Soft Tissue Sarcoma: Why Expert Care is Critical
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Introduction

Andrew Schorr:
Hello and thank you for joining us once again on our Ask the Experts program. I’m Andrew Schorr from Patient Power, and thanks to OHSU, Oregon Health and Science University, in helping us do these programs every two weeks for you. We always connect you with at least one leading OHSU expert and inspiring patients and family members who have been helped by great medical care at OHSU. Our goal is to help people around Oregon, Washington, and really world wide on these Internet broadcasts learn the latest in some of the most serious health conditions.

Now I’m a leukemia survivor. Leukemia is not common, but it affects many thousands of people, but there are other cancers; some that are very common like lung cancer, all too common, and others that are rare. We’re going to talk about a rare one today, and really there are many subtypes, and that will be an important part of our discussion tonight.

We’re going to talk about sarcoma. Now sarcoma can be cancer in the bone, but it can also be in the soft tissues, the muscles and the connective tissue of the body. It can appear almost at any age and all over the body, and it’s often not recognized. Now some can be not too serious and some can be very serious. So first of all how do you get an accurate diagnosis and know what you’re dealing with, and then how do you find a team? It really does, as you will hear, take a multidisciplinary team; not just a surgeon, not just an oncologist, not just a radiation oncologist; but ideally a team. They all put their heads together; pathologists, radiologist, and many support people; so that you get expert care as you fight this cancer hopefully to cure it or at least knock it back and have many years of high quality of life.

Patricia’s Story

Andrew Schorr:
Let’s meet, as we like to begin, someone who’s been affected by this, and it often comes out of nowhere. You never expect it, again, we’re talking about a rare cancer. I want you to meet Patricia Beck. So Patricia Beck is I think a relatively
young woman who lives in rural Oregon, and she lives in the small town, did I get it right Patricia, is it Alicel, is that right?

Patricia:
That’s right.

Andrew Schorr:
Alicel, not too far, about 20 miles north of La Grande, Oregon, farm country, and so not surprising Patricia, she’s been married oh 26 years or so, moved from the Portland area and married Rob, who you’re going to meet in a minute, and it’s a like a fifth-generation family farm, and so she’s out there in the rural area. So what happened back maybe even the spring of 2003? Patricia, you were feeling some soreness in the back of your left leg, right?

Patricia:
That’s right, yes. It started with what felt like a pulled muscle in the back of my left leg, and it just seemed like it was taking a very long time to heal, and along with that after the soreness came I noticed that my left foot would fall asleep when I was sitting on my knees. Never my right foot but always my left, and it seemed to be recurring quite often, and then also my left hip would start to hurt occasionally off and on, and all these things taking place in the left leg, and on top of that I was anemic and didn’t know it. I just was tired all the time.

So eventually I went to the doctor, talked to her about it, oh, and finally after all those symptoms hung around for a long time I could actually see a small lump on the back of my leg, and when I showed my local doctor she suggested I go see an orthopedic surgeon, and he took a look at it. He didn’t seem very concerned, but he did say after I told him all my symptoms, he said, ‘You could have an MRI if you like,’ but when he said “if you like” I thought well you know that sounds optional, so I wasn’t very...

Andrew Schorr:
We should make a point here. It’s pretty hardy people who are on America’s family farms, and you do a lot of physical work, and sometimes it’s miles to go to a doctor or to see a specialist, and you have a lot of work to do, so I know the impression is not to go unless you really have to.

Patricia:
True.

Andrew Schorr:
So you didn’t go right away, did you?
Patricia:
I did not. I waited several more weeks, but I think it was probably the anemia more than anything. I was just so tired and couldn’t seem to get my daily work done, that drove me to go ahead and do that, go get the MRI, and then once he looked at it...

Andrew Schorr:
What happened then?

Patricia:
Well, he looked at the pictures, and he just told us that he could do a biopsy, but he said eventually you’ll probably need to go either to Boise or Portland, and he said they’d probably want to do it over, so you might as well pick a place and go.

Andrew Schorr:
And you picked OHSU.

Patricia:
We did.

Andrew Schorr:
I know your family, Rob’s family, and we’ll meet Rob in a minute, had had good experience at OHSU, and you went there.

Patricia:
Yes.

Andrew Schorr:
Now, I want to check in with your husband, Rob. So Rob, here’s your wife, and she’s got this nagging problem, and then finally you go together to OHSU and she has a biopsy, and then you’re told you have the results, and the doctor who we’re going to meet in a minute sits you down and says, ‘It’s cancer.’ Got to be devastating not just for Patricia but for you as a spouse.

