

## Advances in the Treatment of Soft Tissue Sarcomas

Webcast

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Robert Benjamin, M.D.

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### **Introduction**

#### **Andrew Schorr:**

Hello and thank you for joining us once again. I'm Andrew Schorr in today kind of cloudy rainy, cold Seattle. Hopefully it's nice where you are, and we'll connect with our friends in Houston. Usually it's nice there this time of year. Hopefully things are in bloom as we begin the spring here and think about life and think about if, oh, my god, if you were diagnosed with cancer are there treatments that can help you go on with your life, fight the cancer, beat it and be with the people you care about.

Now, so often we talk about common cancers, lung cancer, colon cancer, breast cancer and prostate cancer, but there are a lot of uncommon cancers too. There's a whole class of uncommon cancers called sarcomas, and they can happen in the bone and they can happen in soft tissue just anywhere in the body as well. And the medical center that has more experience in treating sarcoma than anywhere else certainly in the US is M. D. Anderson. And imagine how scary that can be if you are diagnosed with a sarcoma.

Well, Jennifer Burns, who is 56 years old and lives just a few miles from M. D. Anderson, she lives in the Memorial Park area of Houston, she found a lump in her abdomen. She was visiting her aunt at one of the hospitals. Her aunt was being treated for a very serious cancer, they're all serious, right? She was being treated for pancreatic cancer. And she felt a little knot in her abdomen about the size of a walnut. This was back in September of 2004. And so when she went back to visit her aunt in the hospital the surgeon was there, and she said, Would you mind just feeling this and see if I need some follow up. And he did feel it, and he said, Yeah, you should come by my office and I think we should biopsy it and take a look further. Well, they did, and it turned out to be a diagnosis of a type of sarcoma.

And, Jennifer, thank you for joining us. Had you ever heard of sarcoma that day when they told you that you were afflicted with this?

#### **Jennifer:**

Actually, no, I was not familiar at all with that word.

**Andrew Schorr:**

Yeah, I think most people wouldn't be. So they said given that this is a more rare kind of cancer, very wisely they said, Well, down the road is M. D. Anderson, and I want you to see Dr. Robert Benjamin there who is a specialist, right?

**Jennifer:**

Correct.

**Andrew Schorr:**

That made all the difference.

**Jennifer:**

That made all the difference. That's why I am alive today.

**Jennifer's Story**

**Andrew Schorr:**

Well, we're going to meet your doctor, Dr. Robert Benjamin, who is professor and chair of sarcoma medical oncology in just a minute, but let's talk about what happened in 1994. So you had this kind of lump in your abdomen. What did it feel like? Did it cause you pain, or was it just something you knew shouldn't be there?

**Jennifer:**

Actually, I wasn't sure if it should be there or not because we have so many organs and things, and I just felt a hard lump. But, as you said, I was in the hospital and visiting someone sick, and that's very scary, and I just got scared. And so that night when I went home it was very late and my husband was asleep and my dog was asleep, and I lay down and I just started poking around. I didn't know what I was feeling, but I had had just a twinge, a sensation of fear, so I decided to ask Dr. Veracruz if he could look at it, and the rest, you know, is history.

**Andrew Schorr:**

Right. I'd known, I'd felt little things around my body, and as we get older we say, Well, gee, is this supposed to be there. And I think all of us are used to going to the doctor and you ask them if you have a little concern, they say, Well, it's probably nothing, and they check and it is nothing. This time it wasn't. When they told you it was a sarcoma did you just fall off your chair? I mean it must be terrifying.

**Jennifer:**

No, actually, for some reason I didn't. I was very calm, and I said, well, what next. And then I met Dr. Red Duke in his office, and he said, Why don't you come by and talk to us about, you know, options. And Dr. Red Duke kind of stormed in. He's bigger than life, and he said, I want to send you to Dr. Robert Benjamin. That's the

first time I heard Dr. Benjamin's name. And he did. He called over there, whatever doctors do and sent me over there and, anyway, I won't get ahead of myself.

**Andrew Schorr:**

The point is that you then began treatment with one drug, Adriamycin, certainly women who have had it for breast cancer maybe not so fondly call it the red devil. It's a difficult drug. You lose your hair, and you lost your hair. Now, I understand you never put on a wig.

**Jennifer:**

Never. Never.

**Andrew Schorr:**

Well, I'm bald. Bald is beautiful.

**Jennifer:**

Absolutely.

