

Charlotte H has collected stories from members about their experiences getting diagnosed with Herpes and/or HPV. Some common themes from these stories are:

- **STD Testing**
 - Gives a false sense of security because these viruses are not included in a “complete” STD screening
 - Are often unreliable due to false negatives and inability for the test to detect HSV antibodies soon after the infection occurs
- **People are generally misinformed about HSV and HPV**
 - They fail to specifically request HSV/HPV testing because they assume it is included in a “complete” STD screening
 - They don’t know that there is no FDA approved test for men to detect HPV
 - They don’t know that HSV/HPV can be transmitted while using a condom, on suppressant therapy, and during oral sex
 - They think that the viruses can only be transmitted when there is an outbreak
 - They picture the classic outbreak on the genitals, so do not associate other symptoms, possibly on other parts of the body, as possible signs of the virus
 - They don’t know that HSV1 and HSV2 can cross infect genitally or orally
- **Health care professionals**
 - Are often misinformed about these viruses
 - Frequently misdiagnose HSV and HPV as other conditions
 - Handle telling patients that they have an STD very poorly
 - Discounting the seriousness of the diagnosis
 - Not providing accurate medical advice, especially about preventing transmission and treatment
 - Not providing emotional support resources for dealing with the diagnosis

Luckily I have a Doctor who is fairly well informed, my first OB was little bumps that looked like razor burn in the pubic hair area. When I asked what I could do to help with the razor burn, he looked at it and immediately said, "I don't think that's razor burn, it looks like a rare form of Herpes outbreak." Needless to say I was shocked. **He was very informative and even took what info I learned and made a list of support/dating groups in our area for future patients.** My main problem with this whole thing is that for years I went to Doctors or the Health Dept. and **had routine STD screenings, but never knew that you had to specifically request herpes screening.** I always assumed it was included. If you just ask to be tested, they only test for the "treatable" STDs. Luckily I was able to pin point where I got it and knew I had not infected anyone else. With HSV being one of the more prominent and incurable conditions, **I don't understand why it is not included in the routine screenings or at least offered when you request the screenings.**

Tracy

My gripe is that **every year I would get tested for "all" STD's but never specifically said to include Herpes.** The only reason I was finally tested for Herpes was when my partner had an obvious outbreak. When I asked why they had never tested me for Herpes I was told that so many people have the virus from cold sores that they don't test unless asked to. I think that's lame. Maybe the philosophy is different with each doctor but I think it's something that needs to be addressed. I probably had it for years but didn't realize it.

Sara

I've been diagnosed with HSV2 for perhaps 22 years-a gift from an ex who never had symptoms that I could see, though he had a skin disorder that may have hidden it. **After the original outbreak- where it was "supposed" to outbreak, I had none for another 20 years- or so I thought.** I started believing I'd received a false positive diagnosis, and dang, wouldn't it be great if I wasn't carrying that little impediment! **But I did have an occasional *thing* on my butt- no where near *down there***, you understand. So, I had one while visiting my dermatologist a couple years ago, and you guessed it! That's where the virus found a home. And, since the virus lives at the base of the spine, the butt makes sense. (My virus is apparently lazy and doesn't like to travel far). So, the important part for our Health Dept. friends: ***Nowhere* did I read that outbreaks could happen in places other than the genitals; and nowhere did I read that they could look like what I had.** And sorry, but condoms aren't going to protect anyone against, well, you know.

Bea

I was misdiagnosed at least twice; I seem to recall a third time as well. The doctors told me it was an **allergic reaction or a rash of some sort**. I have had bouts of contact dermatitis and reactions to commercial products before, so this seemed plausible. But I felt something more was wrong because of the regularity of the outbreak -- and the location. When I would have an outbreak (although I didn't know what it was at the time) I'd self-treat it to the best of my ability and refrain from "activity" because it was uncomfortable. As I mentioned, I knew something was wrong and went to the doctor at least twice about it.