Rob:
Absolutely. You know even before that when we went to the orthopedic surgeon he was almost alarmed when he saw it, you know, and he basically said where do you want to go? We said OHSU, and keep in mind either of those places are between 200 and 300 miles away from us, but we weren’t going to mess with it, and so that was the first scare, and then the next one was after the biopsy, and Dr. Hayden did the biopsy. Going into it he said, ‘Oh if it’s something small and if we think it’s all right we’ll just remove it,’ and that’s fine, and in the end he took the biopsy and then said words that I didn’t understand like, ‘It looks like an aggressive tumor to me.’ And before he left I asked well what exactly did that mean? Well, you know, without saying the “cancer” word that’s what we were talking about. Of course we didn’t have the results yet, but he was good enough to kind of prepare me for that,
and then we had an appointment to go back on; that was a Monday, that was the surgery day; to come back on Wednesday, and he had the results, and it just went from there.

**Andrew Schorr:**
Patricia, you mentioned to me on the phone today the quote that Dr. Hayden, as I said we’re going to meet in a second, said to you when it was confirmed that it was cancer. Tell us about that he said, “We’re going to knock you…”

**Patricia:**
Yes, “We’re going to knock you pretty flat, but we’re going to get you through this.” And I heard “We’re going to get you through this,” I just believed him wholeheartedly and hung onto that real tight.

**Andrew Schorr:**
Let’s meet your doctor, and we’ll hear more of your story and your advice to other people from both the patient’s perspective and the family’s perspective from you too Rob along the way and we welcome people’s questions.

**Diagnosing Sarcoma**

**Andrew Schorr:**
Well this physician we’ve been talking about who is a specialist and part of the multidisciplinary team that helps people who are treated with sarcoma is Dr. James Hayden. He is an orthopedic oncologist. He’s an Assistant Professor of Orthopedics at the OHSU School of Medicine, and he has a primary interest in exactly this sort of situation. Dr. Hayden, welcome to our Ask the Experts Program.

Now these cancers are not common, and I understand just in soft-tissue sarcomas there can be like 40 or 50 different types, so I imagine it’s very important to get an accurate diagnosis and know what you’re dealing with.

**Dr. Hayden:**
Yes, it’s very important particularly since each one of the different tumors and their tumor grades often have their own specific type of therapy. So if the diagnosis isn’t accurate we can start off going down the wrong path and definitely end up at the wrong place at the end.

**Andrew Schorr:**
Now here we are where Patricia had this pain and later a lump. Now it could be many other things, and I’m sure that there are people who maybe have this situation and go on like she did for many months. Is that typical where you could have what turns out to be a high-risk cancer but you’ve been living with it for awhile?
**Dr. Hayden:**
It’s very common. I often see patients who have been six months or nine months since they started to have symptoms before they actually get to me, and every once in awhile I will even find a patient like I saw one just recently who had a mass present for four years and finally it got to be big enough and bothersome enough that they sought out therapy.

**Andrew Schorr:**
Now, they may have gone to the doctor, but I would imagine, even though you see a lot of it being a major center on the west coast, the primary care doctor in La Grande, Oregon, maybe Patricia is the only time she’s seen it.

**Dr. Hayden:**
That would be the normal statistics. The average orthopedic surgeon collects more than a general practitioner would, and we think that the average orthopedist will see maybe two or three sarcomas in their entire career. The average person who is a general practitioner really shouldn’t even see one in their career. It’s kind of unusual for them to see one or two. We’re talking about a tumor that may be present in someplace between six and then thousand cases in the United States each year.

**Andrew Schorr:**
Okay, so now we say there are forty or fifty types of the soft tissue sarcomas, so I understand it’s very variable whether this is not a big deal or a very big deal. How do you determine that?

**Dr. Hayden:**
Most of that is determined by the biopsy results and the imaging studies that help us determine where the tumor really is.

**Andrew Schorr:**
All right, now I want to, our focus of our program is how a multidisciplinary team comes into play. So you’re talking about first imaging and also pathology. So we have radiology, we have pathology. Does OHSU have specialists who really know what to look for to determine all these different types?

**Dr. Hayden:**
That’s correct. We have several well-trained bone radiologists that specialize in looking at the extremities and are in particular good at seeing tumors whether they are metastatic tumors or primary bone tumors or soft tissue sarcomas, and then the pathologists that we use also have had extra training to look at sarcomas and bone related tumors.

**Andrew Schorr:**
All right, now carrying on so now we get to the point, so there’s Patricia and Rob sitting in front of you, and you determine what kind of sarcoma this is. Now I
should mention, and Patricia maybe you want to tell us a little bit about it too, for
many people they have never heard this word “sarcoma.” You had heard it before
in your own family. Tell us about that.

Patricia:
Well, you know, it’s terribly frightening. I guess my first emotion was just to be
really scared and then sadness kicks in pretty quick, and a little anxiety and just a
whole lot of negative feelings, but I think I pretty quickly put my faith in the
doctors and my family to help me through it, and a lot of...

Andrew Schorr:
Right, but in your own personal family history you’d heard this word “sarcoma”
though. I thought maybe you’d relate that.

Patricia:
Right. Yes, my father had a I think it’s called a lymphatic sarcoma that was near his
stomach area, and he had his when he was 58 years old, which must have been
about 14 years ago, and chose not to take any treatments, and he was only with us
about eight more weeks, and I’m not sure how he decided not to take treatments,
but that was his decision. So yes, it was scary.