**Andrew Schorr:**

So you do that and then later you were switched to another therapy, Taxotere, and ultimately about a year after diagnosis, maybe not quite that long, nine months, you had surgery in June of 2005. And by then how big was the tumor?

**Jennifer:**

Dr. Pollock, Dr. Benjamin's surgeon, told me that it was the size of a small grapefruit.

**Andrew Schorr:**

And is it started out about the size of a walnut.

**Jennifer:**

A walnut. That's what it felt like. And again, I'm sorry I didn't answer the question directly, no, I had no pain. Absolutely none. In the beginning, none. It never hurt. It just was there.

**Andrew Schorr:**

So then you go on and you have the surgery. Now, the surgery was in June of 2005. We're now in the spring of 2008. What's happened since then?

**Jennifer:**

Well, Dr. Benjamin just has me come every four months and he checks me and we talk. Because he's so busy I never get to see him unless I go in for my checkup. And he says, Okay. Okay, kid, bye. And he doesn't even really go into an explanation. We talk about other things.

**Andrew Schorr:**

There you go. But the point is Jennifer, you've been going on with your life.

**Jennifer:**

Totally. Completely.

**Andrew Schorr:**

So you've got a son, one of your kids, is a builder and so you're planning for the future, and I understand Christopher is building you a new house.

**Jennifer:**

That's correct. That's the good news.

**What is Sarcoma?**

**Andrew Schorr:**

I think that says a lot.

So let's meet this man who has played a key role in your life and probably the lives of many other people affected by sarcoma. And of course he's part of a team because M. D. Anderson has a sarcoma center, and there are very few teams of medical people in the world probably totally devoted to sarcoma, but that's what they have at M. D. Anderson. And M. D. Anderson actually sees more sarcoma than anywhere else certainly in the US.

Dr. Robert Benjamin, thank you for joining us as Jennifer's doctor and also as a specialist in the field where we can learn a lot tonight. Thank you for being with us, sir.

**Dr. Benjamin:**

You're very welcome.

**Andrew Schorr:**

Let's understand what sarcoma is. So, you know, it comes out of left field. It certainly did for Jennifer. I've interviewed other people, and in fact actually our producer, she has a relative where he's a younger man, felt this lump in his shoulder and he gets the diagnosis and told this word sarcoma and you have no idea. What is sarcoma? And when we talk about soft tissue sarcoma how common is it? And is there more than one type?

**Dr. Benjamin:**

Well, depending on which classification you decide to use, there are probably upwards of 50 different distinct types of sarcomas. And some people actually

recognize almost a hundred different sub categories. That said, all of those put together represent only one to two percent of all of the cancer in the United States.

**Andrew Schorr:**

So therefore...

**Dr. Benjamin:**

One percent with a hundred different kinds makes each one very rare. So all of our patients come to us and say, "Well, I've been told that this is very rare," and a lot of them have what I consider a very common sarcoma, and I say, "No, that's not rare." You know, from a sarcoma point of view it's really pretty ordinary.

**Diagnosing Sarcoma**

**Andrew Schorr:**

Well, let's back up. We mentioned Jennifer actually had like a needle biopsy. How is it usually diagnosed?

**Dr. Benjamin:**

Well it's diagnosed by a biopsy, and the question of what method of diagnosis is best, it's enough to get an expert pathologist enough tissue to tell what he's dealing with or at least enough tissue to tell you what needs to be done for the patient. So typically if you ask a pathologist, Would more tissue help you, their answer is always yes, but you have to weigh the advantage of getting a bigger chunk of the tumor versus the risks of interfering with the optimal therapy. So a lot of the time we will simply do what we call a core needle biopsy where we take a very small amount of tissue with a needle that would be considered large by most standards that gives the pathologist a little sliver of tumor, and usually that's enough for an expert pathologist to be able to say, "I can put a name on this," or "I can't put a name on this but giving me more probably won't make it that much more likely that I will be able to." So what the pathologist...

**Andrew Schorr:**

I think there's a key point in what you were saying, though, that I just want to point out to people, and that is there are kind of two parts of this. A core needle biopsy could be done all over. I mean it's done regularly in oncology, but the pathology part of, and you keep saying "expert pathologist" says I've seen that, I recognize it, I know what that is. That matters because your treatments for all these different types of sarcoma vary, right?

**Dr. Benjamin:**

Correct.

**Andrew Schorr:**

So you've got to know what you're dealing with.

