Checking In

My chart

August 1, 1994 By Larry Kramer

I started keeping this chart when I noticed that few doctors ever looked at my past records, which I dutifully brought in a thick folder to our first appointments. Now I hand them this as well. I feel very fortunate to have found a group of doctors whom I trust. Dr. Jeffrey Greene and Dr. Lawrence Horowitz, both of New York University (NYU), monitor my HIV and my liver, respectively. When I'm in Los Angeles I see Dr. Steven Miles at the University of California at Los Angeles (UCLA). For intestinal problems I go to Dr. Donald Kotler (at wretched St. Luke's). I consult them all and they all talk to each other. I also call upon Dr. Anthony Fauci, Dr. Joseph Sonnabend and Dr. Suzanne Phillips for advice. I guess you could say I believe in researching everything as much as possible. I think we all should, and I think our doctors are the first ones to be grateful that we do.

Every AIDS activist I know offers strong opinions, often unsolicited. This can be a mixed blessing because each usually speaks only from individual experience. A good doctor with a broad practice has seen a lot more on which to base a judgment call.

The state of my liver may be more of an immediate danger than HIV. I've known since 1978 that I'm one of the 10 percent or so of people exposed to hepatitis B who never shake it. As a result I have cirrhosis (a bad and scarred liver) which means I must beware internal bleeding and hope and pray my esophageal varies (sort of varicose veins of the esophagus, which can accompany cirrhosis), don't get any worse. Larry Horowitz has brought me back from the brink of very scary elevated liver functions several times, and so I faithfully follow his advice and constant monitoring of my medications. Most of the medicine I take—Zantac, colchicines, propranolol, spironolactone, mephyton—is for my liver.

It was Dr. Donald Kotler who strongly advised me to start AZT. This was not an easy decision. I was having the runs too often and my T-4s were falling, but not to the point where I would have started AZT, particularly with a still OK percentage (Steve Miles believes the percentage is the only thing to pay any attention to, not T-4s themselves). Corroborating this were the results of several tests measuring viral activity—not only the beta-2, but also several from Hoffman-La Roche and several experimental ones done by Dr. David Ho—all of which registered very low viral activity. Donald resolutely maintained that these tests were only monitoring HIV activity in my blood and not my gut or lymph system, and he felt very strongly that the rapidly falling platelet count that everyone could no longer overlook on my chart was due to HIV activity in those places. In fact, he felt so

strongly he called me in the middle of a meeting with Barbra Streisand to tell me I was in danger and must start AZT as quickly as possible. There was by no means general agreement on Donald's diagnosis. There was even a conference call with Fauci, Greene and Dr. Simon Karpatkin, NYU's head of hematology, who'd run some advanced-type tests on my platelets and confirmed I had something called ITP, wherein platelets destroy each other. Once again I discovered the agony of, in the end, having to make a major medical decision myself.

I took my first AZT capsules in Barbra Streisand's guest bathroom, terrified I'd get sick in the middle of our first week working together. I'm happy to say I've felt no side effects. My platelets have risen, if not back to normal, at least out of the truly dangerous area. My gums have stopped bleeding, my runs have not returned, even my T-4 percentage (and count) has elevated. Donald had recommended 600 mg of AZT a day, Jeff had suggested 500 and I've been taking 400. I find when I lower this to 300 my gums start to bleed again and various intestinal rumblings reoccur. I'll continue to play with this dosage as I follow my blood tests, which I have now done every month. If the platelets and percentage fall, I'll raise the dosage; if they continue to go up, I'll try to lower it.

I have no idea how long I'll take the AZT. Joe Sonnabend, of course, begs me to go off it. But there's little else that raises platelets.

I take Shaklee vitamins daily: Multi, E, B-complex, zinc, C and beta carotene, plus NAC. Too much C gives me the runs. I try to take 600 mg of acyclovir a day to ward off genital herpes, but it gives me a stomachache. For the skin blemishes, eruptions, itches and scaling that come with age and/or HIV, I use Eucerin Moisturel, Retin-A, mycology, flucinonide cream and sulfacet-r, all recommended by my dermatologist, Dr. Alvin Friedman-Kien (NYU), who's also helped my similar scalp problems with Nizoral shampoo (or Neutrogena T/Gel or T/Sal).

For my mysterious recurring cough, I've discovered nothing helps except Hall's cough drops. I've tried everything from Hisminal to Humbid, from nasal douches to inhaled steam. I've had every kind of test and seen every sort of specialist. I still cough.

Last but far from least is the constant wearing on my person of some sort of turquoise stone which a fortune teller, many years ago, advised me so to do. Got to cover all the bases, don't we?

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