Andrew Schorr:
So there you are sitting with Dr. Hayden, you and Rob, and it’s determined I think
you had a different type of sarcoma if I’m not mistaken, but then what do you do
about it? It seemed to be a high-risk tumor, and you quoted Dr. Hayden earlier
about how he and the team needed to knock you flat to try to beat this cancer but
that they had faith that they could do a good job in that.

So Dr. Hayden, how do you determine what’s the right treatment for what you’re
looking at in a patient with the biology of their type of sarcoma?

Dr. Hayden:
Related to soft-tissue sarcomas in particular we look at several characteristics. We
want to determine basically if the patient is at high risk for the tumor to move
someplace else, to metastasize, or whether we think the tumor is primarily
something we have to treat the local area as its main course only. So the traits that
we look at for are whether the tumor is really deep and in the muscle, whether the
tumor is large, and large can be defined as something either five or eight
centimeters depending upon what center you’re working with, and then we look at
what’s called the histology of the tumor. Does the tumor appear to be very
aggressive when we look at it under a microscope? Does it have a lot of really
atypical-looking cells in it? Then we combine all that information, and things that
are then big, deep, and have a very aggressive appearance are considered high-risk
tumors. Those people then go down the course of having radiation therapy and
surgery and potentially having chemotherapy.
If the tumor is small and above the muscle layer and doesn’t have high-risk characteristics when we look at it under the microscope then they might just get surgery or surgery and radiation to it.

So those would be the two extremes, and then depending upon how things fall in the middle we sometimes mix and match the therapies to meet the particular patient’s needs.

Andrew Schorr:
Well you and Dr. Hung, a radiation oncologist, and Dr. Ryan, a hematologist oncologist from OHSU, two other key members of the team had authored a paper that was presented at the big national and international cancer conference in May. We’re going to talk about that related to when to have chemotherapy, when to have radiation, when to have surgery, and how it all can happen and in what sequence when we continue our discussion, our Ask the Experts discussion, on soft-tissue sarcoma. We will be right back.

Welcome back to our Ask the Experts program. Andrew Schorr here broadcasting live. Thank you so much for joining us. I know if you’re listening live you’re forgoing the final presidential debate. I’ve got my TiVo® going, but thank you. I know that if you think about your health or your family is affected by sarcoma, this is where you want to be. If you have friends or family who can’t make it tonight, we’ll have a replay posted tomorrow and then we’ll be adding the transcript so that you can use this as an ongoing resource.

We have with us Dr. James Hayden who is an orthopedic oncologist and a specialist in sarcoma at Oregon Health and Science University, he’s an Assistant Professor there at the medical school, and then Patricia Beck who is now a five-year survivor of high-grade sarcoma that developed in her left leg, and then with us also is Rob Beck, her husband of 26 years, and they have two grown children in college now, and we’re going to hear more about how this affects family life when you go through really months of care.

**Treatment Strategies**

Andrew Schorr:
I want to get back to a study that was presented at the big ASCO, American Society of Clinical Oncology, meeting in Florida just a few months ago back in May, and that was with Dr. Ryan who is a prime hematologist oncologist at OHSU, and Dr. Hayden, and Dr. Hung, and it talks about chemotherapy first. So obviously you want to cut out the cancer, and surgery has always been a key part of cancer treatment, but you’ve got these other modalities too. So was this studied to show could chemotherapy first shrink the tumor and give people a better chance of the surgery and the cancer care being successful doctor? And then what was the result of the study?
Dr. Hayden:
Let’s start with the idea of shrinking the tumor. That’s really pretty difficult, and what we find is that for most of the cases the tumor actually doesn’t change size. Now we may kill more of the cells that make up the tumor, and the inside of the tumor may be dead, but rarely do we actually see the tumor get small. Now Patricia was one of the real lucky ones, and her tumor really did get significantly smaller with her preoperative therapy.

The primary reason we give the chemotherapy is for the rest of the body. The surgery and the radiation can do a great job controlling the local tumor, but the chemotherapy is for those small bits of tumor that may have escaped and may be hiding someplace else that we can’t see, and that’s really the goal is to get after that with the chemotherapy. That’s why we give it systemically so that it goes everywhere basically.

So our study did use chemotherapy up front. It also used radiation up front, and by “up front” I just mean before the surgical resection. Then we did our surgical resection and then we give more chemotherapy after the surgery. Again, that idea is even after the tumor is gone there may still be some small pieces that we’re not detecting someplace else, particularly the lung is the most common site for these types of tumors, and so we want to make sure we get after those while they’re really, really small and not become a problem.

Another end-point that we were very interested in is what are the complications that people have and how difficult is doing this process for people. So our study showed that we were able to improve our outcome for local control, and at this point we are still preliminary to say that we did a better job with the metastatic control. We need to continue to follow our patients, but our abstract showed that we were right on course as to where we would expect to be with the metastatic rate.

