

“Infertility and Reproductive Health Risks for DES Daughters”

A. Schachter, CDC Thank you, Dr. Haney. I would like to now open it up for questions and answers. Laurie, who is the moderator, will give you directions.

Moderator We do have a question from a caller in California.

Caller 1 I have a question that touches on what you've talked about and maybe goes a little bit beyond. I have this burning hypothesis. I am a DES daughter, with a lot of visible DES damage, and I've had lots of infertility problems and cancers as well. I just am wondering, has anyone ever considered the question, the more visible and extensive the damage from DES, such as the malformed cervix, the T-shaped uterus, the blocked fallopian tubes, etc., the more the damage, the greater the likelihood of infertility problems and, perhaps, even reproductive cancers?

Dr. Haney I think it's logical, and without a lot of objective data, because it's difficult to quantitate what you see on the cervix and the uterine effects, and you can't see the abnormalities of the tube, per se, even though we know they exist.

I think it would be very logical to assume, and let me just say it's all temporally related to when you mother took the drug, so if the drug was given precisely at the time the Müllerian duct system was developing, you can expect a more complete effect when the vagina, cervix, uterus, and fallopian tubes formed. It's not precisely at the same time, so depending on when she took the drug, you may see some variation from patient to patient and how much effect.

I think if you really were unfortunate and you have effects in all those sites, it is very likely, although logical but unproven, that you're going to have a greater probability of reproductive problems.

The cancer issue is going to be a little bit more difficult to sort out because the only cancer to date that can absolutely be associated with DES is the clear cell adenocarcinoma of the vagina.

I don't know that there's going to be an endometrial, ovarian or fallopian tube cancer increase, that hasn't been demonstrated to date, but I would think clearly the infertility, the more the abnormalities, the more profound it is, the greater the probability of a problem.

Moderator It has been requested today that you limit yourself to one question. We will go next to a caller in Arizona.

Caller 2 My mother took DES when she was pregnant with me in 1950. When I was in my mid 20s, my gynecologist told me that my cervix showed the classic symptoms of DES exposure. I had no trouble conceiving two children, and my question involves my now 21-year-old daughter; she is, I guess, the third generation we're talking about.

Dr. Haney

Correct.

Caller 2

Is there anything in the research to suggest that these third-generation exposed daughters should avoid taking birth control pills?

Dr. Haney

As best we know at this point, it's an effect on your genital tract, and luckily you didn't have a reproductive problem. It didn't get into your genome, it didn't get into your genes, per se, so what you transmitted genetically with your husband's contribution to your daughter as long as the uterus was able to maintain her and she was able to be delivered, I think her genital tract, as best we know today based on Ray Kaufman's data, would suggest she's just fine.

I don't think we would make any specific recommendations about birth control pills or any other endocrine manipulation that would be different for her from someone who was born of a woman who did not have DES in her history.

C. Tedeschi

I would agree with that.

Moderator

We'll go next to a caller in Pennsylvania.

Caller 3

I was trying to get pregnant with my first child and we're having some difficulty. It's been about eight months. My question is, visually and from some tests, the doctors are saying that my reproductive tract looks absolutely normal. Will I still be at a higher incidence of ectopic pregnancy, pre-term labor, or miscarriage?

Dr. Haney

Luckily, that information is known. Dr. Kaufman, when he did a study about DES upper tract effects, divided the patients into those that were not exposed, those that were exposed and had the deformity, and those that were exposed, but didn't have the deformity. The deformity itself was again temporally related in the severity, both dose and time.

What he found was that the group that was unexposed had a baseline risk of problems. The group that had the exposure and clear anatomic deformities had a higher rate of ectopic pre-term labor, incompetent cervix, etc. And those that were clearly exposed, but didn't have an anatomic defect, were in-between. I would typically say that your risk of a miscarriage, pre-term labor, and ectopic is high enough to say you should be treated as if you were at risk, but it's going to be less than the people who have the deformity.