**Dr. Benjamin:**

The more we learn, the more likely it is that we will treat different kinds of sarcoma in different fashion. And that's actually very important. When we first started out treating sarcomas the only drugs that worked were drugs which were so broadly active in the treatment of sarcomas that they might have worked on all of the sarcomas with some likelihood as well as any number of other kinds of cancer like breast cancer or lymphoma or leukemia. As we get more targeted in our therapies we may find that a certain drug will work only for one of these hundred sub types of sarcoma, and then it becomes critical to identify that one type.

**Gastrointestinal Stromal Tumor (GIST)**

**Andrew Schorr:**

Right. You always have to start with a right diagnosis, and so I clearly understand the importance of the right modality for diagnosis, the right people looking at that to see what are we dealing with, and then are there treatments for that. Well, let's just think of an example. We're going to take a break in a second, but, for instance, I met a man just a few years ago who was diagnosed with I think what you call GIST, or gastrointestinal stromal tumor.

**Dr. Benjamin:**

Correct.

**Andrew Schorr:**

Which I understand is a type of sarcoma. And he was near death.

**Dr. Benjamin:**

Okay.

**Andrew Schorr:**

And then they said, if I got it right, there's a new medicine and it's being used in leukemia, CML, but we think it may have application here, Gleevec, tried it, targeted therapy, and the GIST was a target and it responded and it was unbelievable. The guy had a tremendous turnaround. Is that an example of the type of targeted, personalized medicine we'd love to see for many different types of cancer?

**Dr. Benjamin:**

Absolutely. The story of GIST is actually probably the best story of targeted therapy that exists, because prior to Gleevec my job as an expert was to tell people who were referred in "Whatever you do with this patient don't treat with adriamycin and ifosfamide," which is the standard chemotherapy for soft tissue sarcomas, "because we know that it doesn't work in this subtype, and it's very toxic." So if the likelihood of success is reasonable, the toxicity is worthwhile, but if we've

already done the experiment and we know it's not going to work, why put the patient through all of the toxicity with no likelihood of gain?

And then all of a sudden we got this drug, Gleevec, and what used to be the hardest form of soft tissue sarcoma for us to treat became the easiest form of soft tissue sarcoma to treat because all we had to do is give these little pills and 85 percent of the time the patients would have extraordinary benefit. I just saw a gentleman today that we treated in 2001 who could have been the cousin of the person that you just talked about or the twin. He was on death's door, and I just saw him today and he continues to be free of all disease with a combination of Gleevec therapy and surgery.

**Andrew Schorr:**

That's a great story. We're going to take a break, Dr. Benjamin, and when we come back we're going to learn about our hope for targeted therapies for other types of sarcoma. And also the importance right out of the box if you get a diagnosis of going to see specialists like you and also where the team approach comes in, which you certainly have at M. D. Anderson. You're listening to Patient Power as we discuss advances in the treatment of soft tissue sarcomas. We'll be discussing sarcomas in the bone, osteosarcoma on May 6, but today it's soft tissue sarcomas. This is Patient Power brought to you by M.D. Anderson Cancer Center. We'll be right back.

**Andrew Schorr:**

Thanks for joining us this evening as we discuss advances in the treatment of soft tissue sarcomas with a leading expert from M.D. Anderson Cancer Center and his patient, Jennifer Burns with us from Houston who was diagnosed with this sarcoma in her abdomen. She'd never heard of it. So she was diagnosed in 2004. She had one type of chemo and then another type of chemo and then surgery in June of '05, and here she is now in 2008 building a house, or her son Christopher is building it for her, and she and her husband, Greg, are looking forward to hopefully a long, happy life.

We're visiting also with her doctor, Dr. Robert Benjamin, who is professor and chair of sarcoma medical oncology. And just before the break we were discussing how we're in the age of personalized medicine, understanding specific tumor types by their biology and trying to either develop medicines or maybe there's a medicine that worked for something else, like in the case of Gleevec, worked for a type of leukemia, could it also work on a type of sarcoma. It did. Does it work on all type sarcomas? No, it doesn't. Are they trying to develop other targeted therapies? Absolutely. And we'll discuss that.

Dr. Benjamin, let's get back and learn more about it. So these soft tissue sarcomas, can they be found anywhere? For Jennifer it was in her abdomen. Where might you find it, and what would it feel like?

**Dr. Benjamin:**

Correct. So the answer is you can find a sarcoma absolutely anywhere in the body, from the head to the toe. Typically soft tissue sarcomas arise in the soft tissue in the connective tissue between the skin and the internal organs, but sarcomas can also arise from organs.