Andrew Schorr:
All right. Now let’s talk a little bit about Patricia’s care and when it happened. So Patricia, we mentioned you and Rob have a farm, and you grow all sorts of things including sunflowers and evening primrose, and then you have cattle too. So your treatment I believe started in the winter, right? Was it around November?

Patricia:
Yes.

Andrew Schorr:
And it went all the winter and into the spring. Well there’s no good time to have a diagnosis of cancer, but when you have a farm and normally you’re doing a lot of work there, and you had to go, what was it, 300 miles I think you said Rob to Portland that you were camped out in Portland at a time when the crops were not sprouting out of the ground. So there you were in Portland, and I understand all together, you were out some of the time, you were in the hospital about 40 days?
**Patricia:**
I think that’s about right. Four days at a time for each chemotherapy session from November to April.

**Rob:**
Five days.

**Patricia:**
Yes, well five days.

**Rob:**
It was five days, a full week.

**Patricia:**
I had to stay over one night and come back and get a shot before I could go home that would increase my white cell count again.

**Andrew Schorr:**
So you were in this study that we were just talking about, so you were having chemo first and you had some radiation as well, right?

**Patricia:**
Right.

**Andrew Schorr:**
And surgery. Now so you went through all this through the winter and into the spring, and then you get home and you start to recover, and then you had a recurrence, and that was about two years later?

**Patricia:**
Yes, right.

**Andrew Schorr:**
And how did that show up?

**Patricia:**
On the MRI I believe is where we saw it.

**Andrew Schorr:**
So let’s ask Dr. Hayden about that. I understand that when Patricia was being followed closely and comes back, and then there’s something that shows up on the MRI at the same spot where she had the original tumor. Tell us about that. How often does that happen that there is a recurrence and at the same place?
Dr. Hayden:
Fortunately it’s not that often. What we see is if we do follow every patient and we would expect the sarcoma patients who have just the surgical resection to have a recurrence rate someplace between 10 and 20 percent. If we give them radiation therapy in addition to their surgery, then we find our recurrence rate is closer in the neighborhood of just five to ten percent. It’s still high enough, and the risk of having a sarcoma is pretty significant, so we still monitor patients very closely for the first five years.

Our monitoring protocol usually does involve a routine MRI scan, and we do those as frequently as every three to four months for the first two years and then continue on for years three through five at someplace between every six and eight months. We also continue to monitor the areas where we think the tumors are most likely to move, and for most sarcomas that’s the lungs, and so that’s why we do chest CT scans or chest x-rays on the same time schedule.

Andrew Schorr:
Now Patricia, so the treatment you had for the local recurrence I understand was actually radiation, almost implanted radiation, where you had these little catheters, and they dropped these seeds in there, and that’s the treatment you had, not other surgery but this sort of very targeted radiation. Am I right?

Patricia:
That’s right.

The Multidisciplinary Approach

Andrew Schorr:
Okay, and I know that’s done for breast cancer now and some other cancers. So what I get a sense of Dr. Hayden is it’s very important; we’ve talked about radiation oncology just now for recurrence but also as far as the original treatment, we talked about chemotherapy and often a combination of drugs and different drugs depending upon which type of sarcoma it may be, and surgery on your part. I guess it’s very helpful at OHSU at a center such as yours that these specialties come together, and you’re actually in a room together, and you can talk about it rather than being scattered around different medical offices or facilities.

Dr. Hayden:
Yes, it’s very helpful. We actually have a conference that we do right before we have our clinic, and in that conference we have a chance to review all of the new patients; we have a chance to review any scans that appear to be troubling on patients or that are questionable that maybe somebody has a new spot in their lungs or a new spot in their original tumor area, and it gives us a chance to all see the pictures at the same time and to discuss what we think is the appropriate care for those. Then we, all three of us; the radiation oncologist, myself, and my medical
oncologist Dr. Ryan; all go to clinic together, and when a patient comes in they basically stay in one room and it’s us that kind of rotate around and see who we need to see.

Andrew Schorr:
Now Patricia, how did you feel about that, that you had this team?

Patricia:
Oh wonderful. I had all the confidence in the world in all three of my doctors, and if feel blessed that we decided to go there, and they turned out so well.

Andrew Schorr:
How about you Rob, because she was tired through a lot of this, and anxiety is a layer over both of you, but there’s your wife and now you have these pretty eminent physicians working together on her behalf and making recommendations together. How was that for you?

Rob:
I’m a numbers guy and one of those typical “fix it” type guys just like Dr. Hayden and Dr. Ryan. It was obvious, you know I keep a notebook and records on everything that we did and everything that the doctor said and the medications she was on and all of that, I had a lot of time, and it was so obvious to me that all of those guys talked, and they knew what was going on. I mean the one doctor would come in and say, ‘Well yes, Dr. Hayden says this, and we’re kind of thinking that,’ and you know, vice versa. It was just so obvious that there was great continuity. We knew what was going on. They knew what was going on. Even right down to the technicians. You know when we’d go in for a treatment or whatever was going on it was obvious that they knew what was going on too, so this great continuity made us feel pretty comfortable, very much so in fact.