What it means to you is that when you get pregnant, which hopefully you'll do shortly, they do an ultrasound exam at six and a half to seven weeks from the time of the last period to be sure it's in the uterus and not in the fallopian tube, and that your doctor examines you frequently throughout the end of the first trimester into the second to be sure that the cervix stays its normal length, and then treat you as if you're someone who has had pre-term labor in the past. Those are really precautionary, but Dr. Kaufman's

data does suggest, if you're anatomically normal but know your exposed, you're somewhat intermediate in risk.

Moderator We'll go next to a caller in California.

Caller 4 I'm a DES mother, and my 39-year-old daughter, who was finally conceived through a donor egg in vitro fertilization, has a question about – you didn't mention anything about the quality of eggs in DES daughters?

Dr. Haney As best we know, the DES, the estrogen itself altered your genital tract, so your mother took it, you were exposed, and your genital tract then was altered so it's ability to maintain the pregnancy, sustain the pregnancy, etc. that was altered.

However, it didn't get into your genes, per se, and presumably if the donor was exposed, it didn't get into the actual genes of the donor, so the eggs themselves should be as best we know normal, and that's a genetic thing you're transmitting in information to your daughter, so I think you're pretty safe. I don't think you have anything to be concerned about. The issue is really the genital tract itself is deformed. I think I feel pretty comfortable at this stage in the game saying we have no evidence to date to suggest anything wrong with the eggs.

Moderator We will go next to a caller in New Jersey.

Caller 5 Hello, Dr. Haney. My question was also about the surrogacy, using eggs from me. I'm a DES daughter. My concern is that there was that study that just came out recently that showed that the third generation, that there was ovarian carcinoma in an adolescent who was exposed; she was the granddaughter. I'm concerned that there is some genetic deformity with my eggs. I've thought that there have been the studies, the mice studies, and there have been the mutations in the third-generation mice in the male, that perhaps it also is passed onto the third-generation daughters. I know that it's a very large concern among the third generation.

Dr. Haney I think the unfortunate part about this, you're talking about Retha Newbold, Bill Bullock, and John McLachlan. Those mouse studies they did in a traditional mouse model did suggest that there might be an effect on the third generation.

The difficulty with all this is that, obviously, it's a circumstance that we can't tell you isn't true. What we can say is as evidence rolls through we don't see incidents. There's going to be young women with ovarian cancer, there's going to be young women with some of these other problems, and it's an issue of frequency.

Is the frequency any different in the DES-exposed population? Frankly, until that third generation grows up and has enough children or enough time passes, even though I can say I don't think I see the problem identified to date, I can't reassure you that it isn't going to be down the road. All we can really say at this point is that it doesn't appear that the frequency of any of these problems is higher in the third generation.

As they get older, and luckily Dr. Herbst at my institution is still being funded to continue to follow the population and their offspring, as soon as anything that is identified as the frequency is abnormal, then it's going to hit the screen very loudly. It will be on the front page of *USA Today*. Remember, that the clear cell adenocarcinoma, in contrast to all these other issues, basically never occurs. When it was identified, it was so unusual that there's no question it triggered attention immediately.

These issues of ectopic miscarriage, etc., even a cancer in an offspring that isn't clear cell adenocarcinoma, will be looked at in more of a frequency framework. Again, it's very difficult and anxiety producing, but until the population gets old enough to actually know, we can't give you more than that for reassurance.

But, Candy, jump in by all means.

C. Tedeschi

I agree with you. Only one case, you can't panic everybody. Even with the clear cell, they waited until they had about eight cases before they sounded an alarm. So I think this is a generation that we need to keep very careful observation on.

I've seen about three dozen third generation, and so far have not had any problems with them, very similar to Dr. Kaufman and Dr. Noller's results from that. We're very optimistic about the third generation, but we have not let down our guard, and we will watch for any type of problem and would certainly sound an alarm if we start seeing things.

Moderator

Thank you. We'll go next to a caller in Michigan.

Caller 6

My question is, I've had several female problems. I had endometriosis so badly that I had to have a hysterectomy at 31 years old. I was able to have one child; I have a daughter. I had four months of premature labor, bed rest, and I do know that I am a DES daughter also. I'm just wondering, could the endometriosis be caused from that also? I do know that I had cervical abnormalities and now I have had a complete hysterectomy.