Let me just backtrack one second, and I apologize if I'm getting you off, but I just wanted to continue on with the GIST story. At the very end of 2000 when GIST and Gleevec were tried and it was found to be this incredible home run in terms of finding a treatment for a previously refractory disease, we really didn't know more than that. I mean we knew what the target was. The target is a protein, a tyrosine kinase called KIT, and it's over expressed in patients with GIST. In a majority of patients there are mutations in the KIT gene, and so the kind of KIT that's expressed is actually different in different patients.

We now know that Gleevec works most effectively for patients whose KIT is mutated in a specific place called exon 11. And if it's mutated in another place, exon 9, the second most common area, Gleevec can work but it's not anywhere as effective as it was in the exon 11 mutations. In that particular subset of patients with exon 9 mutations, double the dose of Gleevec is much more effective than giving the standard dose. But in everyone else that doesn't help. And there are other tyrosine kinase inhibitors, such as Sutent, which are relatively more effective against patients with exon 9 mutations.

So now as you talk about personalized therapy, I mean the studies haven't really been done yet, but it's very possible that making a diagnosis of GIST the first and most important thing you want to know now is what's the mutational status because it directs the therapy from the very beginning. And there are some patients for whom a standard dose of Gleevec up front may not be the right therapy. So we really are getting into personalized therapy as we learn more and more. And there are a lot of other sarcomas with obvious mutations, but we haven't quite figured out how to target those mutations in the way that we can target KIT. But I'm absolutely convinced that in the next ten years or so we will have those targeted therapies so that we'll have a specific treatment for each of these mutation-associated sarcomas.

I just wanted to get that point out before I forgot to make it.

**The Importance of Seeking a Specialist**

**Andrew Schorr:**

Sure. No, we welcome that, sir. So as I listen to this it's kind of a Patient Power epiphany for me, and I've said this many times, and I'll repeat it here. And that is, and I'd love your perspective on it, sarcomas are rare, and there are many different

types, but when they get to you and they say, Well, I understand I have a rare type of cancer, you say, Well it's not rare for us, we see it.

So why is it so important for someone to go to somewhere such as M. D. Anderson where you're very experienced with sarcoma? Why can't they start out somewhere else? Who would be the downside?

**Dr. Benjamin:**

So it's not only unfortunate but actually probably the single most harmful thing that can be done in the management of a patient with a sarcoma is starting out the wrong way. It's always difficult to play catch-up, and most doctors, even expert oncologists, be they medical oncologists, surgical oncologists, are not experts in sarcomas because sarcomas are rare and most people frankly are just not interested in them. So in fact the most important thing in the management is to get to a center where there is a team that's interested in sarcomas, and that team includes both the diagnostic portion and the therapeutic portion.

We talked about getting the right diagnosis. Well, there are only a few pathologists in the country who see enough sarcomas to be able to have a good chance of making the proper diagnosis the first time. And so what often happens is the patient gets a biopsy somewhere, and then the slides are sent around to some expert reference pathologist but not at a place where the patient is ever going to be treated. And that's a waste. What you need to do is get the biopsy done at the center that's going to treat the patient. Or if not, rather than worrying about the precise diagnosis when they suspect sarcoma, say, "If this is a sarcoma I want to send this patient to M. D. Anderson or I want to send this patient to Memorial Sloan-Kettering or I want to send this patient to the University of Michigan, or I want to send this patient to Dana Farber." Those are all places with big sarcoma programs, or on the West Coast, UCLA. Get the patient there with the slides before anything else is done so that we don't do the wrong thing in the management. And so that step of making sure that the expert pathologist looks at the slides is critical, but you also need expert radiologists who know what they're looking at.

**Andrew Schorr:**

Right. The whole team.

**Dr. Benjamin:**

So for example, a patient whose case we reviewed today in our multidisciplinary clinic had the most common form of sarcoma in the area where Jennifer's was, which is a retroperitoneal liposarcoma, that's not what she had, but that's what this patient had, and a surgeon went in took out a portion of the tumor because he failed to recognize that all of the fat around the area that he was removing actually was a portion of the tumor. He thought it was just regular fat.

**Andrew Schorr:**

Oh, my.

