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Q&A with oncologist Dr. Sedlacek

Denver, Colorado

My last chemo (with Taxotere and Carboplatin) was March 31, 2009. Why am I still battling alopecia?

He said, "Why are you still battling alopecia? Well, it's because you had Taxotere." He was very matter-of-fact about it.

If Taxotere is the culprit of my alopecia, then is there an 'antidote' that I can take to reverse this side effect of Taxotere?

He said, "There is no antidote." He said he didn't know of any way to reverse this side effect.

Can my hair loss be reversed?

He said, "I don't know of any way." He said that maybe I would be a good candidate for a hair transplant. He suggested I meet with a hair transplant specialist, to go over my options.

What can I do to increase my chance of hair growth?

He said, "Nothing, really. You can try Rogaine." I then told him that my dermatologist at Sloan Kettering in New York suggested that I use Rogaine. And I said, "But the problem is that I have to apply it every 12 hours. It's really too much. I can't do it." And then he said, "And do you realize you have to do that for the rest of your life? And if you stop using Rogaine, your hair will fall out?" I told him, yes, that I understood all of that and that's why I can't do Rogaine. It's really asking too much of me. He agreed. He wouldn't use Rogaine either if he were me.

Are my hair follicles dormant or truly dead?

He said, "They are probably dead."

How does food and nutrition affect hair growth?

He said, "It can."

Why or how did Taxotere affect my follicles like this?

He said that he didn't really know. No one really knows, he said.

Is there a database doctors maintain, other than the one kept by the pharmaceutical companies?
If so, are there any updates regarding Taxotere?

He said, "No! There's no database! Nobody wants to talk about this."

Taxotere has been used to treat breast cancer since March 2001, according to Sanofi Aventis, the manufacturer of the drug. Dr. Sedlacek, in your study you mentioned 'poor hair regrowth up to seven years.' I wonder if there are any people out there whose hair suddenly grew back after seven years? Have you had any patients whose hair has returned?

Sedlacek corrected me. He said, "Taxotere wasn't approved for breast cancer treatment till 2001, but we actually started using it for breast cancer in 1996." He told me no, that no patient of his ever re-grew their hair. He said that of all his Taxotere-alopecia patients, only one patient agreed to try Rogaine, and it did help to increase hair growth. But, he said, the existing hairs grew with Rogaine, sure, but he said that Rogaine did not help the patchy thin areas at all. Rogaine didn't grow new hair in the dormant/dead follicles----it only helped continue growing the already-growing hairs.

Is my inability to grow hair indicative of a greater health issue?

He said, "No, it's not. No."

How 'messed up' is my system if I cannot grow hair?

He doesn't think my system is messed up at all. He thinks my only problem is that Taxotere killed my follicles. He doesn't think there's another underlying problem at all.

I always had long, thick, blond hair. My hair is coming in 100% gray. What caused this change in color? And is that change in color indicative of anything else?

He read this question aloud then skipped it. And come to think of it, the color of my hair is the least of my worries!

What type of medical professional specializes in treating chemo-induced permanent hair loss? I have spoken to oncologists, dermatologists, and endocrinologists, and no one has any solution to my problem. Surely there is someone in the world who can solve this chemo-induced permanent hair loss problem? Dr. Sedlacek, can you please recommend a doctor?

He said, "In New York, there are actually doctors called trichologists who specialize in hair." He kind of rolled his eyes. I told him that I was recently in New York (which he wasn't aware of) and that I had made a million phonecalls, looking for a doctor who specializes in alopecia. He said that the best thing would be to go to a regular doctor and get some tests run. For example, he said, your thyroid should be checked because thyroid levels could affect hair growth. I told him that my thyroid was checked recently at Sloan Kettering in New York and my thyroid is fine. And then he was like, "Oh well!"

My last chemo was fifteen months ago. My hair has still not fully come in. Is my alopecia considered 'permanent'? What is your definition of 'permanent'?

Yes, he said, my alopecia is permanent. And by permanent he means that my hair will not grow back in my lifetime.

What are the chances of my hair ever returning?

He basically said that the chances of my hair ever returning is probably never.

At what point in time should I give up all hope?

After reading this question aloud, he looked up from the paper, looked at me directly and said, "Never! Never! Never give up hope!" And I said, "Well, you're not giving me much hope here." And he basically said, true, but still, don't give up hope.

Why are oncologists reluctant to inform patients that Taxotere may cause permanent hair loss?

He said that oncologists are reluctant because Taxotere is a wonderdrug. He said, "It's a great drug!" Oncologists want to prescribe whatever drug is best for their patients. They want their patients to survive and live and thrive. Killing the cancer is the prime focus. The side effects are secondary. Then I said to him (and I was really cautious about asking this), "Dr. Sedlacek, do you warn your patients that Taxotere could cause permanent hair loss?" (Believe me, I was so nervous asking him this direct question. I didn't feel right about putting him so blatantly on the spot. I didn't feel right because he's been so nice to me and generous with his time.) He paused, took a deep breath, and said to me, "I tell my patients that they will lose their hair but that it almost always returns." And I said, with respect, "So I

guess that covers you.” And he said yes, it does. He said that it’s really rare that hair doesn’t re-grow after Taxotere.

