada is on my side – he is on salary and is not paid on a fee-per-visit basis.

A few years ago, I was referred to an HIV specialist for therapeutic drug monitoring

(TDM) to have my drug levels tested. When discussing side effects, the topic of lipodystrophy came up. The specialist reviewed my cholesterol and triglyceride levels but neglected to ask about body fat changes. I told him that I had noticed a big loss of fat on my arms, legs, hips, and buttocks plus fat gain around my waist. I was distressed by this, and finding clothes to fit was a challenge. He asked me to stand up so he could take a look at me. He responded to my concern by saying, “Frankly, I've seen much worse.” End of conversation! I felt dismissed and not respected. Looking back, I could have expressed my discomfort with his remark and insisted that he address my concerns.

***“I do
my own
treatment
research
and I am
prepared
to question
my doctor
when needed.”***

Recently, taking charge of my healthcare became more important than ever. I developed extreme anemia and recurring fevers, the causes of which went undiagnosed for ten months despite being seen by several specialists. I endured weakness and fatigue and required blood transfusions every 2-3 weeks. It was further complicated by a diagnosis of hyperthyroidism, which was initially believed to be the possible cause of the anemia. As a result, no further tests were done for about two months while we waited for the outcome of the thyroid treatment.

Waiting was very frustrating, especially since I felt there were other avenues to explore. When my thyroid condition resolved but the anemia and fevers persisted, the doctors were at a loss. At this point, I realized that I really needed to take charge and use all my resources. I asked to see another HIV specialist for an opinion. Although I knew it was necessary, it was difficult because I was worried that my doctor might feel I was losing confidence in him. I explained my need for more opinions since we were not making any headway and he was very supportive.

I also researched on the Internet constantly and discussed my findings with my doctor. I recruited the help of friends, one of whom was on her way to an HIV conference in San Francisco. She knew that a specialist who was presenting there might be able to help my situation. She approached him and he agreed to talk to my doctor about my case. As a result of that connection, my doctor sent my CT scan to that doctor and two others for their opinions. Unfortunately, a diagnosis was still not made, but I was grateful for and impressed by their willingness to cooperate. In the end, my anemia (and fevers) was resolved after my doctor suggested I stop taking Videx (ddI), even though anemia is not a known side effect of this drug. I witnessed first hand that strange things can and do happen on these meds.

This experience really highlights for me that there is a lot of unknown territory in HIV treatment and that doctors are still learning. I realize the importance of being resourceful and taking an active role in my treatment. Advocating for myself in this situation may also have brought about the resolution more quickly. This gives me hope and a sense of control.

Kath Webster is a volunteer HIV treatment educator with the British Columbia Persons with AIDS Society in Vancouver, BC, Canada. She was diagnosed in 1995 and has been HIV-positive since 1987.

Personal Perspective: Both Sides of the Pill Bottle

by Richard S. Ferri, PhD, ANP, ACRN, AAHIVS, FAAN

Sometimes the numbers just don't add up. You're sitting there in an exam room and everyone is telling you how wonderful you're doing. *Your numbers are just great!* Your T-cells are way up and your viral load is way down. What could be better? The answer is – you. In this high tech medical world of measuring and monitoring every branch of DNA, viral particles, and countless other laboratory parameters, sometimes something very strange happens. The patient (and that would be you and me) gets lost in the lab limbo tango. What makes matters worse is that people with HIV sometimes jump right into this dance with glee.

Look, good numbers are good numbers, but they are, after all, just numbers. It isn't uncommon for people with high T-cell counts and undetectable viral loads not to feel so great, while those with low counts and high viral loads feel just fine. Grand even.

It's a very hard disconnect for lots of people with HIV and clinicians to make. There are many reasons why symptoms appear regardless of your counts. However, one of the main reasons is that treatment and disease side effects are poorly handled. Sometimes we feel like we have to just tolerate it.

Okay, time to face the music. As a person with HIV and an HIV primary care nurse practitioner, I can jump with great skill from one side of the exam table to the other. But I'm going to let you in on a little secret. So listen up and lean in a little closer. I thought I was "doctor nurse smarty-pants" – doing outstanding HIV medicine before I tested positive myself. I would often hear the Mighty Mouse theme song ring in my head: *"Here I am to save the day...!"* I was smart, compassionate, dedicated beyond all expectations, and down right foolish. I learned more about being HIV-positive in the split second after getting my test results than in ten years of graduate school.

HIV was no longer an abstract concept. I was now both patient and clinician.

I started to see things differently. I realized that many clinicians were fixated on the numbers. Monkeys could be flying out of my butt, and all that mattered was my numbers. My concerns about fatigue, pain, my career, and family were sometimes seen as less important.

Take fatigue, for example. Fatigue is estimated to happen to 50% to 80% of people with HIV. It can happen throughout all stages of HIV infection and sometimes can knock you down. Even if your antiretroviral therapy is pulverizing your virus, you can still experience fatigue because of anemia, hormonal imbalances, depression and anxiety, lack of physical activity, and on and on.

When we talk to our healthcare team, we need to make it clear

how fatigue – or any symptom for that matter – is affecting us. Everyone gets tired, but not everyone gets HIV-related fatigue. So if it's keeping you in the house and out of life, your healthcare providers need to know that, and they need to figure out what's wrong.

Correcting anemia, improving levels of testosterone, treating depression, and developing an exercise plan are all good solutions. But sometimes the cause of the fatigue remains vague. However, studies have shown that certain psych drugs, such as Ritalin and Cylert, can really help with HIV-related fatigue. They may perk you up and get you going again. Remember that the numbers don't tell the whole story.