Dr. Haney

Prior to that, did you have any conization or freezing or anything else of the cervix done?

Caller 6

No, I did not.

Dr. Haney

The data as exists, Dr. Stillman in Washington, D.C. looked for that specific question – was the frequency of endometriosis, which again is very common, but was the frequency higher? He found, not in a well-controlled trial because he didn't have a population of randomly assigned take it or not take it women and then follow it over time, but it did appear that the frequency of endometriosis is higher.

Endometriosis typically is that the cervical canal is narrow and it's harder to expel the menstrual debris, and some of it regurgitates out the fallopian tube, attaches, and then we

call it endometriosis when we see it in the abdominal cavity. The cervical canal in DES-exposed women is narrower and so that made perfect sense.

The patients who are at the greatest risk, I think, are not just women who have had DES exposure, that probably increases the risk somewhat, but those that have had a conization, had some surgical procedure done to the cervix because of a dysplasia, the incidence of a very narrow stenotic cervix and hence endometriosis in that population is very high.

I think it's probably true and they may well be related, although the background incidence of endometriosis is also very high. In any individual patient I couldn't tell you whether you were destined to get it anyway or it's related to DES, but overall I think you're exactly right; it's a higher frequency in DES-exposed women.

C. Tedeschi One thing I would caution, for women who do have abnormalities caused by dysplasia, be very careful of the type of treatment that you have because DES daughters' cervixes tend to scar a little more than non-DES exposed, so they tend to narrow that canal down. We have changed a lot of our procedures on how we treat DES daughters and how actually we treat women in general with dysplasia. We are backing off a lot and doing a lot more watching. Be very cautious about getting treatment unless you absolutely need to.

Dr. Haney I couldn't emphasize that more; that's exactly the right way to do this. Don't treat the cervix of a DES-exposed patient with any surgical manipulation, unless you absolutely have great confidence I must do this.

Moderator We will go next to a caller in North Carolina.

Caller 7 My question is, I have a T-shaped uterus and I've been exposed to DES, but my question would be knowing that with that I have a higher risk for miscarriage and pre-term labor due to the DES, and then with the T-shaped uterus I obviously I have a higher risk for those things. We're in the process of insemination now. We've tried one cycle ..., but it hasn't worked so we're in our second cycle now. Looking forward, thinking about possible moving on into IVF, my question would be what would my probability be of success with IVF, and then how much would I want them to put back in me?

Dr. Haney How many embryos?

Caller 7 Right. Because I wouldn't want, obviously, too many because I'm at the high risk for all these other things I've just talked about, but then at the same time I would like probability of conception, so where do you ...?

Dr. Haney That's a hard one to judge. Hopefully, you won't get to the point of needing IVF, but if you do need it, I think the data would suggest that your likelihood of conception, and again, it wasn't well controlled for exactly how many embryos transferred, but your likelihood of conception is slightly lower; it's not dramatically lower, but lower.

The flip side is, if I try to compensate by putting more embryos back, if you had a set of triplets your likelihood of delivering them far enough to get viability would be less than a person not exposed.

On that score, I wouldn't argue that you should get any more embryos than a non-exposed patient. To try to compensate for the slightly lower pregnancy rate and then get a multiple gestation, even twinning, and have a less likelihood of walking away with living children, I don't think is a good bargain.

Although, I don't think there just hasn't been enough scrutiny to know. But I would have argued, probably, if you get to IVF, which hopefully you won't, but if you get to IVF that you ought to use the same rules everybody else does about numbers of embryos based on age and circumstances.

Moderator We will go next to a caller in Florida.

Caller 8 Dr. Haney, I am the mother of two DES daughters. My oldest daughter has two children, the first of which was born pre-term three pounds. He survived; he's doing well. He does have some medical problems.

My question is about the younger daughter. She recently married and she has numerous medical problems, among which is Crohn's disease and a tipped uterus. I would like to know if you can give me some ideas to give her as to what her problems would be in carrying a pregnancy?