**Dr. Benjamin:**

And it's probably because his radiologist didn't comment looking at the CT scan that this is obviously abnormal fat so it has to be considered part of the tumor. And in fact just looking at the x-ray you can make the diagnosis that this is some form of a liposarcoma, and then the exact details may require further biopsy of a portion of the tumor. The pathologist who got the slides said, Well, gee, I'm very glad to look at the x-ray because nothing that they gave me had any fat in it so while I thought that this was a liposarcoma I can't call it on what I see because I didn't have that x-ray, but now that I see the x-ray it's obviously a form of liposarcoma.

**Andrew Schorr:**

Well, this certainly tells the story. We're going to take a break, Dr. Benjamin. When we come back, I know Jennifer is itching to echo how glad she is that she went to M. D. Anderson, a center that specialized in sarcoma. So, Jennifer, we're going to be with you after the break in a second.

And the other part of it, too, is that I know that the treatments, I mean it's great if everybody could have, not have GIST but have a targeted therapy where you take just a few pills of Gleevec and it works, but I know for the treatment of many sarcomas these are heavy-duty, often complicated therapies. Jennifer certainly went through that but for a great result. So you need a team that's experienced at that, and, Dr. Benjamin, I know you'll help us understand how that is managed well at M. D. Anderson.

We're going to take a break and. We'll be right back, then we're going to get to your questions. Remember, you can send us an e-mail to [patientpower@mdanderson.org](mailto:patientpower@mdanderson.org). We'll be right back.

**Andrew Schorr:**

We're back on our live worldwide webcast. We do webcasts with M. D. Anderson every other Tuesday typically, and we're doing a live webcast tonight hour-long with Dr. Robert Benjamin from M. D. Anderson. He is chair of the sarcoma medical oncology area there, and, as we talked about, they have a sarcoma center. Well, one of his patients in a success story is Jennifer Burns, 56 years old, who had sarcoma in her abdomen, soft tissue sarcoma diagnosed in September of 2004, and now we're in the spring of 2008. She's building a house or her son is building it for her and her husband, and they're looking forward to a longer life. Has no treatment now.

Jennifer, couple points that I just wanted to go over with you. It sounds like your doctors at another hospital were really smart not to do anything, just say, We're going to get you to Dr. Benjamin to a sub specialist in the area where they see

sarcoma regularly. And then I want to talk to you about the complexity of treatment. But, first, what would you say to people about getting to a sarcoma specialist?

**Jennifer:**

I would say just get information, and the thing is if you don't know that you have it, you know that's tricky, but I was lucky enough to live in Houston where of course we have M. D. Anderson, and I was lucky enough to, like Dr. Benjamin said, have a pathologist that recognized it. I would say go to M. D. Anderson, go to Sloan-Kettering, like Dr. Benjamin said. Go to one of the best hospitals that you can possibly about to. Don't fool around with it. Don't fool around with cancer.

**Complicated Treatment**

**Andrew Schorr:**

Right. I definitely would agree with that. That's what I did with my leukemia. Actually came from Seattle to M. D. Anderson, Houston. I'd never been to Houston before, because there were specialists in my type of leukemia there. We're going talk as we go on about that doesn't mean just accessing what people believe is the current treatment but it also may mean being part of a clinical trial of giving you a shot of what could be tomorrow's medicine today. Imagine there were people with GIST, the gastrointestinal stromal tumor, there were early people who otherwise could have been near death who then said, Well, let's experimentally try Gleevec, and it worked. And imagine what a difference it made for them. Well, that could be a situation that you would encounter at M. D. Anderson with another type of sarcoma as part of a clinical trial. So we'll talk about that.

Jennifer, one other thing. You went through chemotherapy, first with adriamycin and then with Taxotere, and you were getting shots to boost probably your white cells and red cells and things like that. The treatment was somewhat complicated, wasn't it?

**Jennifer:**

Very. Very complicated. Extremely complicated.

**Andrew Schorr:**

And you didn't feel well.

**Jennifer:**

No. I was very, very sick with the first round of treatment. But then Dr. Benjamin switched me, and it was like day and night. It was much better.

**Andrew Schorr:**

So, Dr. Benjamin, I know it varies by sarcoma, but another reason, I would think, for going to deal with a team that specializes in the treatment of sarcoma is, A, get

the right diagnosis and people who are familiar with it and what would be likely to be effective for your cancer, and then, B, if it's a complicated therapy have it where they can manage that. My understanding from an earlier conversation with you is that the treatment can be complex and you need a team that's skilled in that.