Finally, I had an outbreak during a scheduled routine PAP smear. The OB/GYN was immediately suspicious and took a sample, which was more like a slice of skin taken with no warning, and sure enough I had HSV. Unfortunately, **her bedside manner when telling me the results was absolutely deplorable. I was sitting there in her office -- crying, embarrassed, ashamed -- and she proceeded to chastise me for overreacting, kept telling me "you've had it this long, what's the big deal," and gave me no information or support. She didn't even close her office door! I jumped up to do it! I had to pick up brochures myself on the way out.**

I immediately switched doctors, and my new OB/GYN was especially sensitive and informative. He gave me more information, reassured me, and put me on Valtrex, which has been extremely helpful to me.

Not long after my official diagnosis, I also came across an article in a woman's magazine that talked directly about woman who had HSV who had been misdiagnosed. This article helped a lot and was somewhat reassuring. I felt a little better that I had tried to do something about it, but the medical community had let me down. Unfortunately I did not save the article and I wish I had. If you Google **"misdiagnosing HSV in women,"** there are other articles. It's very interesting -- and a real concern -- how often this seems to occur.

Chris

Before I was actually diagnosed with HPV...I went to the Health dept.... had an STD screen (with my normal 6 month check up), came back clean... 2 months later went to the H.D. to have a breast lump examined, so I had another STD screen.... went for the results, they said it was clean. About 3 weeks later me and my partner (of about 3yrs) picked up the mail, there was a letter from the H.D. I said "well, open it"

He said "wtf it says you have HPV! *%\$# etc etc." I was like "wtf, I just got those results a month ago and it said I was fine!" I pulled over, read it, called them and sure enough.... 2 "clean" std screens within 4 months.... 7 clean std screens within 3 years (every 6 months +) One partner within 3 yrs... Plus, all of my other normal every 6months checkups before I met him and **all the sudden I have HPV!!!** (just goes to show, you never know.)

The H.D. was kinda informative about it... They told me what it was, treated it as if I had the flu and sent me to another doc to have tests done.... the other doc was able to answer a lot more of my questions, the H.D. didnt know much. They could only answer questions about HPV if it had to do with warts and I don't have the type that causes warts.

Moral of both of my stories: IF YOU HAVE HSV1 (genitally) OR HPV (no warts)
THEN YOU WILL HAVE TO RESEARCH IT YOURSELF AND TELL DOCS.

My doc (from a Health dep) was sure i had herpes just by looking, called another doc (while he was in the middle of fam. dinner) and asked if she could give me a free script of acyclovir (sp?).... did the tests, gave me the script, sent me home. Went back for the test results and it said **I had HSV1 genitally** (swab and blood test), So she told me to throw the acyclovir away 'because it was only for HSV2 and it wouldn't help me'. **She said the only thing I could do for type 1 was "keep it clean and dry". "You have the GOOD herpes and the worst should be over."** (yeah f'in right!)

She did give me advice on how you get it and how it was spread.... except that really big part IT CAN BE SPREAD EVEN IF YOU USE PROTECTION.

She did not give me any advice for soothing OB's or how to prevent them. **No advise on support groups or outside help (even though I was crying so hard that she felt the need to walk me to my truck and ask if she needed to call someone to pick me up)** Also, that was my second test within 2 weeks... the 1st came back clean. I demanded the 2nd pap and std test because I had another sore and knew something was wrong.... I was right.

Vicki

January 12, 2009

[HSV/HPV DIAGNOSES STORIES]

As for my Doctors, they were great and **told me that it was pretty common and nothing to be ashamed about**; my one Doctor said that we're humans, we interact and things happen. All in all I felt much better and calmer after that, they then gave me a prescription of Acyclovir which I filled but didn't take because I wanted to see what would happen although he made me take it on my follow up visit even though it was gone by then.