Richard Ferri lives in Provincetown, MA and is managing editor of NUMEDX and the author of the novel Confessions of a Male Nurse to be published by Haworth Press in 2005.

***"HIV was
no longer
an abstract
concept.
I was now
both patient
and
clinician."***

Working With Healthcare Providers *(continued from first page)*

Considerations when Choosing a Doctor or Other Healthcare Provider

Qualifications:

- Clinic providers are often infectious disease (ID) or internal medicine doctors.
- Does the provider have at least two years of HIV experience?
- Does the provider see many HIV patients?
- Do they keep up to date? Do they read journals, attend conferences and seminars, and participate in other ongoing HIV-specific medical education?
- Nurse Practitioners (NPs) and Physician Assistants (PAs) who are specifically trained in HIV care are also appropriate choices for care.

Location: How far do you have to travel? You may not have a choice.

Personality: Sensitivity to your particular issues – drug use, gender, sexual orientation, religious or spiritual beliefs.

Relationship: What kind of relationship do you want to have with your healthcare provider? There are various possibilities:

- **The provider is in control.** He or she tells you what to do, and you follow orders. You rely on him or her to know what is best for you.
- **A collaborative effort.** The two of you make decisions, and you are partly responsible for your care.
- **You make all the decisions.** The healthcare provider is more of a consultant. In this case, you have to be very educated on what treatments are available and how to use them.

Word of mouth: Ask other people who their healthcare provider is and how they like the service they get.

Finding the right setting: Depending on your circumstances (Medicaid, private insurance, uninsured), you may have different choices regarding where you can get your care – a private physician, a private clinic, or a public clinic.

- If you'll be going to a clinic, make sure that you'll be able to see the same provider each time you go.
- *Continuity of care* is important. You don't want to have to start from scratch with a different provider each time – and you shouldn't have to.

Making, Keeping, and Preparing for Appointments

- If you receive your healthcare at a clinic, make sure that your provider will be there to see you on the day of your appointment.
- Office visits are usually short – maybe a half-hour or only 15 minutes. Make it count! The first visit should last longer – 45 minutes to one hour.

It's Your First Visit – Bring Your Medical History

- If you can get your records from your previous provider, it makes things easier.
- You have a legal right to copies of all your medical records.
- Keep a copy of all of your records.

Take Some Time Before Seeing the Provider

- Make a list of everything you'd like to ask about. This way, you won't forget the important things or the little things that have been bugging you.
- Check the list with a friend before you go to make sure that your questions are clear.
- You probably won't get the chance to ask everything, but think of it as a wish list.
- Check off five things that you really want to ask about, so that you're sure to get to them. Things like:
 - New symptoms or recent illness you may have had.
 - Medications, natural, over-the-counter remedies, or vitamins you're taking.
 - Lifestyle changes, like changes in your diet, your living arrangements, your job, or your activity level.
 - Let your provider know about any emergency room visits.
 - Questions you have about your medications or new medications you've heard about.

Make a Plan for Talking with Your Healthcare Provider

- For example, if you don't usually talk with your provider much, let him or her know that you want something different to happen this time.
- Start with something like: *I know we haven't talked much in the past, but I really want to ask you some questions. I've written some things down...*

Don't Hesitate to Stop Your Provider the Moment You Don't Understand Something

- Lots of times, things snowball – the provider starts saying something and you're not really sure what it's about. But you're a nice person, so you nod, and the provider keeps talking, and suddenly you realize that you really don't know what they're talking about at all.

Take Notes

- If you find it hard to listen or hear what your provider says (and who doesn't?), bring paper and pen to write things down.
- Keep notes of the important points of your visit.
- You can bring a friend or family member to help you remember what the healthcare provider said. You can even bring a tape recorder (although the tape recorder might make the provider nervous).
- Ask your provider to write treatments or instructions down on paper.

Keep Copies of Your Lab Results

- File your lab results by date.
- Pay close attention to any unusual changes in lab results.
- Discuss any changes with your healthcare provider.

Ask About Your Medications

- What is the name and the purpose of the medication?
- Will there be any interactions with any other medications you're taking?
- What is the dosage of the drug and how often should it be taken?
- Are there any dietary requirements you should know about?
- What are the possible side effects? And how can you manage them if you experience them?
- Is there written material about the drug that you can take home with you?

Get the Names of Other People Who are Part of Your Medical Team

- Social workers and nurses at the clinic.
- Get to know the receptionist – he or she can be a huge help to you in the future!

Waiting for the Visit

- Providers almost always run late, sometimes as much as two or three hours.
- Keeping you waiting this long isn't acceptable – find care elsewhere (if possible).
- Clinics are sometimes the worst in terms of the amount of time spent waiting.
- Be patient, bring a magazine, maybe a treatment newsletter. If the provider is always very late, mention it and ask if a later or earlier appointment would help.

Bring Information to Your Healthcare Provider about Subjects You Want to Discuss

- Providers like it when you're prepared.

Missing an Appointment

- If you miss an appointment, always call beforehand and cancel, if possible, or at least call later.

Communication Skills / Conflict Resolution

- **Open Up:** Don't feel embarrassed about bringing up sensitive health issues. If your provider makes you feel uncomfortable when you discuss your lifestyle or a particular issue, you may need to find another provider.
- **Be Honest:** Don't be tempted to tell your providers what they want to hear – for example, that you are taking your medications regularly and in the correct way when you're really not.

