Soft Tissue Sarcoma in Adults
Webcast
July 30, 2008
Chappie Conrad III, M.D., F.A.C.S

Please remember the opinions expressed on Patient Power are not necessarily the views of Seattle Cancer Care Alliance, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That’s how you’ll get care that’s most appropriate for you.

Introduction

Andrew Schorr:
Hello and welcome to another edition of Patient Power sponsored by the Seattle Cancer Care Alliance. I'm Andrew Schorr. One of the cancers that is less common but certainly concerning in children and also in adults is sarcoma, and there are many different types and certainly there's a lot of expertise at the University of Washington and the Seattle Cancer Care Alliance about it, about 10,000 new cases a year in the US. One of the leading experts is at the Seattle Cancer Care Alliance and that is Dr. Chappie Conrad. Dr. Conrad is professor and co-vice chair of the orthopedics department at the University of Washington and also the director of the Sarcoma Service at the Seattle Cancer Care Alliance.

Dr. Conrad, when we talk about sarcoma I know that it can be cancer in the bone but it also can be in the soft tissue. When we say soft tissue, what do they mean? What does it look like and how can it show itself?

Dr. Conrad:
Well, we like to tell the patients it's the tissues that hold you together. It's the connective tissues, so it's muscles, tendon, arteries, nerves, all the tissues that are not glandular tissues.

Andrew Schorr:
Well, for someone listening, what would it feel like? Like you feel a little lump, does that necessarily mean it's cancer, or do these distinguish themselves in some way?

Dr. Conrad:
They distinguish themselves mostly by the size of the lump. If you have a lump bigger than a couple of inches it's probably something that needs to be imaged.

Andrew Schorr:
Now, there are benign or nonmalignant lumps like that just in fatty tissue or things like that. How do you differentiate what is a malignancy and really needs to be dealt with more aggressively?

Dr. Conrad:
There are two or three clinical signs that we use when we're looking at a lump. Obviously there are lots of people with small lumps that are not cancer. And those
clinical signs involve the size of the tumor. A sarcoma is more likely to be a couple of inches in size rather than a half an inch or smaller than an inch. The density of the tissue, usually the tissue is firm if it's a sarcoma. It's firmer than normal muscle. And they don't usually hurt. It's usually nontender so pain is not a sign of malignancy when it comes to a soft tissue sarcoma.

**Journey to Accurate Diagnosis**

**Andrew Schorr:**
Now, often somebody will have something like this and they'll go to the doctor and it won't be recognized for what it is. What's the difficulty in getting an accurate diagnosis? Is it just that it isn't that common and it's probably something else, or why do people have this journey of getting to an accurate diagnosis?

**Dr. Conrad:**
The journey is difficult because there are lots of other little bumps that aren't cancer and they confuse the issue and these tumors are unusual. The most important rule of thumb is to follow your own lumps and if they change in character then to pursue basically an MRI for soft tissue tumors if you have concerns that your lump is getting bigger.

**Andrew Schorr:**
Now, are they more often on one part of the body than another?

**Dr. Conrad:**
They have a tendency to be in the lower extremities, in the legs more than the arms.

**Andrew Schorr:**
Now, we mention that there are many different types of sarcoma so I assume that you develop treatment plans that are not one-size-fits-all. How do you determine what you're dealing with if in fact it is a malignancy, a sarcoma, and then which type?

**Dr. Conrad:**
We like to do three or four things. We like to do imaging, and the imaging for soft tissue tumor in an extremity or on a pelvis or thorax would typically be an MRI, and that will give us a pretty good idea of what we're dealing with. If we're concerned about what we see on an MRI then we'll recommend a PET scan and a biopsy.

**Andrew Schorr:**
Now, where are we today? If there are 10,000 new cases, that's kind of scary. What's the prognosis, or how does it vary by sarcoma type?

**Dr. Conrad:**
We have about, you know, 15 or 20 subtypes of soft tissue sarcoma that we deal with commonly, and half a dozen of those are worrisome types that are
fast-growing tumors and don't respond to the current therapies that we have. And those are the subtypes that we refer to as high risk in our clinic.

**Research, Progress, and Clinical Trials**

**Andrew Schorr:**
Now, at the Seattle Cancer Care Alliance I imagine you're doing a lot of research. So if we haven't made as much progress in the past, are we working hard in research to make progress now and in the future? And are there trials that are available to people if they find they're in this high-risk group?

**Dr. Conrad:**
We've made significant progress in being able to tell what patients have risky tumors, tumors that are at risk to threaten their life, and we can do that with better biologic techniques in our biopsies and better imaging with better MRIs and the onset of PET scans. We need to be able to cure the patients who have high-risk subtypes, and that involves solving the drug resistance problem that we have with high-grade, fast-growing tumors and their relative resistance to chemotherapy, which is still a major issue for almost half of the patients with a high-grade sarcoma.