Dr. Haney Luckily, I would be pretty optimistic. Let me put aside a minute the Crohn's disease and other medical issues, and simply say you had two DES daughters, both of whom have effects; one of whom has already had children and clearly had the problems we anticipate. If your younger daughter then says, what do I do now, I think that the experience has been uniformly good in simply knowing and treating her for pre-term labor, and understanding what actually her risks are because, just like women who have pre-term labor in a previous pregnancy, they do much better if their high-risk obstetrician is aware this is what the history is.

This is going to sound kind of bizarre, but there is increasing evidence that administering a steroid, not a progestin, it doesn't mean hydroxy progesterone, which is a naturally secreted product in pregnancy of women, if you simply increase that you sedate the uterus and lower the risk of pre-term labor. That's not been applied to the DES population, but it's clear – there's a big randomized trial going on right now and it does appear to be effective.

Whether you chose that or any of the other measures used for pre-term labor, and I'd be interested in Candy's response too, I think that I would be pretty optimistic that when your physician knows that you've had this as a risk and addresses it prospectively when you get pregnant, the outcomes are much better than your older daughter, who this came out of the blue to her, and then boom, she ended up with a three-pound offspring.

I would actually be pretty optimistic. Crohn's disease is a separate issue, and as long as she hasn't had any operations, hadn't had her colon out, hadn't had things that would scar her pelvis, has been able to be treated with medication, I would still think she's pretty optimistic about having children.

What do you think about the pre-term labor issue in that, Candy?

C. Tedeschi I basically think what you have to do is follow these women very carefully. Usually by the end of the first trimester we're watching them every one to two weeks. You're looking at the length of the cervix. You're educating the woman to exactly what she is feeling and to know when to call you, to call her physician to report anything. I think the more aware the physician is of the woman, and any physical changes that she might have and anything she's feeling, the better able the doctor is to react and to prevent pre-term labor.

Dr. Haney I would concur entirely.

Moderator We will go next to a caller in Massachusetts.

Caller 9 I am a DES daughter, as you know. What I wanted to say is that my mom took the drug the first three months with me, and then she started to bleed. They took her off the medicine and she was on bed rest until she had me. I was supposed to be born on May 17th and I came out April 3rd weighing four pounds.

I've had some dysplasia and some laser in my cervix. I've been married for a year now and I've been going through all the tests, and I've had three miscarriages. My last one was just October 16th. Everything was going fine and everything looked great. I went in for the second ultrasound and the baby's heartbeat had stopped. When they ran all the tests, they said I did not have a T-shaped uterus, my cervix looked fine, and they were going to give me a cerclage as a protection when I reached my 13th week, and I was nine weeks when I lost this last one.

I guess my question is, the doctor now wants to talk about more options. He also talked about IVF. I don't understand why IVF would be an option for me when I already get pregnant. You just mentioned that it has a lower implantation rate. Would we just skip the IVF and continue to do what I'm doing now?

Dr. Haney Let me say a couple of things. First of all, you said that you didn't have a DES-looking uterus on the x-ray?

Caller 9 Correct. He said it had no T-shaped whatsoever and everything looked fine.

Dr. Haney So you fall in that intermediate category. There's clearly a problem called repetitive pregnancy loss, and it's first trimester pregnancy loss. There are several different things unrelated to DES, and frankly, repetitive first pregnancy loss or early pregnancy loss

hasn't really been a DES thing. It's a higher frequency overall, but not what you're experiencing. The testing you typically do is an x-ray, as you've had, looking at the carrier types, the chromosomes of the parents to see if somebody has a funny thing called a reciprocal balance translocation, and then looking for blood clotting abnormalities in the mother.

If all of those things are normal, then there are some, if you will, empiric therapies, but IVF doesn't have really any appeal at all, because if you're able to get pregnant, I see absolutely no advantage in doing IVF. It's not going to make anything different in terms of the fetus, the implantation, the uterine environment, your maternal reaction from an immunologic point of view. None of those things matter or would be affected by IVF so I'm in your camp. I just don't see how IVF can help you.

I think you need to be sure you're thoroughly evaluated for repetitive pregnancy loss and then for the known causes. About half the people will not find an identifiable cause and then undergo the empiric therapies. I hate to tell you, but you sound like you're somewhere in the Boston area from your accent. That's not an underserved medical community. There are plenty of people there who are very good a reproductive repetitive pregnancy loss.