They only negative thing I can say is that **when I asked my Doctor on follow up if it made a difference on type HSV1 or 2 he said not really** but after doing some research I found out that's not the case so I had an IGG blood test 3 months after, Type 1 was 0.10 and type 2 was 0.87 which are both negative but I had a feeling the type 2 was going to go higher, I had a 2ndIGG a couple of months ago type 1 was still 0.10 but type 2 was 3.37 or something.

Looking back the only other negative seemed to be the **lack of knowledge concerning shedding** and it still beats the heck out of me why they don't include the Herpes test in the standard std test, I mean it really just gives people a false sense of security and it's no wonder most people don't realize they have this.

Mark

When I had my first outbreak it was VERY painful...prompted me to go get checked out...but I honestly thought it was just a scratch, I had felt a scratch when we were having fun...no details there, but you get how it happened. At any rate, I go in, the **nurse swabs but says that she would be VERY surprised if it turned out to be herpes. Never warned me about spreading infection** just in case or anything else. Well...turns out it WAS herpes,...and luckily for me, I had researched just in case and knew not to touch my eyes, mouth and nose. But what if I hadn't? Or worse...what if I had taken her for her word and had unprotected sex with someone?

Anonymous

I found out via the health department and they were less than human with me. **They handed me a pamphlet and sent me on my way. I was very scared and very confused. They made me feel like I was a dirty degenerate.** I have never been the sleeping around type either.

Joey

"I" decided to get tested for it on my own about 4 years ago. I have always been very good about my female health and seeing the Dr anytime I was uncomfortable about a symptom I was having...to the point where my family Dr. would poke fun at me for being paranoid. 3 kids later, I was tested for all kinds of things in 2000 prior to my 4th child being born, seeing as though I would most likely have a vaginal delivery.

All my vaginal viral tests were negative. But I wasn't specifically blood tested for HSV as far as I know. I never asked. Didn't know I had to. HSV wasn't on my radar screen. **I started having symptoms down there again, and was told the intermittent itches, sore areas, etc were everything from ingrown hairs, to allergies to sanitary pads and laundry detergents.** The same old crap answers. All the usual STD tests always came back neg. Female infection tests always came back neg. When I did finally get tested, I was really upset with my Dr. who I had been going to my entire life about this. **The fact that he never suggested a blood test for it disturbed me. Especially when I was pregnant.** You would think as prevalent as it is, it would be a standard test. I was swabbed only once with neg result. And didn't think about it again until my niece told me she had herpes. Anyhow, I requested a blood test, and it was pos for Type2. I was devastated. I have no idea how long I have had it. I know my ex husband has it. Don't know if I gave it to him or if he gave it to me. Or if in my past I gave it to someone and never knew it. It troubles me often. **Pregnant women should be specifically tested prior to birth.** Drs should ask their patients if they would like the option when having annual bloodwork done. I realize we are responsible to practice safe sex, but you can get this bugger while practicing safe sex !!! What is the problem with our medical community !!!!!!!

Lexi

Before I was diagnosed, **I was sleeping with someone who I knew was positive, but I didn't know that I could become infected outside of an outbreak.** I went for my annual obgyn exam and asked to be tested for all STDs, including HSV. **My doc is great - and she always asks specifically which tests I want to have done and suggests anything I might not think of.** She also offers every time I go, which is helpful for those who might not think to ask.

Anyway, she tested me and I got a call the next day that it was negative. Day after that, I started feeling sore, and thought she had scratched me with the speculum or something - lol. I started to have horrible lower abdominal pain, to the extent that I could barely walk. A co-worker saw me and said I looked like I had the "PID shuffle" which was awfully embarrassing! (For those of you who don't know what PID is, it's pelvic inflammatory disease - and people apparently "assume" you're promiscuous if you get it).