Andrew Schorr:
I’m so delighted.

Dr. Hayden, we got a question in from Levi in Oregon, and he asks, ‘Is this multidisciplinary treatment planning only available for higher-risk sarcomas or at OHSU do you apply it to other cancers as well?’

Dr. Hayden:
Well for me I’m not as involved in the other cancer care as far as a large team member, but yes it is applied to other teams. We apply the same multidisciplinary clinic approach to prostate cancer, and the breast cancer people are working on it as well, and it’s becoming a much more common approach to us. It’s particularly advantageous to us because we have all of the specialists kind of under the same roof, so to speak, and what we really just need to do is pry them away from seeing patients and get them together for a period of time so that they can sit down and talk about the individual cases and make sure that everybody’s in agreement and then let him go back to taking care of their patients.
Andrew Schorr:
We have more e-mail questions for you, and we invite questions from folks who are listening. We have questions that have come in from Beth, and we have questions from April in Seattle and Kyle in Walla Walla, Washington, so we’ll be getting to those in just a minute. You’re listening to our “Ask the Experts” program produced by Patient Power and sponsored by Oregon Health and Science University. We will be right back.

And we’re back live on our webcast. Thanks to some of our friends in the sarcoma community; Melissa Hill with the Northwest Sarcoma Foundation, so dedicated, thank you for helping get the word out, and also the folks at the Sarcoma Alliance; and hopefully this program is very helpful to families connected with this. Remember, we put all our replays on the ohsuhealth.com website /experts, so ohsuhealth.com/experts. We’ll have the replay of this one there, and then also two weeks from tonight we’ll be doing a program in a different area, but you may know someone affected. That will have Dr. Craig Broberg, and we’re going to be discussing congenital heart disease. That’s two weeks from tonight.

Questions from Listeners

Andrew Schorr:
Let’s go back to our discussion though of soft tissue sarcoma. Now we were talking about recurrence, and it happened to Patricia, and we got a question in about that from Kyle in Walla Walla, Washington, Dr. Hayden, and he writes in, ‘How do you assess whether high-grade tumors are likely to move somewhere else in the body? Is there any way to predict that?’

Dr. Hayden:
Well right now we don’t have a perfect system for that. We do look at the characteristics that help us define a high-risk tumor, and those are how aggressive the cell looks under the microscope, how large the tumor is, where it’s located whether it’s in the deep tissue or whether it’s superficial, but those are all really secondary measures. We don’t have a way to look at a specific tumor yet and say this tumor is going to metastasize, and this one is never going to metastasize. There is a lot of research into that to try to identify those factors, but as of yet we haven’t been able to really define those clearly enough to use that as a clinical decision tool.

Andrew Schorr:
Now we were talking about just monitoring and follow-up, and you talked about it more frequently and then less frequently. Patricia, how often do you make the trip to see Dr. Hayden these days?

Patricia:
Right now we’re on an eight-month schedule.
Andrew Schorr:  
I like that. I remember just with my own doctor when things had been looking good, and he said, ‘You want to come back in 4 months?’ and then I’ll say, ‘How about five?’ and then later he’ll say ‘How about five?’ and I’ll say, ‘How about six?’ Now I’m on a six-month schedule. That sounds good to me. Eight months sounds really good.

Patricia:  
Yes.

Andrew Schorr:  
So that was a question we got from Beth who’s in Oregon. Dr. Hayden, tell us about that follow-up schedule. When do you get to the point where it can be even less frequent, and is there a point where you can feel you’re kind of out of the woods with some of these high-risk sarcomas?

Dr. Hayden:  
Most of the sarcomas, if they’re going to recur and if they’re going to show up as a metastasis, do so usually before two years. Then it kind of rapidly tails off with fewer and fewer patients developing problems. By the time patients are five years out we feel that we’ve caught probably 90 or 95 percent of those patients who are going to have a recurrence or a metastasis. There are still some patients who show up with problems after five years, and that’s why we like to keep in touch with them at least once a year until we get to ten, but by the time we get to ten then it’s pretty rare that anybody shows up with a problem.

Andrew Schorr:  
Now we’ve been talking about high-risk soft-tissue sarcomas, but you mentioned at the outset that somebody might have a sarcoma for even years. Can it be more benign, if you will, or less aggressive and then change?

Dr. Hayden:  
Yes, tumors do have a tendency to evolve, and we see that demonstrated in some of the tests we do on the tumors. We often try to look at the chromosomes that are in the cells of the tumors. That helps us make some of the diagnosis. But when we do look at some of these chromosomes we often find that we might have ten or fifteen cells that we look at and might find four or five of them or more that have very different mutations in them. So that tells us that something has happened along the course of the tumor as it grows, and it has changed in some way.

So yes it is certainly possible for people to have a little bump that’s maybe growing relatively slowly and then something changes in it and it starts to suddenly grow quicker.