Moderator We will go next to a caller in New Jersey. Please go ahead with your question.

Caller 10 I've had five pregnancies, and my first child, thankfully, I successfully delivered at 36 weeks, so I went into premature labor at 28 weeks and had total bed rest. Then all my problems really started happening. It takes me two years to get pregnant and the last four have been nothing but consecutive miscarriages. They all seem to have the same pattern. At the sixth week I start spotting, little by little, and at the eighth week I'm totally hemorrhaging, and either I will lose the pregnancy at that point or I also went on as far as to the 16th week.

Though, with this last pregnancy they did find out I did have a Factor V Leiden, the blood clotting disorder, so they were giving me injections. I think they were ...

Dr. Haney Heparin.

Caller 10 Actually, Lovenox.

Dr. Haney Lovenox, the low molecular weight Heparin. Yes.

Caller 10 Yes. So I was taking that twice a day, but then I did have the miscarriage at the 12th week.

Dr. Haney Let me ask you a question. The 12th and the 16th, those two, did they see viable looking healthy fetuses?

Caller 10 Yes. Both were.

Dr. Haney Good heartbeats and everything?

Caller 10 Yes.

Dr. Haney Did the baby then deliver, and as best they could tell was simply a premature non-viable, but otherwise normal baby?

Caller 10 Yes. Both were.

Dr. Haney What I typically think of when I say first trimester pregnancy loss is not that. You sound like you have the extreme of an incompetent cervix. Depending on how much cervix extends in the vagina, I would have argued that you need an abdominal cerclage. You need to be able to put a band around the upper part of the cervical canal. Some people would do it vaginally, but my experience in DES patients is that the deformity of the cervix makes that real difficult.

Putting a cerclage in, because essentially the internal construction of your cervix, just right below where the uterine cavity sort of enters the canal of the cervix enters the cavity, that isn't holding, so when you get to these 16, 18, 12 even week losses, what you're seeing is the structural problem with the cervix that, frankly, we can pretty easily treat. That's not hormonal, it's not genetic abnormality.

Clearly, the early losses that you see may be related to clotting abnormalities, like a Leiden Factor, or one of the other thrombophilias ..., but this sounds like a structural problem that a cerclage will help. Again, if you have normal, healthy fetuses and can conceive, even if it takes you a little longer than average, you have an excellent chance with a cerclage that you'll deliver a normal baby. I would certainly pursue that avenue.

Caller 10 Even though, all of them, like I said, started spotting little by little at the sixth week, even these just 12 and the 16th one, by the eighth week it's unbelievable, just hemorrhaging like you cannot believe.

Dr. Haney If your ultrasounds are okay, what you're seeing is the cervix changing. So it's shortening, and as you funnel the products of conception, the membranes, the placenta, and the fluid, it's like bloody show for a term delivery. Clearly, as the cervix is changing you'll get bleeding to occur. It's the detachment of the membranes from the lining of the uterus as this process of things coming out is occurring. But if you have a nice band and you really keep the cervix tight and sort of in its normal anatomic construction, artificially made with a band, rather than your own structure, you have a very good chance that you'll just be a pregnant woman to get you well into the third trimester. Unfortunately, you need to have a cesarean section if you do that, if you do it abdominally as opposed to vaginally, but either way, I think you have a much better chance of delivering.

Moderator A caller in New York has a question.

Caller 11 My question was my daughter, when she came time to deliver, the cervix did not open, and she had to have a cesarean because of that. Now is that something that would be a DES situation, where she didn't dilate?

Dr. Haney I think Candy can answer this one.

C. Tedeschi That's not typical. DES daughters tend to have more of a problem where they dilate too soon. It's not a typical change; I mean it can happen to any woman.

Dr. Haney I would agree. I would think that a cesarean section isn't something that's in higher frequency in DES-exposed women. If you look in my hospital, we deliver a tremendous number of premature babies at our hospital, so our section rate is approaching 30%, just trying to make sure no trauma occurs with those babies. That's a very high number. Whether it's unable to deliver because of size or other things, I don't think I would say that's related to DES.