Communicate Treatment Requests in a Spirit of Mutual Respect

- Some providers don't feel comfortable discussing unap-

Healthcare Providers Don't Receive Any More Training than the Rest of Us in How to be Human Beings

- Some are kind, some aren't so smart, some are malicious, and some are really great people.
- They may be nervous and hate that they sometimes don't really know what to do.
- They hate that they don't have a cure to offer you.
- They rarely try to cause harm.
- They're often overwhelmed, but rarely admit it. They carry their arrogance mostly to protect themselves, not to hurt you.
- As in any other relationship, calling them on their stuff can sometimes help communication.
- If it's not working, move on if you can!
- Never forget that the healthcare provider works for you. It's *your* body, *your* health, *your* blood tests, *your* HIV. You are paying the provider's rent for him or her every time you walk in the door.

proved or unfamiliar medications – especially complementary therapies.

- Prepare yourself to discuss them with your provider.
- Know as much as you can about the treatments you want to talk about so that the discussion will be profitable.
- Of course, your opinions may still differ.
- Remember that even if you disagree with your healthcare provider's opinion, his or her opinion may still be valid.

Be Prepared for the Emotional Content of the Visit

- New health problems or a new diagnosis can be emotional.
- Getting too emotional will distract you and your provider.
- If you need more time to make a decision about something, tell the healthcare provider that you need to think about things and will call later to make another appointment – or schedule another appointment before you leave.

Ask for Things in a Friendly But Firm Way

- If the healthcare provider disagrees with your request, ask why. There might be a good reason.
- Ask questions – repeatedly if necessary. If things still aren't clear, ask for a simpler explanation.

When You Find a Healthcare Provider Who's Good, Let Him or Her Know

- Like anyone else, providers like praise.

Tell Friends that You've Found a Good Healthcare Provider

- Recommend him or her to others.

What to Do When Your Provider Isn't Available

- When you call the clinic or the doctor's office, your provider usually isn't there or isn't able to take your phone call.

(continued on next page)

HIV Specialists

Some states have specific requirements in order for a healthcare provider to be designated a specialist in HIV care. In New York State, for example, providers must have the following experience and knowledge to qualify as HIV Specialists:

- Direct care of at least 20 HIV-positive people during the past year, including managing antiretroviral therapy in those patients;
- Ten hours of CME (Continuing Medical Education) each year that includes information on the use of antiretroviral therapy;
- The latest information about HIV disease and treatments;
- State-of-the-art diagnostic techniques, including viral load measures, resistance testing, and immune system monitoring;
- Management of opportunistic infections and diseases;
- Expertise in the management of HIV-positive patients with common co-morbid conditions, including tuberculosis, hepatitis B, hepatitis C, and syphilis;
- Access and referral to clinical trials;
- Proper referrals to other providers for specialty care (oral, ophthalmologic, obstetrics, gynecology, dermatology, nutrition, drug treatment, etc.);
- Strategies to promote treatment adherence;
- Patient education, including risk reduction/harm reduction counseling;
- Post-exposure prophylaxis protocols and infection control issues;
- An understanding of counseling for women of childbearing age, including knowledge of contraceptive methods and ways to prepare for a healthy pregnancy.

Working With Healthcare Providers

(continued from previous page)

- Depending on what you're calling about, you can often get help from the nurse, the PA, or someone else who works there. That's one reason why it's a good idea to know the names of everyone on the medical team.
- If it's a serious problem and you must speak with your doctor, be clear that you'll be waiting for a return call – and be sure to be available at the number that you leave.

Healthcare Providers are Human

- They make mistakes, too.
- When problems arise between you and your provider, discuss them politely.
- If you don't think that the provider adequately addressed or solved the problem, ask again.
- Being an aggressive, inquisitive advocate for yourself is not rude or hostile.
- Most providers can handle disagreement as long as it does not get personal.
- A good healthcare provider is one who will fight for you:
 - Try to get you access to particular medications, even if your insurance or payer doesn't cover them.
 - Get you into a clinical trial if it is right for you.
 - Refer you to a specialist if the need arises.

Firing a Doctor or (a Better Term) Switching:

- Find a new one first.
- Sometimes a relationship just doesn't work for a variety of reasons.
- Give it a lot of thought before switching.

Special Issues

- If clinic providers are always changing, ask to see the same provider each time you go.
- If the provider has moved to another location, find out where he or she is.
- Some women may want to visit a women's clinic so that they can get all their care in one place.

Getting a Second Opinion

- Maybe see another doctor if you aren't satisfied with your regular provider's opinion about an important issue.
- Seeing another doctor may be particularly helpful when you're confronting a significant decision about treatment options.
- Think about enrolling in an information-gathering trial in which you can get free blood work.

This article evolved from a fact sheet originally created by Sally Cooper and the staff of the PWA Health Group. It has been expanded over time by ACRIA's treatment education staff with input from ACRIA's Community Advisory Board and the clients with whom we work.

Personal Perspective: Avoiding the Power Struggle

by David Elfstrom

At times, a meeting with your doctor can feel like a battle. Perhaps you've read about a new treatment that sounds exciting. Who knows your body better than yourself? You've read the drug information book, you know what symptoms to expect. You're being an educated patient. And yet here's the doctor shooting holes in your arguments and resisting your suggestions of new treatments to look into. What's gone wrong?

First of all, avoid bringing published material and printouts to the appointment. Instead, fax the article a few days ahead of time with a short note saying that you'd like to discuss it at your next appointment. But there is something else to consider: the medium itself and how it is delivered, rather than the message. A printout from the web has less impact than a professionally printed, multi-colored pamphlet. My doctors are well aware of the misinformation and scams present on the web. In fact, they instantly turn off when I say the "Internet." So I've stopped saying "Internet" or "the web." Now I say, "This information is from a non-profit organization that specializes in ..."