Andrew Schorr:  
Now let’s talk about those little bumps because I know I went, I think I was in my 20s, and I thought I had a little bump on the inside of my arm, and I went to the
primary care doctor and he kind of felt it, and he said, ‘No I think it’s just some fat deposit or something like that.’ He wasn’t worried. I had never heard the word sarcoma then, so I wouldn’t have even known to think of anything else. My question is, do you have some people who are referred to you at OHSU and while in the case of Patricia you did the biopsy and the exams, and it was an aggressive cancer where other people come and they were worried about that, and then you do the exam and it’s not cancer at all?

**Dr. Hayden:**
Yes that does happen. A lot of times we find masses that can be kind of disturbing on the imaging studies, and they certainly define that you have a five or six-centimeter mass in your thigh for instance and can be very troubling to patients, and by the time we finish all of the workup and get the biopsy, we can find that nope this really was just something simple and benign, and we can just take it out and you can go about your business.

**Andrew Schorr:**
Those are happy conversations.

**Dr. Hayden:**
Well interestingly sometimes they’re the more difficult ones to have because most of the time patients get to me and they are somewhat programmed that they have a cancer. Even though it’s something that people want to hear, ‘No you don’t have cancer,’ they’re sometimes in a little bit of disbelief because they’ve been so programmed that they need to go through all of these steps and go see the expert, so sometimes it actually takes a little convincing.

**Andrew Schorr:**
Let’s talk about going to see the expert, and I want to talk to Rob about it. So Rob, there you are, you’ve got a farm. You and Patricia and you’ve got kids back there who were in high school at the time. Every reason to be there and not making a drive of 300 miles. But are you glad you made the trip because it would seem to me that with a rare cancer you want to draw on people who are really familiar with it.

**Rob:**
Yes, we would never make the decision any other way. We used to go to Portland to vacation and visit friends and that kind of thing, and you can’t get us to drive to Portland. We vacation the other direction now because we really don’t want to go there, but for that we definitely do. It was a great decision. It was very good.

As far as the farm, it was the best time it could have happened. October, late October is when it was diagnosed, so we had the winter to take care of that. Our kids were old enough, they’re responsible, they’re farm kids. They pretty much lived alone even though my parents are right down the road, but they were as much of the support team as anybody, so no it wasn’t a horrible experience; I wouldn’t recommend it to anybody, but we’ve survived it so far.
**Benefits of Seeing an Expert**

**Andrew Schorr:**
I want to make a point. You kind of touched on it. You know a lot of us get on planes and trains and automobiles and we go somewhere distant for vacation, and maybe if the price of gas comes down a little more we’ll do that more often, but at any rate sometimes though we’re diagnosed with something really serious where that’s a concern, and we think well let’s go where it’s convenient around the block, and I would urge you at least for a second opinion if not for treatment too, go to where the experts are.

I want to ask a question of Dr. Hayden. Dr. Hayden, there’s kind of a line in cancer care that your first shot is your best shot. Has it been your experience, or I know you work with Dr. Adler as well who’s come from elsewhere in the country, he’s a surgeon who works with you now, where sometimes you wish people had gotten to you first and it’s a little more complicated when they have not?

**Dr. Hayden:**
It certainly is. Sometimes things can happen with the original biopsy where it can actually make the surgical resection more difficult to do or it can make it so the surgical resection really is not even a viable options anymore, and that sometimes happens because part of the field that we really need to protect, some important structure like a nerve or an artery has been contaminated during the biopsy process, so it really is kind of important to try to have the same person who is going to do your surgical resection try to do your biopsy as well.

When I plan biopsies I really so much don’t plan the biopsy, I’m planning the surgical resection in some ways, and I want that biopsy to be done with the thought of how am I going to take this tumor out because I’m going to have to take out everything I touch doing the biopsy when I do my surgical resection. So that’s why it needs to be done kind of by the same person.

Now I’ve been very fortunate in the Oregon and Northwest area in that most of the physicians are like Patricia’s physician who said, ‘Ah, this is not something I really take care of. You’re going to need to have a biopsy, and if we do it here they’re just going to repeat it or they’re going to want to do it themselves, so I’m just going to send you before I do anything.’ So I see very few patients who have actually had a biopsy before they get to me. Most of them who have brand new tumors come with just imaging studies, which is very good. Then we can ensure that any procedure that’s done for them is done with the thought of how do we take the tumor out, how can we make it so they have the least amount of complications as possible.
Andrew Schorr:
Now I have a question about speed. Now I know there are all different types of sarcomas, but how important is it to try to look at what you’re dealing with earlier and then sometimes do you need to initiate treatment right away because I know in Patricia’s case it happened pretty fast.

Dr. Hayden:
We try to move things along as quickly as we can, but realistically if we take a week or two weeks to try to figure out exactly what the tumor is, I try to get my patients to understand that that is really time that is very well invested. It’s much better for us to make a good decision whether this tumor is low-grade or high-grade, whether it needs to have real aggressive therapy or not aggressive therapy than it is to rush right in and start something and go down the wrong path.