**Dr. Benjamin:**

Oh, absolutely. The surgery is complicated, the radiation is complicated and the chemotherapy is complicated. And, as Jennifer said, the initial chemotherapy, the chemotherapy we use most frequently for the majority of patients with sarcomas, is a combination of adriamycin and ifosfamide. And what we've learned about that combination is that the higher the doses you can give the more likely the treatment is to be effective, but that also means the more likely it is to cause serious side effects, and so you need to get doctors who do this all the time, who are familiar with the management of those side effects, not to say that we're going to make them disappear but simply to say that we can get patients through the treatment so that they are likely to survive the therapy and give themselves the best chance of having long-term survival of their tumors.

**Listener Questions**

**Andrew Schorr:**

Dr. Benjamin, we have a number of questions coming in now so we'll try to get to those. So there are two "C" words here operative. One is cancer, the others is cure. And we got a call from Illinois a couple of minutes ago and the woman said, "Can sarcoma ever be cured?"

**Dr. Benjamin:**

Absolutely. So that also depends on what your definition of cure is. Mine is very simple. After you've lived your life you die of something else. So by that definition you can't be alive and be cured, but your likelihood that you are cured goes up every day. We have patients with sarcomas whose sarcomas can kill them after 20 or more years, so we don't like to say that in two years they're cured or in five years that they're cured. But the longer they go, the better the chances, and we have many patients who do in fact live normal lives and die of causes totally unrelated to either their cancer or its treatment, and those are the ones that have been cured.

**Andrew Schorr:**

Right. Let's go through some other questions now. I've said we have people listening from around the world, and Grant, who is 28, is listening in the United Kingdom. And he's diagnosed with stage IV rhabdomyosarcoma, if I said that right. And here's his question. "What are the developments on the anti-IGF, insulin growth-like factor trials? I've heard it's promising for the Ewing's sarcoma group, but I also heard of a rhabdomyosarcoma patient who did not respond whatsoever. Is this the sarcoma wonder drug so many are hoping for?"

**Dr. Benjamin:**

So the answer to that question is it's not the sarcoma wonder drug. It's early in its development and it has great potential to be one of the major advances in the treatment of any number of sarcomas, among which high on that list is rhabdomyosarcoma. In experimental systems patients with rhabdomyosarcoma, the cells from patients with rhabdomyosarcoma over express the insulin-like growth factor pathway, and so a treatment which can block that pathway, and the IGF-R antibodies that currently exist can do that, that should be effective. It should be an effective way of treating some of those patients.

The studies are very early in their experimental phase, and so it's certainly too soon to tell, but there's every reason to believe that the anti-IGF-R antibodies will be at least as effective against rhabdomyosarcoma as they are against using Ewing's sarcoma. And they may not be the answer by themselves, and eventually I'm sure they will be added to the effective chemotherapy regimens that are used in that disease so that the overall chances of cure will go up, and so that's very similar to for example Rituxan in lymphoma or Herceptin in breast cancer, where by themselves they have some minimal activity but in the right group of patients combined with chemotherapy they can markedly increase the efficacy of the treatment.

**Andrew Schorr:**

Okay. That's a great answer. Thank you for that. And, folks, as we listen to Dr. Benjamin, remember he's a world-renowned expert giving you the latest thinking in what may come together and be a benefit to you. We'll be right back with Dr. Robert Benjamin and his patient Jennifer Burns right after this.

**Andrew Schorr:**

I appreciate you all tuning in from around the world for our live webcast. Remember, there will be a replay pretty quickly afterwards, and then we'll add a transcript so you can come back to it, tell other people you know who are touched with sarcoma, even your doctor, other providers. There's expert perspective here from Dr. Robert Benjamin, who is chair of the sarcoma medical oncology area at the sarcoma center at M. D. Anderson.

So, Dr. Benjamin, here's a question we got from Texas, Jeff in central Texas. He wrote in, "The media has recently discussed the potential ability to use radio frequency waves in combination with nanoparticle technology for cancer treatment in the very near future. How promising do you think this approach will be for sarcoma treatment?"

**Dr. Benjamin:**

So that's a treatment which is not specifically aimed at an individual kind of cancer, and for those listening who watched the 60 Minutes broadcast about it the other

night, which was excellent, the key issue in terms of making this an effective cancer treatment strategy is figuring out how to target those nanoparticles into the tumor cells and not into the normal cells, and that is a very complex area, and if it can be done then that strategy ought to be tremendously effective. And if it can't be done that strategy will ultimately fail, except potentially for the treatment of some localized tumors.