Do all that you can to earn the respect of your doctor. To do this, you need to make your doctor's job easier. Hopefully you've done that already by keeping a diary, being educated, using an agenda, and being assertive. One extra skill that takes a lot of practice is clearing a mental path for your doctor to follow and allowing her to do her job.

For example, when I first started taking the antibiotic minocycline, I did not go to my doctor and say, "I'm experiencing a Jarisch-Herxheimer reaction." Leave the diagnosing to them – it's their job. Instead, describe the symptoms. If they don't make the connection, give them a hint, but be subtle. Pretend you just thought of it. Say, "You know, I think I've heard about this type of thing before, only it was in people who had Lyme disease. They often get a fever after

taking antibiotics too, don't they?" *By leaving the diagnosing to your doctors but helping them along, you can safely leverage their knowledge and earn their respect at the same time.*

You see, it's entirely possible that you may be wrong. I was once convinced that the annoying thirst I was experiencing was due to the methotrexate I was taking for psoriatic arthritis. After all, the drug book recommended I drink lots of fluid with this drug. But when I told my doctor about this, he said the medication I was

taking could not cause me to be thirsty. The next time we met, I again told him that I was thirsty, and insisted it was the methotrexate. He sidestepped the issue and quietly snuck in some extra blood tests that I wasn't aware of. As it turned out, he uncovered a problem in my thyroid gland, something completely unexpected. I was correct to be assertive because the symptom turned out to be very important. But I was wrong to be telling him what my diagnosis should be. If I had brought up the subject differently, he would have told me what tests he was running instead of being secretive.

Always let doctors think of things for themselves. You're coming to the doctor to ask for their professional advice, not to tell them how to treat you. If you want to try IV-delivered antibiotic therapy for inflammatory arthritis, you'll have to guide your doctor so he will conclude on his own that IV antibiotic therapy will be beneficial. You can help by earning their respect and providing them with the information that they ask for. Sometimes it will take two or three more appointments. Stick with it, be assertive, be patient.

David Elfstrom, 32, is a Toronto-based web developer and photographer. He has had psoriatic arthritis for 17 years but no longer requires medication for his condition after making significant dietary and lifestyle changes over two years' time.

"You're being an educated patient, yet here's the doctor shooting holes in your arguments and resisting your suggestions. What's gone wrong?"

Personal Perspective: Person First/Patient Second

by Paul Stabile, PA-C

As the Director of Clinical Care of the William F. Ryan Community Health Center, I provide medical care to people living with HIV as part of a multi-disciplinary treatment team. The Ryan Center is a not-for-profit community health center that provides primary and preventive care, including integrated HIV clinical and support services to underserved, minority communities in northern Manhattan. As part of my duties at the Center, I spend a lot of my time administering quality assurance projects, but I also have the pleasure of providing an orientation to medical services for each new HIV-infected patient. I have found the approaches discussed below to be helpful in establishing good working relationships with my patients.

Every patient I treat is an individual. I try to remember that your previous experiences with the medical profession may have been minimal to non-existent. When you come through the Center's doors, you arrive with a unique set of experiences with health care (the good and the bad): varying degrees of knowledge about HIV infection and the treatments you may already be taking, and your own approach to dealing (or, sometimes, not dealing) with your health issues.

HIV is unlike any other disease treated today. Social stigma against people living with HIV still exists in many communities, and many patients have almost no knowledge of treatment advances. This includes both the "good" advances (highly effective therapies that have moved HIV infection into a chronic care model) and the "not so good" advances (daily pill taking, regular blood draws and medical visits, side effects, etc.).

Your First Visit

Your first visit with any medical practitioner is critical. It is at this visit that a patient obtains the sense of where he/she fits into the care process. The practitioner may give the impression that you are just a "number" or he/she will make you feel like an individual with unique issues that

need to be addressed. At my center, every new patient attends an orientation to medical services. It does not take place in an examination room but in my office. In this non-clinical setting, we can sit and talk face-to-face. If you are newly infected, I immediately find out how you are coping and offer emotional support and a mental health referral, if needed. The focus of the orientation goes beyond simply obtaining an initial medical history and ordering your first blood tests. You are provided with a framework for your future medical care.

“It is important to remember that you, as the patient, are the leader of your individualized healthcare team that includes the medical practitioner, nurse, case manager, and other support staff.”

It is important to remember that you, as the patient, are the leader of your individualized healthcare team that includes the medical practitioner, nurse, case manager, and other support staff. The staff assesses your medical and psychosocial status and, based upon their knowledge and experience, makes recommendations for treatment. However, you always make the final decision on any treatment course. This is especially important if you

feel that HIV has taken control of your life – understand that you are still in charge.

Also, during this visit, I explain the basic blood tests that we will monitor together and encourage questions. At our clinic, every patient receives a packet of information, including brochures on the Center's services and information on HIV infection, blood testing, and others. ACRIA has some excellent patient information booklets we use that provide simple but complete information on HIV care issues – visit their website or call them.

We all have trouble remembering every question we want to ask our healthcare practitioner, so I encourage patients to go through the information in the packet at their leisure and to write down their questions so that they can ask them at their first clinical visit. If you cannot bring materials home because your family or housemates may not yet know of your diagnosis, I suggest reading the materials while you are in the clinic. Most clinics have HIV information booklets and magazines available in the patient waiting areas (POZ, HIV Plus, etc.) for everyone to read. For those patients that have literacy issues, I refer them to support groups and/or individual sessions with support staff.

At our clinic, patients are also given a Pocket Health Journal. This combination datebook and treatment guide provides more information on care issues as well as a place to keep a medication list and to track T-cell and viral load measurements. Tracking of T-cells and viral load is an excellent way for you to keep an active role in your medical treatment.