So we do try to work them up as quickly as we hear about them. We try to get all their studies that they need done and including their biopsy done relatively soon, and then we try to get them started on whatever therapy as quickly as we can, but if there’s any kind of a little hitch or a question or if something doesn’t seem to all pan out and match, like if for instance what looks like on the imaging study to be a high-grade tumor looks on the biopsy specimen to be a low grade tumor, then we often take a step back and reanalyze the data, and that can take a little bit of time, but it’s time that’s very well invested.

Andrew Schorr:
Yes, you want to get it right. I have one other question I want to ask you before we take another brief break and that is so you talked about you want to cut out the cancer, but that may leave a space. So where does reconstruction come into play? Is that something that you focus on too as you complete the surgery?

Dr. Hayden:
Yes it is, and in many ways the reconstruction is as important or more important for the overall goodness of the patient than just taking the tumor out itself. Taking the tumor out follows some basic rules. You need to get all the way around the tumor. You want to have a layer of normal tissue all the way around it to ensure that you’ve removed all of the tumor and not left anything behind. So those are kind of straightforward simple rules, and we can teach a lot of surgeons how to do that.

What is a little harder to do is to figure out how do we reconstruct this limb so that it functions well? What things can we take away and still have good functions? What things can we put back and what things can we move around to fill any defects? So sometimes I have to move a muscle from place or another to fill a space. Sometimes we have to move something, rearrange maybe where a tendon attaches so we can get some function out of say an ankle or a knee, and we use a lot of those techniques, and those are actually some of the more complex portions of the case. Many times it takes me twice as long to actually do the reconstruction and get things all closed up as it does to take the tumor out.
Andrew Schorr:
I hear the professor talking there. It sounds like I’m in med school, and I’d love to have you as my professor if I were a doctor, and as a patient I know we’ll hear more from Rob and Patricia, it’s great that you’re dedicated to people going on and having an active, full life.

We’re going to hear more from Patricia Beck and Rob Beck about that life going forward, and we welcome your questions. We will be right back with more of our Ask the Experts program discussing sarcoma.

Andrew Schorr here with our Ask the Experts program in our final segment, and I want to look forward and see where we are now with Dr. Hayden first. Dr. Hayden, so how hopeful are you that we’re doing better and can do better in the treatment of these soft-tissue sarcomas, and what are the obstacles along the way?

Dr. Hayden:
I’m very hopeful about how we’re doing with soft-tissue sarcomas. I think we used to just do surgery on them, and in the last ten years or so we’ve had very good data presented that shows that radiation therapy makes a significant improvement in our overall therapy, and we’re now starting to work in the chemotherapy realm, and the biggest hope is that we can find targeted therapies for specific sarcomas that makes the chemotherapy less toxic and more effective similar to the same thing we’ve been able to do recently with Dr. Drucker’s work with some of the leukemia-type drugs. If we can find things that allow us to target specific mutations and then move ahead with those, I think that is a very promising area for us.

The second area that’s really promising for us is figuring out which types of tumors actually are going to metastasize. As I mentioned earlier if we can target that and figure out which ones are then we know that those are the patients that we need to give the more aggressive therapy to, and if the patient has a tumor that really doesn’t have that metastatic potential, then we can focus more on localized therapy and maybe not have to give them such aggressive therapy.

The biggest hurdle for us in sarcoma is really in some ways a good thing, and that is that very few people get sarcomas. That makes it difficult for us to do research. It makes it difficult for us to have enough patients in clinical trials. It also makes it difficult to have enough support financially to do research. If you were wanting to develop a drug you would want to have thousands of patients that might need it, but if you’re developing a specific drug for sarcomas you might only have two or three thousand patients that might benefit from it. So as far as from a company perspective it’s not a very good marketing decision. So that type of thing makes it difficult for us to really make great advancements, but I think in some ways the world is starting to realize that understanding what happens with the biology of sarcomas is nature’s own unique laboratory, and it can help us understand how other things that affect musculoskeletal tissue diseases can be changed or improved. Things as simple as understanding what happens in a sarcoma may help
us understand how basic wounds heal or some of the tumors that grow in bone, understanding their biology may help us better to understand diseases like osteoporosis.

So as we start to learn that there’s an interesting relationship between sarcomas and other diseases then I think it will become more likely that we’ll have people who are interested in working on sarcomas so that they can indirectly affect the larger diseases.

Andrew Schorr:
Dr. Hayden, I know all of us listening and certainly Patricia and Rob, I want to thank you and the physicians and nurses and the rest of the team who at OHSU and people around the world in your specialties are so dedicated to this, and we wish you all the best in helping families affected by this.

I want to hear from Rob. Rob I know when someone goes through really like six months of treatment and then you have the worry of a recurrence or could something happen or even beforehand, what are you dealing with, the family members are patients too, so you’ve had to be both a supporter of Patricia and then kind of steel yourself for this whole thing too. You’re a parent and you have a farm and you’ve been married 26 years, so it’s a family affair isn’t it?