Moderator A caller in Pennsylvania has a question. Please go ahead.

Caller 12 My question has to do with research more than anything else. I'm more concerned about the mothers losing their records and passing on what they may or may not be DES exposed. What's your theory about biomarkers?

Dr. Haney That's going to be a very complicated question. We could spend a lot of time telling you. The place to look is either with John McLachlan or Retha Newbold. They were at NIEHS, and they spent a lot of time looking at proteins made in the endometrium or made in the vagina that were altered when these animals were exposed.

We don't have anything comparable in humans that we can use for markers. I'm not saying it isn't going to be true, but I don't think practically we're going to be able to give you something that will be helpful and useful. It may actually be the case, but I don't think in humans it's been worked out well.

I personally wouldn't want anybody to bank on or think about biomarkers because I think it's going to be by the time we learn enough to say we might have something, the population, hopefully, that's exposed isn't going to be concerned with that because they're going to be after menopause. Whether the biomarkers will be present after menopause predicting other disease, it's too far in the future to speculate on, but I'm pretty skeptical about biomarkers being useful.

Moderator A caller in New York has a question.

Caller 13 Dr. Haney, I'm actually starting my second IVF protocol at Cornell, so I wondered what changes might you suggest to the standard IVF protocol for a DES daughter, particularly given, as you mentioned, the lower implantation rate? I wondered if there was anything else I should be asking the doctor?

Dr. Haney Did you have any difficulty with the stimulation the first time around and the number of O sites retrieved?

Caller 13 No, I did very well with that. I did fine with that. There was more a problem with the embryo quality, so the doctor is changing the drug protocol, as well as doing co-culture this time.

Dr. Haney Right. You're in an excellent place. I'm not going to do it better than he does.

I don't know that I could say anything about changing an IVF protocol, as long as, as you say, the two things: one, I have plenty of oocytes that were retrieved; and two, if the embryos didn't grow well in the lab, that he does what every institution will do; they'll make adjustments to deal with that.

I think the issues with DES really are implantation, so if the embryo number is okay but the quality is not good, then they can address that issue. I don't think I would make any dramatic changes. Luckily, again, you're not in an underserved place. The people are very capable so you'll get the best opportunity I think you can.

Caller 13 Absolutely. Thank you so much.

Dr. Haney My pleasure.

Moderator A caller in New Hampshire has a question.

Caller 14 I'm a DES daughter and was able to conceive and sustain a pregnancy to term. I'm pregnant again. My question is, do I now have reason to expect a normal second pregnancy or ...

Dr. Haney How far along are you?

Caller 14 I'm not sure, actually. I never got my period again following my first pregnancy, so I don't know. I'm wondering how quickly should I be seen by a physician?

Dr. Haney Promptly.

Caller 14 Okay.

Dr. Haney And get an ultrasound to get as early documentation. This is difficult, because you want to know exactly – they can tell by the fetal size how far the pregnancy is, so you can date it well. I would tell you, even though you did well the first time around, I would still put you in the high-risk category.

Caller 14 Do I have reason to press with the physician to get me in to be seen sooner? It's been, as I said, two weeks for me to wait.

Dr. Haney Let's put it this way, since you don't know when you conceived?

Caller 14 Right.

Dr. Haney Two weeks means nothing. Two weeks from what? I would get an ultrasound to find out just – if I saw a sac or a fetus or the fetal measurements or how far along it would be. You don't know what you're dealing with because you didn't have a menses to actually time it. Waiting two weeks, I don't think really matters. I would immediately go in and just say scan me, make me feel better. I know how far along I am; I can begin the dating process.

I think luckily since you didn't have a pre-term labor before, you're probably not going to be concerned specifically about the length of the gestation at this point in time, but I would still be just as cautious because if you have a weak cervical canal and you may have an incompetent cervix this go around. So I would clearly treat you as if you were just as risky as anything else, as any other DES patient, and I'd clearly want to know where you are right now.

Caller 14 You would see those ...