The Unengaged Patient

Many patients do not take an active role in their medical care. While this can be due to many factors (lack of comfort in a medical setting, language/cultural barriers, literacy issues, etc.), I try to engage the patient, even briefly, during each visit to discuss their care. To help start a dia-

(continued on page 16)

Personal Perspective: What If God Was One of Us? *by Mark Milano*

My journey to find the right doctor has been long, difficult, and frustrating. Before AIDS, I had viewed doctors quite simply: they were godlike beings who gave you pills that made you better. So in 1982 when I was told I might have AIDS, I was surprised that my “infallible” doctors didn’t know what to do or even exactly what it was. In hindsight, this was a blessing in disguise – it forced me to re-evaluate my relationship with doctors. Suddenly I was on my own. When told there was no treatment, I said, “Thank you, I’ll take care of it myself.” I went to the health food store, began reading what little was available, and ate up every news story that mentioned AIDS.

As is common in HIV disease, nothing much happened for the first few years. It wasn’t until I moved to New York in 1987 that I was forced to make some serious treatment decisions. The head of the Multicenter AIDS Cohort Study (MACS) – an observational study I had joined in 1984 – called to say that my CD4 count had dropped precipitously to 120. He recommended “the best AIDS guy” in New York, and I immediately made an appointment. After waiting weeks to see him, I arrived at the clinic to find that he was out of town and that I could only see an assistant. He proceeded to thump my abdomen and tell me there was only one clinical trial available (AZT) and that I didn’t qualify for it. “Nothing else?” I asked. “Not here.” “Any other trials elsewhere?” “I don’t know of any.” “Gee, thanks.” I received a \$200 bill the next week for this five minute chat, but when I called the payment department I scared the woman so badly that I never heard about the bill again!

So, I took a two-pronged approach: finding another “best doctor” in New York, and joining ACT UP to work with activists who were ferreting out all the clinical trials in the New York area. The latter step revealed a bunch of trials – but none that I wanted to join. Joining ACT UP also led me to another doctor, who was a member. What could be better than

a gay activist doctor? Now here was someone I could work with.

Our first visit started out well enough. He wanted to know everything about me – did I have a doctor? (no) did I have a dentist? (no) did I have a boyfriend? (no) did I need a therapist? (no) – lots of detail. That was good. Then he asked me to disrobe and lay on the exam table. He walked over, took a look, and said, “God, you’ve got a beautiful body.” Nowadays, I would love to hear that (not from my doctor, of course), but back then it made me uncomfortable in a way that I didn’t label as sexual harassment until years later. Imagine a straight male doctor saying that to a woman – can you say “lawsuit?”

***“Suddenly
I was
on my own.
When told
there was
no treatment,
I said,
‘Thank you,
I’ll take care
of it myself.’ ”***

But I knew he was one of the few HIV experts in the city, so I ignored it and asked what he thought I should do. Unfortunately, by this point I knew about as much as he did about HIV treatment. AZT was only approved for people with CDC-defined AIDS and, besides, I wasn’t sure it was that useful. So all he could offer were some referrals and advice to keep working out. Luckily, my CD4 count went back up to 300 and stayed there.

Nothing much happened until 1989, when AZT was approved for anyone with a

CD4 count below 500. Even though I was still stable at 300, my activist doctor felt it was time to start AZT. I raised concerns about side effects and drug resistance. He insisted it was time to start. “Well, if I start, I would want to take 300mg a day, since that’s the lowest dose that has been found effective in some studies.” “I won’t prescribe it at that dose.” “Well, you can prescribe a higher dose, and I’ll just take 300mg – is that the kind of relationship you want?” The visit ended in a near-shouting match, and I was without a doctor once again.

For the next few years, I bounced from doctor to doctor. I relied on my annual visit to the MACS in Chicago for my blood work and ran to the clinic if I had some treatable infection. But all the doctors seemed to fall into two categories: dictators who demanded I do what they said, or scribes who were so impressed with my knowledge that they basically asked me what I wanted them to prescribe.

One prescribed Prozac when I was battling mild depression. I began taking it and was abruptly dumped by my new boyfriend when I had problems in bed. When I saw the doc, he asked if I had any side effects. “No, I don’t think so. But I have been having difficulty getting an erection.” “Oh, that’s a common side effect of Prozac.” “And you didn’t warn me?!” “Well, I didn’t want to increase your anxiety level.” No, he just wanted me to lose my boyfriend, I guess. Funny – since I was on Prozac, the breakup didn’t really bother me. Still, it taught me to check into every drug I’m prescribed before I start taking it.

In 1994, I thought I found the kind of doctor I wanted: a freethinker who was happy to debate various approaches with me and was comfortable when we disagreed. But he was a GI doc (gastroenterologist) who wasn’t really interested in providing primary care, and when I began developing significant neurologic symptoms, he was too busy to see me. I was forced to pick a

(continued on next page)

Person First/Patient Second *(continued from previous page)*

logue with you, your medical practitioner may ask you open-ended questions to encourage discussion, instead of questions that can be answered with a “Yes” or “No.” For example,

Instead of asking: “Are you having any problems with your new medication regimen?”

I would ask: “What side effects have you noticed since taking your new medication?”

Instead of asking: “Do you have any questions about your blood work?”

I would say: “Tell me what you think about your current T-cell level.”

I want to hear what you think about your treatment plan and your quality of life. Also, I never underestimate the value of other care team members in providing you with information. Visits to nurses,

case managers, and social workers are all part of the care process where you can get information. Some staff might have a closer relationship with you or perhaps can speak your language more fluently, and they can help you get more informed.