But patients with cancer in the majority of cases, certainly the majority of cases of patients with sarcomas, the tumor that you can see when the tumor first starts out is not what's going to kill you. It's the microscopic disease that has spread to other areas of your body that we can't see that will kill you. And the favorite target area for most sarcomas is the lung. So there has to be a way of somehow targeting those cancer cells that have spread to the lungs so that they can then be destroyed by this radio frequency wave treatment.

**Andrew Schorr:**

Dr. Benjamin, people are listening worldwide, as I said, so we had Grant in United Kingdom. Kim is listening in Montreal, Canada, and writes in this question. "My brother, 40 years old, was diagnosed with a rare tumor in his groin, malignant granular cell tumor. We're from Canada and nobody here seems to have any information with regard to treatment options. We're desperately seeking a doctor in the US or anywhere else that has seen this and treated it." She asks, "Does this type of tumor fall under any other type of sarcoma and does it mimic any other type of sarcoma, and how and where can we find information and specialists who may be knowledgeable? Where should we go?"

**Dr. Benjamin:**

Boy, again, the way you have to get to one of the big centers, so--

**Andrew Schorr:**

She's in Montreal.

**Dr. Benjamin:**

She's in Montreal, and I'm just trying to think. So there certainly are people who deal with sarcomas in Montreal but it's not a major sarcoma center. Probably the only area in Canada where there's a truly big program on sarcomas is in Toronto. But granular cell tumors are very, very rare, and there is not an expert in the world on the treatment of these tumors. They are somewhat similar to paragangliomas, and they can respond to chemotherapy and to radiation. And of course the primary tumor is something that could be addressed surgically.

**Andrew Schorr:**

Wow. That's where people are confounded, I think, when they are diagnosed not just with this idea of sarcoma but then this sub type, it can be so rare. Jeff has been listening as we said in central Texas. He came back with another question.

He says, "What basically is a stromal cell? And what would it mean if pockets of stromal cells were found in the tissue biopsy in the area of a previously resected soft tissue chondrosarcoma tumor?"

**Dr. Benjamin:**

So the first answer is that not all stromal cells are the same, so it's a description of the sort of skeleton on which the tumor is formed. That's what's called the stroma. And there is normal stroma in normal tissue as well as in tumors. What I guess is being described in the case that he mentioned is that chondrosarcomas can produce a material that's usually referred to as a matrix, and so there may be areas of this chondroid matrix without necessarily finding any chondrosarcoma cells present. But I'd probably need a whole lot more specific detail to address the question.

**Andrew Schorr:**

Sure. That's a point I'd like to make, sure, for Jeff. Jeff, obviously we can't practice medicine over the internet. Let me ask you a question that came in from Sarah in San Jose, California. And I think it's what everybody wonders when they are faced with this. "What are the possible causes of soft tissue sarcomas?"

**Dr. Benjamin:**

Well, in the vast majority of cases we do not know the cause. That said, there are certain specific familial or genetic abnormalities which can lead to the development of sarcomas. But in the vast, vast majority of cases these tumors are not hereditary. But every once in a while you run into a family where multiple family members are affected with different kinds of cancer, and often family members are affected with multiple kinds of cancer.

And one of the most common associations would be bone sarcoma, soft tissue sarcoma, breast cancer, brain tumors. And this is found in a syndrome called Li-Fraumeni syndrome, which is an abnormality of one of the tumor suppresser genes that's called p53. So in those cases you may well cure several of the sarcomas, and the patient may die of still another one or another kind of tumor. Leukemia is another one that goes in that family.

For most patients, though, there are no genetic predispositions, and we don't really know the cause. I guess another known cause, probably the most common known cause of sarcomas is radiation. Radiation that could be most likely in the form of treatment for some other previous cancer.

**Andrew Schorr:**

Right. I've heard that.

**Dr. Benjamin:**

The risk is low with radiation, and obviously it's important to cure the cancer that you're dealing with, but sometimes when you do cure the cancer that you're dealing with then there's a risk of a second cancer.

**The Future for Sarcoma and Sarcoma Research**

**Andrew Schorr:**

Dr. Benjamin, we're drawing late in our hour, and I wanted to get a final comment from you and from Jennifer. And I want to kind of be a reporter for a second and just mention some things that I've been hearing loud and clear here and I want to underscore for people.