**Andrew Schorr:**
Well, let's talk about a different cancer where we know we've made progress and compare. So now we're telling women with breast cancer we have a whole array of drugs, and it's individualized to your breast cancer type, and these drugs are often effective and even after a woman has had surgery for breast cancer there are drugs to try to keep the cancer cells as bay, if you will, if there are some remaining. Why aren't we able to do that with sarcoma?

**Dr. Conrad:**
Well, there's an intriguing overlap between a breast cancer patient and a sarcoma patient, but there are enough exceptions to make it challenging, and that's sort of the essence of the biology of the cancer world that we live in. So we have about 25 percent our patients will have a genetic reason for having a difficult tumor, and the rest of the patients just have challenging tumors, and we have to decide what grade and what type and what treatment they need. The ones that have high-grade, fast-growing tumors are the ones that are drug resistant, and it's actually a little bit of a similar proportion for sarcomas as it is for high-grade breast cancer patients if you subtract the lower-grade cancers and the less active cancers from the fast-growing, high-grade cancers. So it's a little bit of a similar story no matter what kind of tumor subtype you're dealing with.

**Andrew Schorr:**
In our programs in breast cancer we know that many women typically breast cancer is fueled by estrogen. Is there anything we know that's fueling sarcoma malignancies?
Dr. Conrad:
We don't have an estrogen marker for sarcoma patients that has an endocrine hormonal relationship that we understand. The only extreme example of that is the negative example, and that is a young female who happens to be pregnant and have a sarcoma. We know that their tumor is fed by the hormonal storm of pregnancy in a negative way, and that's a particular red flag for us when we see young women who happen to be pregnant with sarcomas.

Sarcoma in Adults vs. Children

Andrew Schorr:
Now, we hear about sarcoma sometimes in children and different types. How is sarcoma different in adults than it is in children?

Dr. Conrad:
Well, gratefully children don't have as much drug resistance and have a significantly higher survival. The survival for a child with a high-grade sarcoma is approximately 75 percent five-year survival, whereas an adult is 50 percent depending on the subtype. And that's a significant difference, and that is inherent in the age difference between adults and children. And it's a biologic research question we're just beginning to try answer now, and that is why does a 15-year-old with a soft tissue sarcoma that's otherwise a similar tumor to an adult have a significantly higher survival and less of a problem with drug resistance than a 45- or 55-year-old patient.

Andrew Schorr:
Well, I hope you can get answers to those questions as research marches on. For people who are listening who may well be diagnosed or are fearful that they have this diagnosis, let's talk about the process. So they may have had a journey from doctor to doctor, maybe getting to a subspecialist such as yourself, and then they get an accurate diagnosis and you stage it, as you say, and see what you're looking at. You mentioned MRI and you've mentioned PET scan. Where does PET scan come in? And help us understand what a PET scan is that's different that gives you information that's important.

Dr. Conrad:
When a patient comes in with a bump, we usually say they have three basic questions to answer. One is it a tumor or not. That's pretty quick. They've already got the tumor problem by the time they see us. Second is whether their tumor is benign or malignant. And again, not always, but most of the time that screening process has already happened. And that screening process happens with a biopsy or an excision of their tumor depending on how big it is after they've been imaged with an MRI. The most important question for patients to answer is if you have a sarcoma is it fast-growing or slow-growing, because a slow-growing sarcoma is really not much of a threat to your life. Ninety percent of those patients never have a problem with a tumor threatening their life. They may have some minor problems with tumors coming back locally.
But if you have a fast-growing, what I call a red-hot mama, if you have a real sarcoma and it's a threat to your life, we can determine that by the biopsy and we can determine that actually even more accurately with a PET scan. And those are the people that we want to identify early because we want to give them early therapy with radiation and chemotherapy both, and we want to intensify their treatment dramatically. We want to do it earlier in the course of their disease. We don't want to sort of recognize it after we take it out and it comes back. We'd much rather get treatment going early.

So assessing a patient's risk earlier and determining where a tumor is and where it isn't, what we refer to as staging, is really the critical and most important part of somebody's evaluation once it's decided that they have a sarcoma.

**Andrew Schorr:**
Now, PET scanning also helps you as you start treatment, right, to know how you're doing?

**Dr. Conrad:**
It is most reliable at telling us within two months of beginning chemotherapy that their treatment is working or not working, and that's a dramatic improvement in care. Ten years ago they got six or eight months of therapy. We had to wait until the tumor progressed or something wrong, bad happened, like tumor in their lungs or recurrence in their leg before we realized the chemotherapy wasn't working. And today we can image a tumor before it gets chemotherapy with a PET scan, give it two months of chemotherapy, repeat a PET scan and an MRI and really very, very accurately tell that patient that those drugs are working or not working. And that is a very, very predictable way to make treatment decisions quickly and switch to new drugs or stop using drugs that aren't working for patients. That's a dramatic improvement in patient care that's occurred in the last ten years really.