Finally, our responsibility as medical practitioners is to encourage open communication with you and to have a genuine interest and regard for your well-being. It is important for you to know that you are more than the “sum of your laboratory values and physical assessment.” Demonstrating that I care for my patients as individuals goes a long way toward making every visit an educational opportunity.

Too Many Issues/Too Little Time

If you have many questions, sometimes it may be impossible to adequately answer all of them during one visit. When this

happens, I try to focus on your one or two major questions and then, if necessary, schedule another time to come back to continue our discussion. These follow-up visits are during the hours I set aside for medical education appointments each week. They take place in my office and focus solely on answering your questions regarding your care. I have found that this consultative approach also helps to foster the spirit of collaboration as a team.

Remember, ask questions and continue to educate yourself about HIV. You are in control.

In addition to his work at the Ryan Center, Paul Stabile, PA-C is a member of the New York State Department of Health, HIV Quality of Care Advisory Committee and a former member of the New York City HIV Health & Human Services Planning Council (Ryan White Title I).

What If God Was One of Us? *(continued from previous page)*

doc out of my insurance company’s book of providers – a classically arrogant doctor who called for lots of GI tests but didn’t bother to check into the numbness in my arms and legs.

After weeks of not being taken seriously, I awoke one morning and found I couldn’t walk downstairs without holding onto the handrail for dear life. I put the word out to my fellow activists that I needed a good doctor immediately. One of them came through, and I was in his doctor’s office that day. I explained my symptoms and said, “I want you to imagine a big red neon sign above my head. It’s flashing: DANGER! DANGER!” He said, “Would you like to go to the hospital?” Thank god – someone who understood that no one knows better than the patient when something is really wrong with their body.

Two days later, I was diagnosed with advanced neurosyphilis. Granted, I presented with an unusual set of symptoms,

but I did have symptoms, goddammit, and someone should have taken them seriously. I eagerly began my first infusion of penicillin and went to sleep to allow the healing to begin. Suddenly at 2 am I awoke with chills and the shakes. The shakes became so violent that I could barely stay in bed. I rang for the nurse. “I think I may be having an allergic reaction to the penicillin! Call my doctor!” She wouldn’t wake him, so an intern came in and frantically began doing all kinds of tests – a chest X-ray right there in my bed, arterial blood gases, the works – all while I was shaking frantically.

Everything came back negative, and the shaking eventually stopped. When my doctor came in at 7 am, he said, “How are you?” No one had told him anything about the previous night’s chaos. When I did, he said, “Oh, that was just a Herxheimer reaction” Just? What the hell was that? “It’s a classic response to

an antibiotic when many infected cells are being killed off.” Three different doctors had seen me just before I began the penicillin and not one of them had bothered to tell me about this relatively common reaction. “You should be happy – that means the penicillin is working.” I would have been happier if someone had had the courtesy to warn me ahead of time.

But this experience just reminded me of what I’ve seen time and again over the last 22 years. Doctors aren’t gods. Like the Joan Osborne song says, “What if God was one of us? Just a slob like one of us?” I guess they are – just looking for the answers like we are. And the sooner we realize that, the sooner we can all work together to find the path to a long, healthy life.

Mark Milano is a longtime AIDS treatment activist and a treatment educator at ACRIA.

Personal Perspective: Learning to Trust

by Penni Cleverley

It's hard to talk about my relationship with my physician without first talking about my experience before I became sick with the dreaded PCP (*Pneumocystis pneumonia*). Prior to getting PCP, I was not a compliant patient, nor was I very open and honest with my physician. I only took my medications if I was around someone who would notice that I *wasn't* taking them. My doctor's office is an hour and a quarter each way by car, and every time I went, I knew that I would be forced to wait at least an hour. I'd cancel my appointment if I could think of any good excuse to do so. Hang nail or headache anyone?

Each time my doctor saw me, he would try to explain my health. It would just go in one ear and out the other, as if he were talking to someone else. I was in total denial. I flushed big amounts of medication down the toilet at least three times a year. To this day I don't understand why I even picked them up from the pharmacist. It was easier for me to deny what was happening than to live with the side effects – diarrhea, nausea, vomiting, fatigue, and headaches.

In 2000, PCP came to visit my body. I remember calling my doctor only because I really thought that I was about to die and I was scared. I was a single mother of two children, and there was nobody else good enough in my eyes to finish raising them. I was sitting in the emergency room, and the doctor came in and told me that he thought that I had PCP. I remember crying, thinking, okay, this is it, my number is up. He sat down and talked to me. I think this was the longest discussion that I had ever had with him. He explained what was happening and what the course of treatment would be. He explained what a respirator does and told me that there was a possibility that I would need one. He explained how he would go about putting me on it if needed and that he would eventually get me off it. I was horrified, but I had reached rock bottom. I needed to trust someone. He told me that he felt that he could pull me out of this if I followed his directions to the letter.

For the first time in my life, I realized that

doctors really do care about their patients and that they're human beings, too. I realized that he truly cared and was going to try his best to help me get through this. From that point on, I realized that my care would be more beneficial if I responded openly and honestly to his questions. I also felt more comfortable bringing concerns to him. He knows that I won't just call because of a hang nail. He respects that it is ultimately my body and my choice, and I like that he respects that. He tells me what he would like to do for me, and we talk about it. We work as a team to figure out what will and what won't work. Before getting sick, I would agree to anything and then only do what I chose to do. Before getting sick, my doctor was only getting half of the picture.