Shouldn’t patients be informed of possible side effects?

He said, “You bet!”

What is your opinion of laser treatment for hair loss?

He said that he’s not aware of laser treatments for hair loss. He said that he knows that “lasers kill tissues.”

What is the latest progress with stem cell therapies? And, does it provide concrete hope for hair growth post Taxotere treatment?

He didn’t really have anything to say about this. He only said, “They’re working on stem cells.”

I believe that Taxotere has caused my permanent hair loss. But, can that be medically proven?

He said, “Yes. It’s the Taxotere.” He said that it’s no mystery. “Everyone” knows it’s the Taxotere. He basically said that it doesn’t need “to be proven” because it’s already a fact.

Or, could my permanent hair loss be ‘blamed’ on something else? And if so, what?

He said no, my hair loss can’t be blamed on anything else. He said it’s the Taxotere. Then I specifically asked him, “Was it the Taxotere IN COMBINATION WITH the Herceptin or the Carboplatin that I took?” And he said, “No, it’s the Taxotere.” He kept on implying that “everyone” knows it’s the Taxotere. It’s no mystery. We can’t blame this on anything but the Taxotere.

Dr. Sedlacek, how did you make the connection between Taxotere and alopecia? Was it simply casual observation of clients at your clinic?

He told me that many years ago, he had an appointment with a breast cancer survivor. She was sitting in his office, and he looks at her, and he says, “Are you wearing a wig?” And the patient said, “Yes.” And then he said, “Why? Why are you wearing a wig? You’re two years out from your last chemo.” And the patient said, “I’m wearing the wig because my hair hasn’t come back yet.” And that was the first

instance where Sedlacek thought that something might be up. He obviously thought it was odd that the patient's hair had not come back yet after two years post chemo. To me, though, the really odd thing was that the patient never apparently complained about the lack of hair. She was wearing her wig and being very patient about her hair coming back. So, anyway, that was the beginning of Sedlacek's research into the link between Taxotere and permanent alopecia.

What is the 'mechanism' in Taxotere that causes long-term alopecia? I know that Taxotere is a taxane and that it's supposed to prevent cell mitosis, but aren't all chemo drugs supposed to do that? What's 'special' about Taxotere?

He couldn't really tell me what's 'special' about Taxotere. He only really knew the success rate of the drug. "It's a great drug!" he says. I asked him about Taxotere and how it affects things in our bodies that quickly re-generate. For instance, I reminded him that during chemo and afterward I had many, many mouth sores and almost a constant bloody nose-----because Taxotere affects mucous membranes that are supposed to quickly re-generate. Likewise, fingernails. So, I said, isn't hair the same? Hair re-generates quickly like fingernails and mucous membranes? He said no. Hair is different. He doesn't know how it's different, but it's different.

Why does a patient receive Taxotere, rather than the cheaper, just-as-effective Taxol, also a taxane?

He confirmed my suspicions and basically agreed that yes, Taxol is generally given every 7 days, and Taxotere is generally given every 21 days. He said that it's more convenient to prescribe Taxotere. So I said, with respect, "More convenient for whom?" And he said, "More convenient for the patient." Then he said, "How long did it take you to drive to our center today?" I said, "Ninety minutes." Then he said, "Would you rather make that drive once a week-----or once every three weeks?"

Is it true that many oncologists and chemo nurses prefer to give Taxotere because it requires administration only every twenty-one days (and therefore requires less traffic in the chemo lab), as opposed to Taxol that requires administration more frequently (often every seven days)?

Yes, he said. It's more convenient for everyone, he said----the patient, the doctor, the chemo nurses, the lab, the pharmacist, etc.

Do you have any plans for future studies involving chemo-induced permanent alopecia?

He said, "Yes, absolutely, I hope so!"

Is the 6.3% figure in your study still valid? Has it changed?

He said, "It's still 6 percent." Then he said, "It's between 3 and 6 percent."

When you attend breast cancer conferences, what is the climate among your colleagues with regard to Taxotere? Alopecia? Informing patients of the risk?

He said that, by and large, oncologists love Taxotere. "It's a great drug!" He said that when he started publishing studies about the link between Taxotere and alopecia, and when he started giving speeches and presentations at conferences, he had oncologists coming up to him at the conferences-----these oncologists looked baffled and then would say something like, "That was an interesting study you made. Come to think of it, I may have some patients like that. They had Taxotere and their hair still hasn't returned." Sedlacek said that it was interesting that oncologists never really put two and two together until he started publishing his ideas.

What percentage of oncologists, would you guess, inform their patients of the link between Taxotere and permanent hair loss?

He said he didn't know. He couldn't guess. But he thought that most oncologists don't warn their patients about the side effects of Taxotere.