First of all, you want to make sure you get an accurate diagnosis where there's a skilled team looking at your slides, looking at the results of your test, you have the right tests. And second of all, you don't want to embark on therapy, I would say definitely in sarcoma, unless you consult with a sarcoma subspecialist and also where there's a team. Because as you said, you're in medical oncology but you've mentioned pathology, surgery, radiation, and I know you have nurses and counselors and others in your sarcoma center that come into play as well.

**Dr. Benjamin:**

Oh, absolutely.

**Andrew Schorr:**

You need that. So it's a team approach.

And then the second thing I would say is that recognize the treatment as best they can will be personalized to what you're dealing with, but research goes on. So what was thought to be not an opportunity for personalized treatment a few months ago maybe there are newer medicines, experimental or developed for other cancers that might apply as they understand your specific cancer situation.

So are you hopeful, Dr. Benjamin? Are you a hopeful man in this field that you've been in for a long time?

**Dr. Benjamin:**

I'm a medical oncologist, so that defines me as being hopeful. Medical oncologists are optimists. But I'm an optimist because I see patients who benefit tremendously from the treatments that we give, and I know that there are treatments today, like we talked about Gleevec for GIST, that didn't exist for the majority of my career. I am absolutely convinced that there will be new therapies that will completely change the way we practice over the next ten or 20 years.

And, we didn't really mention, but we should, Jennifer was treated with a combination of drugs, gemcitabine and Taxotere, that we still have trouble getting insurance companies to approve because they think they're experimental for sarcomas. We've done the studies that show that they are effective, but it takes a while before new treatments get integrated into the standard.

One of the things which has been most helpful is that sarcomas are rare enough that even in the United States the various groups, the various centers of expertise have gotten together and agreed to cooperate and do studies together. We have a consortium called SARC, S-A-R-C, where the sarcoma experts from around the country get together share patients, participate in common trials so that we can move the field ahead. And we're very optimistic that eventually we'll succeed in effecting new therapies that will help maybe one disease at a time, maybe all of sarcoma at a time, depending on the kind of therapy that is being given.

**Andrew Schorr:**

Well, wouldn't that be great, but of course it all comes down to individual patients.

Jennifer, you're a lady who is a success story. Maybe one of Dr. Benjamin's success stories. Do you want to say anything to him? Because after all you sort of lived to tell the tale. What would you say to your doc?

**Jennifer:**

I'll tell you what I'd say, and I know, because I tell him this all the time, I'm very, very grateful to be his patient. I'm honored. I'm blessed. Well, there are no words. I wish I could repay him somehow for saving my life. For always being there for me. He's very generous with his time with you. He's kind. Of course he's brilliant, but he's such a good man and all I can say is thank you.

And I would like to add one more thing.

**Andrew Schorr:**

Sure.

**Jennifer:**

Aside from of course having the best doctor in the field I think that a positive attitude and a deep spiritual connection to your higher power is extremely important. And on my darkest days, my darkest moments, that's what pulled me through. When Dr. Benjamin wasn't there what pulled me through was my belief that God was taking care of me. And for whatever it's worth that's what I would like to contribute.

**Andrew Schorr:**

Well, here you are, and medical science and your spirit and help from wherever it came from. Thank you for being with us, Jennifer.

**Jennifer:**

Thank you.

**Andrew Schorr:**

So Christopher is going to build you and Greg a great new house, and you're going to live in Memorial Park there in Houston for a long, long time. I'm going to be down and speak to the folks from the Anderson network, the big volunteer network, in September. So I'm going to come see you. We're going to sit out on your deck, okay?

**Jennifer:**

And we'll have Margaritas.

**Andrew Schorr:**

Okay, there you go. So thank you, Jennifer Burns.

Dr. Benjamin, all the best to you with your really life-saving work. Thank you so much to you and your team and what you do at the sarcoma center at M. D. Anderson. Thank you for being with us, sir.

**Dr. Benjamin:**

You're very welcome. Thank you.

**Andrew Schorr:**

Okay. It's fun and gratifying, and I'm delighted to play some small role in these webcasts we do every two weeks. Now, remember that on May 6 we're going to have a program on osteosarcoma with Dr. Christopher Cannon, who is an orthopedic surgeon in the sarcoma center at M. D. Anderson. We invite your questions then.

As always, knowledge can be the best medicine of all. Hopefully we've given you some great insight into how you can learn about and fight sarcoma and hopefully win. We'll see you in two weeks. Have a great evening. From Seattle, I'm Andrew Schorr.

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