***“I flushed
big amounts
of medication
down the toilet
at least three
times a year.”***

I've learned some important lessons because of my experience. I've learned that starting and stopping my medications so many times was worse than if I hadn't taken any at all. I developed resistance to a lot of medications by starting and stopping them so often. I burned a lot of opportunities, and now I pay the price by not having those medications available to help me today. I also learned that doctors are human beings trying to help us. But we, as patients, need to do our part, too. It's important to understand what's happening and to report changes that we notice. As patients, we're the best ones to tell our doctors what our bodies are feeling. Doctors and patients need to work as a team. It's sad that it took my getting really sick for me to realize that I needed

to build that relationship with my doctor. I think that I originally went into such denial because of my first doctor-patient relationship. I had received a letter from the Red Cross stating that I needed to get a follow-up HIV test after donating blood. When I found out my status in 1985 (from a different doctor than my current one), he told me that I had six months to live. I remember him asking me all kinds of personal sexual questions that I was in no way comfortable answering.

My husband was with me, being tested for HIV for the first time. One doctor pulled me into one room while my husband was pulled into another one. We were both drilled about our sexual experiences. I was horrified. I felt that I had done something very wrong and very dirty. The hardest part was knowing that I *hadn't* done anything wrong – I had fallen in love and married, which, to this day, I do not feel was wrong. I couldn't understand why they kept asking the same questions over and over about who I had had sex with and how and where, when I didn't even understand what HIV stood for. These experiences made me afraid to talk to anyone who called themselves a doctor or a nurse. Even though I changed doctors, I carried this feeling with me until I became sick and eventually realized that I could, in fact, trust my physician.

Things are a lot better now. My viral load is undetectable, and my T-cell count is 367, from a low of 8! As of the year 2000, I have taken every dose everyday and been 100% committed to my health regarding medication. I am committed to sharing my past experiences with others to make their HIV/AIDS travels more knowledgeable and smoother.

Penni Cleverley lives in St Johnsbury, Vermont and works for Vermont CARES (Committee for AIDS Resources, Education, and Services). Penni is Co-Chair of the Vermont Department of Health Community Planning Group (CPG) and a member of the Vermont Department of Health's HIV/AIDS Services Advisory Council (HASAC).

What Do All Those Letters Mean, Anyway?

Healthcare providers and researchers often have many letters following their names. These titles indicate, at least partly, their training, experience, and qualifications. The following list isn't exhaustive, but it explains what some of those abbreviations refer to:

AAHIVS – American Academy of HIV Medicine (AAHIVM) HIV Specialist

An MD, DO, PA, or NP who has completed 30 hours of continuing medical education (CME) credit in two years, has seen 20 or more patients with HIV within two years, and has passed a qualifications exam on HIV care. Two thousand providers are registered by the AAHIVM as HIV specialists. When choosing a healthcare provider, be aware that many providers may have equivalent experience in HIV care, but aren't certified by the AAHIVM.

ACRN – HIV/AIDS Certified Registered Nurse

A registered nurse who has completed 70 hours of CME credits, has at least two years of experience in HIV/AIDS care, and has passed a certification exam for HIV/AIDS care.

DO – Doctor of Osteopathic Medicine

A Doctor of Osteopathy has the same rights and privileges as a Medical Doctor (MD). They can prescribe medications and practice medicine in all fifty states. The training that a DO receives is comparable and, in some cases, identical to that of an MD but may have more of a "whole person/whole body" approach. DOs tend to consider the psychosocial as well as the physical well-being of a person, as well as how individual symptoms of a certain part of the body may affect others. DOs also receive additional training on the musculoskeletal system and Osteopathic Manipulative Treatment.

FAAN – Fellow of the American Academy of Nursing

A distinction given to nurses in recognition of their accomplishments in nursing. Many fellows have high levels of training (82% hold a doctorate in nursing), and most have leadership positions in academic, research, government, or community settings.

GI – Gastroenterologist

An MD or DO who specializes in the care of the stomach, intestines, and liver.

MD – Medical Doctor

A physician who holds a medical degree and is licensed to practice medicine and surgery as well as prescribe medications.

NP – Nurse Practitioner

A registered nurse with advanced clinical and academic experience, often including a master's degree. A Nurse Practitioner's abilities vary depending upon each state's regulations. In many states, a Nurse Practitioner can prescribe medications.

ANP – Nurse Practitioner (adult care)

FNP – Nurse Practitioner (family care)

GNP – Nurse Practitioner (geriatric care)

PNP – Nurse Practitioner (pediatric care)

PA – Physician Assistant

Clinicians who provide healthcare to individuals under the supervision of physicians (MDs or DOs). Their training is not as long as that of MDs and DOs (two years as opposed to four), but their responsibilities are quite similar. They routinely take medical histories, examine and treat patients, order and interpret laboratory tests and X-rays, make diagnoses, and prescribe medications. They also treat minor injuries by suturing, splinting, and casting. PAs also record progress notes, instruct and counsel patients, and order or carry out therapy. In rural and inner city areas, PAs may be the principal care providers when a physician is present only one or two days a week. They are able to practice in 47 states, all of which require PAs to pass a certification exam and are then designated as a PA-C (Certified Physician Assistant).

Ph.D. – Doctor of Philosophy

A doctorate (advanced) degree in any subject matter (not necessarily philosophy or medicine).

RN – Registered Nurse

A nurse who has completed a Bachelor of Nursing program.