C. Tedeschi You could even have an ectopic there.

Dr. Haney Yes. The same issues, you have to rule out ectopics. If you did an ultrasound and it was a little too early, that's no harm; do it again two weeks later and you'll know where you are. You don't have an ectopic and you'll be able to date your pregnancy. I would clearly do that.

Caller 14 Thank you.

Moderator We will take our last question from a caller in New York.

Caller 15 I had a fibroid removed from my cervix in May. I have a history of structural deformities. I have a coxcomb cervix. I didn't hear any mention about that. I understand that's quite common – and a ring of tissue that's sort of narrows the vagina, which has been a huge problem. I didn't know about the risks of cervical surgery before I had my myomectomy. I do have scar tissue and I'm just wondering if anything can be done.

Dr. Haney Let me ask you a question. Where was the fibroid itself? Was it the cervix itself, or in the uterine cavity and they went through the cervix to take it out?

Caller 15 They went through the cervix. It was on the cervix in the cavity.

Dr. Haney Fibroids can occur as cervical fibroids, but that's fairly unusual. Most of the time they're from the muscle, not the connective tissue of the cervix, and the muscle is above the internal opening at the top of the cervix into the uterine cavity Actually, it can be low

in the cavity, but I would first ask your doctor was it actually the cervix itself or was it in the endometrial cavity, and you went through the cervix to take it out?

Because if that's the case, I don't think you have much to be concerned about.

Caller 15 I'm extremely tender. I can't even withstand an ultrasound, and that's been going on since the surgery in May. I just don't want to live with that for the rest of my life.

Dr. Haney If it was truly of the cervix and there is a deformity, that in cutting out the fibroid, they actually altered the upper vagina and cervix, then you may well have what you're experiencing, a change in symptoms.

C. Tedeschi She's also mentioning a band in the upper vagina, which doesn't happen real commonly, but it is one of the structural defects that we see in DES daughters; they get this narrowing. Sometimes, laser surgery can loosen that up a little bit, but again, it has to be done with extreme caution by someone who's experienced, but that may be why even the sonogram probe or even intercourse may be painful for you if he's hitting that narrowed area at the top. That's something that you need to discuss with a doctor that is caring for you.

Caller 15 Yes, we've discussed ...

C. Tedeschi Exactly what your problem is.

Caller 15 Yes.

Dr. Haney If that fibroid was actually in the cervix itself or right at that area, then I think it does make sense that scarring may be a result of that because these are notoriously difficult to heal without scarring. But if it's in the cavity, I think this is, as Candy said, probably related to the band and not really related to the cervical surgery, per se.

Caller 15 It was nine centimeters, which sounds very large.

Dr. Haney That does sound large.

Caller 15 I feel like it probably was in the cavity.

Dr. Haney Was this done as an outpatient procedure?

Caller 15 No, I was in the hospital.

Dr. Haney They didn't open your abdomen? It was done cervically?

Caller 15 No.

Dr. Haney I don't want to go too much further because I'd almost have to know the details of the surgery, because that's a very large fibroid to take out from the cervix.

Caller 15 In pieces it was removed. Yes, I know. I couldn't believe it myself when I heard.

Dr. Haney We do take nine-centimeter fibroids out of the cavity too. They really make you bleed and uncomfortable. If it was actually of the cervix and that large, you may well be having scarring because of the surgery. That's going to be a pretty detailed question related to the actual surgical procedure. Good luck.

Caller 15 I'm not sure what to do after that, but thank you.

Moderator Dr. Haney, at this time I'll turn it back to you.

Dr. Haney All I can say is I think I'm going to give it to Amy, but I do appreciate the opportunity to speak to everybody tonight. If you have other questions, I think the CDC has a terrific Web site and you get a lot of information from that. By all means, visit and visit often.

A. Schachter, CDC Thank you, Dr. Haney and Candy, for a very informative teleconference. I'd like to remind everyone that additional information is available on the Web site, and that address is www.cdc.gov/des, or you could call 1-888-232-6789. Again, thank you, everyone, and have a good night.

Moderator That does conclude our conference call for today. I'd like to thank you for your participation and for using AT&T Executive Teleconference. You may now disconnect.