Rob:
Absolutely. Absolutely. You know and I think the fear, when I think back on that, “Tish” and I of course talked to you today when we were knowing that we were going to do this tonight, the fear was just initially, and then you get in the hands of very capable people that have a plan and know a lot more than you do and were confident in that plan, then it was more that you’ve got a task rather than a fear, and so of course those people like your wife had to be strong for you, and I had to be strong for Tish so you put that away, you put your fears away, and keep those in the back of your mind, and then you work for them.

Then of course we have kids at home and the rest of our family that you have to be strong for, and I think that just comes in that parent-type mode where you are just a support. So that was my job. My job was to make sure that all those other things happened that she didn’t have to worry about and support her. So we’re fortunate in the way that we met people who were under Dr. Hayden’s care as well that were working while they were going through treatments, and the same treatments that she went through. You know they were trying to hold down a job, and their spouse worked and couldn’t be there. A lot of people were there on their own, and then I was there all the time with Tish. I never left her side other than I’d leave at 10:00 at night from the hospital, and I’d be back there at 6:30/7:00 the next morning, and we were very fortunate that we could do that. You have to play all those roles, and we just stuck our head down into the wind, and that’s what was going to happen, we knew what the outcome was going to be, and certainly was a blow two
years later when she was going to get her six month, you know we were going to get to six months back instead of three months back to be checked, and we had to start over again.

So again, you just put your head down. There’s only one outcome.

Andrew Schorr:
Right, right. So I call you Patricia. Your husband and close friends call you “Tish” So I’ll call you Tish now, but Tish, so how do you go on every day now and how does your family help you face the day in a positive way? I know you have a dream of dancing at your kid’s wedding, holding grandkids. You know you have a good shot at that hope.

Patricia:
Oh yes, I believe I do, and like Rob was just saying, the support of family and friends was just huge, and I leaned heavily on prayer and called my sister quite often, and sometimes we’d have a good cry and just get on with the day, but that’s just part of it for everybody facing any kind of cancer. You’re going to have days where nothing seems right or good and you just need to have a good cry and then just get on with it and focus on the positive.

You know I had so much family and friends support that it was just wonderful. So you’ve got to find positive things, and even when the day is bleak there are good things to focus on. So that’s the key.

Andrew Schorr:
I want to mention again those organizations, The Sarcoma Alliance, Northwest Sarcoma Foundation. These are not common cancers, but there are people on the Internet and some meet in groups occasionally, and your centers such as OHSU can connect you with other people so you’re not alone, and then you can get information and also help you family and friends understand what you’re dealing with.

So Patricia, you’d heard this word with your dad and then it came up for you, sarcoma, and now we’re five years out. There may be somebody listening who’s newly diagnosed. What would you say to them?

Patricia:
Well I think the first thing is don’t be afraid to lean on the people that love you. They want to help, and they’re there for you, and take advantage of that. I think for awhile it was hard for me just because I was used to being a helper, not looking for help, and it was quite an adjustment to just let people help and not feel like if somebody brings me a basket of food or something not to feel like I should reciprocate and jump up and bake some bread or something, but let them help, and turn to people when you’re feeling blue and have a good cry if you need to and let people help.
I kept a journal, which I think was very helpful for me, and I had some good books that were very helpful that friends gave me during my chemo.

Andrew Schorr:
Patricia, do you think you made the right choice as far as medical care?

Patricia:
Oh yes. I’m certain of it.

Andrew Schorr:
And Rob, it sounds like you do to.

Rob:
Oh absolutely. No question. We’ve talked to other people who have gone other places, and you know of course everybody when the outcome is good feel that they’ve made the right decision, but we’ve recommended, you know if anybody says anything about cancer at all we just say here’s our experience, and this was a great place to be.

Andrew Schorr:
Well I want to wish you all the best. Will you send me pictures Patricia when whether it’s your 19-year-old daughter or your 21-year-old son when they get to the point, not too soon, when they’re getting married or they’re graduating from college I want you to send me pictures, and we’re going to put them on one of the websites here and celebrate that. I wish you all the best, and we’re headed into winter again. Maybe you can relax a little on the farm, but the sun will shine again when the crops come up Rob, and hopefully you all will have many years together. I wish that for you.

Patricia:
Thank you.

Rob:
Great, thanks.

Andrew Schorr:
I want to thank you both for being with us. This is what we do on Patient Power. And Dr. Hayden, I’ve got to say a big thank you to you too, and as I said earlier, all the best, and I know it must be very gratifying to hear Rob and Patricia’s comments and real validation for your team’s dedication to helping people like them.

Dr. Hayden:
It certainly is.

Andrew Schorr:
Yes, thank you. These programs can be inspiring for all concerned. Well as I said, we’re going to be back in two weeks, and we’re going to be doing a program in a
whole different area, congenital heart disease with Dr. Craig Broberg. So that’s in two weeks, and then the replay of tonight’s program and all the programs we do with support from OHSU are on the website ohsuhealth.com. So I’ve got it right Blake. Ohsuhealth.com/experts. That’s where you look, and all the replays are there, and then we add transcripts.

Thanks for joining us. I’m Andrew Schorr. Remember knowledge can be the best medicine of all. Good night.

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