ACRIA Study of SAM-e Published

On November 11, 2004, the peer-review journal, *BMC Psychiatry* (www.biomed-central.com/bmcpsychiatry), published results from ACRIA's independent pilot study of SAM-e (S-Adenosylmethionine) used to treat depression in HIV patients. ACRIA decided to study SAM-e because there are repeated reports of high levels of untreated depression in the HIV population. Many people are reluctant to add yet another drug with potential side effects to their already onerous anti-HIV drug regimens. Fortunately, our study showed promise with the use of this natural alternative (SAM-e). Publication in a peer-reviewed journal is a demanding process. Yet this process is essential; otherwise the results would not be known or trusted. Since the study results were promising, ACRIA is now planning to conduct a larger clinical study of SAM-e, possibly in older adults with HIV who have been diagnosed with clinical depression. There is still too little clinical data on the efficacy of this agent. Hopefully, our further examination of SAM-e will serve to confirm its potential benefits for people living with HIV.

ACRIA Presents at Gerontological Society Scientific Meeting

ACRIA's research staff was invited to present our seminal data on an over 50 HIV population at the 2004 Annual Scientific Meeting of the Gerontological Society of America November 19-23, 2004. This meeting represented the first time in the society's history to offer a symposium specifically on the aging HIV population. ACRIA was naturally very pleased to have played a central role in discussing this emerging topic of interest to gerontology researchers and care providers of older populations across the United States. ACRIA's presentations were:

- *Socioeconomic Status: An Overlooked Factor When Describing Cognitive Function in Aging People Living with HIV*; and
- *Does Cognitive Function Impact the Well-being of Today's Aging HIV Population?*

Anyone interested in reading the abstracts and viewing the PowerPoint slides used for these presentations can visit the Research section of www.acria.org.



is looking for new COMMUNITY ADVISORY BOARD members.

ACRIA's Community Advisory Board (CAB) fosters partnership between the education staff and the local community impacted by HIV/AIDS. Involving community members in the development of our education programs ensures that community values and cultural differences are respected in ACRIA's educational work.

Community Advisory Board members meet every other month, review program materials and help us identify education needs.

For more information about the CAB or if you are interested in volunteering at ACRIA, please call Mark Milano at (212) 924-3934, ext. 123.

Free HIV Treatment Education Technical Assistance Program: Capacity Building for New York City Community-Based Organizations

ACRIA offers a capacity building program for community-based organizations that provide services to people with HIV in New York City. The goal of the program is to help non-medical service providers incorporate accurate, comprehensive, and up-to-date HIV treatment education and counseling into their agencies' work.

This two-part program includes:

- A four-day HIV treatment information and skills-building training to be held March 21 – 24, 2005; and
- Ongoing follow-up support and technical assistance for each participating agency

ACRIA will work with participating organizations to share the information and skills acquired during the training with other staff and develop strategies to integrate treatment education into agency services. Participation in the training is limited to 25 people. For information about the program and how to apply, go to www.acria.org/treatment/nycta.html or call Donna Kaminski at (212) 924-3934 ext. 129.

generous contributions

Thoughtful donations were made in memory of the following individuals:

Cliff Adams
Roberto Alonso
Barry Binkowitz, MD
Bill Black
Nathan Block
Gary Bonasorte
Michael Callen
Steve Cattano
Robert Chesley
Ira Davis
Patrick Englese

Al Isaac
Leslie Kaliades
Armando R. Larrea
George Locayo
Tommy McClain
Oswaldo Peres
Anne M. Reynolds
Thomas Saporita
Ray Tighe
Robert Woolf

Contributions in support of ACRIA's vital research initiatives were made in honor of the following individuals:

Steven & Judy Gluckstein
Daisy Graciano
Michael Roper
Robert Russo

Gerard Stricker
J Daniel Stricker
Gerry Valentine

The following persons, corporations and organizations made major donations between September 18 and December 14, 2004 to support ACRIA's research and education efforts:

Abbott Laboratories
Altria
Frederick Anderson & Douglas Hannant
Annalee Newman Fund
Robin & Mark Avram
Mr. Scott K. Bessent
Mr. Robert M. Browne
Sue & Bob Cochran
Mr. Douglas S. Cramer
Ronald & Ellin Delsener
Tiffany & Louis Dubin
Mr. Brandon Fradd
Ms. Deborah Gimelson
Mr. Tom Gladwell & Mr. Andy Reynolds
Mr. Fredric Hanson
Gale Hayman & William Haseltine MD
Mr. Stephen Hays & Ms. Valerie Hughes
Reinaldo & Carolina Herrera
In Style Magazine
Mr. Jay Johnson & Mr. Tom Cashin
Mr. David Kleinberg
Ms. Leslie R. Klotz
Douglas & Kathy Landey
Mr. Chad Leat
Jean-Pierre & Rachel Lehmann

The Gerald & Sandra Lippes Foundation, Inc.
Mr. Joshua Mack & Mr. Ron Warren
Helen & Brice Marden
Ms. Angela Mariani
Mr. & Mrs. Peter Marino
Mr. Mark Montgomery & Mr. Stephen Kinsella
Ms. Martha Nelson
The Stavros Niarchos Foundation
Judith & Samuel Peabody
Platinum Guild International
Pharmavite
Ms. Isabel Rattazzi
William & Katherine Rayner
Mr. Charles J. Roumas
Dr. & Mrs. James Scheuer
Mr. Nicholas S. Shahid
Joan & Mark Sherman
Mr. John Silberman
Russell & Kimora Simmons
Mr. William F. Trinkle
Blaine & Robert Trump
W Hotels
W Magazine
Ms. Jane Wenner

AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA



230 West 38th Street, 17th Floor
New York, N.Y. 10018
T 212 924-3934 F 212 924-3936
www.acria.org

Change Service Requested

NON-PROFIT ORG.
U.S. POSTAGE PAID
New York, NY
Permit No. 4732

**ACRIA Update is sponsored in part by
unrestricted educational grants from:**

