Web Crawler: Marty Howard

Cybernaut Marty Howard still goes to the doctor

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Marty Howard created and maintains one of the most comprehensive AIDS information sites on the World Wide Web, minimalistically called Marty Howard's HIV/AIDS Site. Designed to link the user to as much HIV-related information as possible from one starting point, PWAs can surf all over the U.S. and the world from Howard 's one address.

Howard is 53 years old and earned his chemistry and zoology degrees at Brigham Young University, Hawaii, where he was president of his graduating class -- "not bad for a nice Jewish boy at a Mormon school!" He has been married for 25 years to Debbie, a first-grade teacher, and they live with their three kids in Valencia, California.

HIV positive for 10 years, Howard is participating in a gene-therapy trial run by Viagene, a biotechnology drug company. POZ *spoke with Howard about his life, his treatment and using the Web as a personal medical consultant.*

I have severe hemophilia. I had been in a transfusion safety study for a few years and was, HIV negative all the way through. But in September of '85, just a few weeks after taking the first of a new lot of clotting factor, I tested positive.

I did zip as far as early treatment goes. I didn't want to do anything that would further assault my immune system. I figured that HIV could do that well enough on its own. Luckily, I didn't smoke, drink, play with recreational drugs or do other immunesuppressive things, so I wasn't faced with painful behavior changes.

I didn't start any treatment until about 18 months ago. Three blood tests over a three-month period showed that my CD4s had dropped below 500. I then negotiated treatment with my immunologist. He makes the final decisions, but with my input. I know that he considers my thoughts and feelings carefully, so I'm OK with giving him that authority.

We negotiated dosage more than choice of treatment. I react strongly to meds and usually half the standard dose is enough for me to benefit. So when I started AZT and ddC, my immunologist agreed to a much reduced dosage.

Still, both drugs failed me -- ddC caused a major attack of pancreatitis and after that AZT started irritating my pancreas as well. At that point I quit all antiretrovirals, since I had no symptoms and my various counts and percentages were just fine.

I recently started d4T as my CD4 count went under 400, though I attribute that to having blood drawn just following a minor attack of pancreatitis. I have had no opportunistic infections at all, yet, and hope not to for quite some time.

I am disabled, not primarily due to HIV but to severe osteoarthritis and its complications. When it is irritated, it causes a joint bleed requiring thousands of dollars of medication to control.

I'm also on meds for irritable bowel syndrome, high blood pressure and anxiety. I take pills every six hours. Only the d4T is HIV-related.

I am in an HIV gene therapy trial. It involves introducing genetic material on the back of a virus that has been humanly engineered not to cause disease. This virus deposits the genetic material where it is supposed to go and is itself killed off by the body in about three days.

I was involved in the first study phase -- the toxicity part -- which was neither blind nor randomized, so I knew what I was getting. I also knew that there was some risk involved. After the first stage showed no toxic effects, the study went forward.

I had *no* adverse reactions during the study. Actually, I'm confident that it has helped increase the overall health of my immune system.

Gene therapy gets right to the root of the immune system. It can turn on cells to be killer cells, and those cells can be instructed to do many things. I think this is the type of technology it will take to control HIV.

I started my Web page when I couldn't find a place for an Internet "newbie" to go and find information on AIDS without knowing how to use Internet search tools. I figured that a decent jumping-off point was in order, so I created it. I now average 1,000 hits a week.

I recently received a request from a major pharmaceutical firm to post its open HIV-related clinical trials along with descriptions of each, what is needed to qualify, and the list of 150 or so sites where people can apply. I'm flattered by that one.

I've also received more than 1,000 emails asking me to post HIV-related services for various geographical areas. That is, users want to be able to see what food, legal, transportation, housing and other services are in their area. I'm working with a government agency now to obtain such a database. If I can get one, I'm fairly sure I can persuade one of the many software providers to give me a small search engine for it.

I've received many requests to provide information specifically pertinent to hemophiliacs who are HIV positive or have AIDS. The National Hemophilia Foundation has no online database of articles, not even in their offices. They are trying to provide me with timely information.

The Internet isn’t the best source for HIV information -- yet. Right now, my immunologist can provide me with far more information on current thinking than anything I can find online. A couple of drug companies are writing their own Web pages; time will tell just what they post. Genentech and Viagene both have a presence, but very little content.

Science hasn’t yet managed to cure a single viral infection, so I don’t think we’ll ever have a cure for AIDS. But I do think that within a couple of years, we will be able to classify HIV as a chronic, manageable disease. For those of us positive a long time, I don’t think it’s an automatic death sentence. The key is how healthy we can keep ourselves for the next couple of years.