I was in so much pain that I left work early and went to urgent care. **The PA that saw me said she doubted someone "like me" would have herpes,** but I asked her to check for everything. She did a pelvic and said she couldn't see anything, but to be "safe rather than sorry" she gave me a shot for gonorrhea, meds for a yeast infection, and basically meds to treat any other STD other than HSV. I left and took my meds, but got SOOO sick over the weekend that I couldn't walk upright. I had a fever of 103 degrees when I finally called the doc on call at my obgyn.

They got me in first thing in the morning and when my obgyn did a pelvic - it wasn't 2 seconds before she said, "That's definitely herpes. My God, you must be in excruciating pain - you're insides are completely ulcerated." I was already crying and completely ashamed. **She actually held my hand and insisted, despite what I was saying, that it wasn't my fault and that it wasn't the end of the world.** She promised that she could help me feel better quickly now that she knew what was wrong and apologized that the test I had - only 5 days prior had been a false negative. She did a culture and for sure it was positive. **She put me on Valtrex and gave me all the samples she had.** I started to feel better the same day. **She also gave me a cream, Denavir, which really helped the outbreak site.**

I've never had an outbreak or an experience as bad as that since, for which I am SO thankful. I really thought I was dying at that time. I took Valtrex for about 2 years and only had one very minor ob in that time. Since I have been seeing someone who is also positive, I've stopped taking the Valtrex as a preventative. However, I keep some on-hand and when I get the sense that an outbreak might be coming on, my doctor advised me to take 1000mg of Valtrex for 3 days. I do that and I've never progressed to a full outbreak since.

I think that it's unfortunate that so many people have had nightmare experiences with their doctors. Mine was great, but I remember one at Planned Parenthood when **I was 18 and was diagnosed with HPV. She was a witch. She told me that I got what I deserved for being promiscuous and she wouldn't be surprised if I had 20 partners by the time I was 25** - despite the fact that I had only been with 2 partners (and still only 2 at age 25, thank you very much. I never went back to her!

January 12, 2009

[HSV/HPV DIAGNOSES STORIES]

I agree with those of you who say that the stigma is worse than the illness. I had one guy break up with me when I told him and one of the things he said was, "My God it's just tragic that you have to go through that. It must be horrible for you." I told him that the outbreaks were less of an annoyance than having a period every month. **The real tragedy is having to tell people who I think care about me and then receive the reaction like I'm a damn leper all of the sudden!**

And one last thing - even though I've gone on much longer than I wanted to! **I'm sick of people with "cold sores" on their mouths acting like all they have is a pimple and what I have is some horrible defect of body and character.**

Christina

I got HSVII from someone who thought he was free from any STDs because (same story) he asked to tested for STDs when his 10 year+ marriage ended and they didn't test for HSV. (He'd probably had it since early in his marriage or before, but he and his ex-wife were asymptomatic and didn't know.)

So.... **I got the mother of ALL outbreaks, yet didn't suspect an STD because we'd both been tested.** By the time I went in, the outbreak was waning but I'd gotten a secondary skin infection. So, **the test came back negative for HSV and positive for the infection.** My GYN (who I really liked) said, "**congrats! you don't have an STD; it's just a skin infection! Here's some cream.**" Two weeks later, I got a secondary outbreak, went in, she said "I don't like the look of that...." She swabbed again and it came back positive for HSVII.

My only problem with the diagnosis end is that I think she was SO eager to tell me that I DIDN'T have HSV (because of course I was freaking out about the possibility) that I thought her "you're all clear" was the end of things. Then, **when the second test came back positive, it was a double-whammy/let-down, because I'd thought I was in the clear.**

I wish that doctors would give the "good news" about a negative swab test with a grain of salt, letting people know that the swab test is notorious for false negatives, particularly if people wait until the sores are drying up before they go in for the test. In other words, **let people know that it is good news that they got a negative result, but that they should still consider coming back for the Western Blot test in a couple of months,** and/or be vigilant to look for future outbreaks and come in early for re-testing if they see anything suspicious.

Carla