**Surgery for Sarcoma Patients**

**Andrew Schorr:**
Dr. Conrad, where does surgery come in for soft tissue sarcoma?

**Dr. Conrad:**
Surgery is essentially for biopsy and for removal of the tumor. It's an essential part of treatment for both low-grade and high-grade tumors. Low-grade tumors basically get surgery with or without radiation therapy, and high-grade tumors get all three disciplines. They get a surgical resection, which we actually prefer to do after they've had chemotherapy and radiation therapy. And organizing all of that is really a major challenge, sort of an orchestration in care. And it takes a team that's totally connected together and used to doing it to really do it efficiently and in a timely basis.

**Andrew Schorr:**
Let's talk about that team aspect. So since sarcoma is not common—now, I don't mean to be self-serving here, but the Seattle Cancer Care Alliance is one of those
centers that specializes in it. It seems like if you had many different types of sarcoma, it's an area of active research, it would seem worthwhile for someone to connect with a center such as yours to really bring the latest to bear.

**Dr. Conrad:**
Yeah, I think there is a value to experience, and there is definitely a value to teamwork. And there are many teams around the country that like to specialize in sarcomas, and there are several teams in even the Northwest. The SCCA is obviously an excellent resource. There's a group that's matured in Portland that's a good group for sarcomas. But having a team that really meets on a weekly basis in clinic and in conference and is discussing new patients and patients that are having problems really is an essential part of having a team. And if you're not doing that and you're not doing that specifically for sarcoma patients, then I think you don't really have a program that's focused on trying to make things better diligently for a pretty high-risk group of patients.

**Andrew Schorr:**
Let's talk about some of the key members of the team. I know there are many, but let's start with knowing what are you dealing with. So part of it, I would think, with the imaging would be radiology. Part of it with biopsies, etc., would also be pathology. If you have many different types of sarcoma you need to know what type. So having an accurate diagnosis through imaging and pathology, I would guess, would be an essential starting point.

**Dr. Conrad:**
Ironically you can't even--it's difficult to get in to the door now to see the specialist unless you've had x-rays and pathology and the slides have been read to confirm it. There's tremendous controversy in reading the slides by the supposed experts for sarcomas. Those techniques are getting better, and some of the best discussions we have are about the basic issues with regards to imaging and pathology, and those are really essential members of the team on the sarcoma team.

**Andrew Schorr:**
Okay. And then we mentioned surgery. There's also radiation that can come to bear, and of course medical oncology as far as the drugs. So those are three more members of the team, right?

**Dr. Conrad:**
Without a doubt.

**Andrew Schorr:**
So how does that work together to determine--in some of the cancers we've discussed sometimes for instance chemotherapy is done first to try to shrink the tumor. Where does that come about in sarcoma? Where are you with that, with what do you do when?
**Dr. Conrad:**
So we have the patients come in and see the surgeon if there is any doubt about whether it's a sarcoma or not so a biopsy can be arranged, either in an operating room or in a CT suite so that a biopsy can establish the diagnosis. Most oncologists are being careful about who they're seeing and will not see a patient until they have a diagnosis. So the biopsy's logistics are sort of solved unfortunately by the surgeons, and that's sort of the front door of the service.

**Andrew Schorr:**
So then you get the biopsy, but for instance do you ever have then with a confirmed diagnosis chemotherapy first and then say, okay, now we've shrunk the tumor and then we'll cut out what we can see?

**Dr. Conrad:**
For better or for worse around the world, it's sort of one-third, one-third, one-third. One-third of the world still doesn't believe in giving chemotherapy for high-grade sarcomas, one-third of the world does it after a resection, and one-third of the world does it before resection. The vast majority of big cancer facilities in North America, the overwhelming majority if not 90 percent of them are trying to recognize sarcoma grade up front and giving chemotherapy before resection because the time of the treatment is important. The treatment effect on the entire body is more helpful early on. And it also helps the surgery so that you can do a more effective surgery and take out less normal tissue and have a lower recurrence rate if you give the chemotherapy or the radiation therapy before the surgery.

**Radiation for Sarcoma Patients**

**Andrew Schorr:**
So there could be radiation first. I usually think of radiation following surgery. Where does radiation come in? And how does a vary by sarcoma type?

**Dr. Conrad:**
Some tumors are more radiation sensitive than others. The tumors that have a rapid blood flow or have a glandular elements in them are a little less radiosensitive, but overall the majority of these tumors are relatively radiosensitive and respond relatively well to radiation therapy. I would say half the time it's given before surgery and half the time it's given afterwards. The radiation therapists like to give it before because they think the targeting is better, the tumor is still there. The surgeon hasn't contaminated any of the tissues around the tumor so they can give a smaller dose to the tumor and the surrounding tissues. They have a preference to treat before resection, but it can be done either before or after.

**Andrew Schorr:**
You just mentioned something that I wanted to talk to you further about. You used this word of the surgeon "contaminating" the tissue around it. So if somebody gets a sarcoma diagnosis, and let's say they're out in the hinterland, there's not really a specialist near there, is it important to get to a specialty center without further
intervention so that things are not—well, you used the word contaminated. What's the risk of doing it wrong first to your further care?

**Dr. Conrad:**
That's a great question. Some of the patient advocacy groups refer to that as "whoops" surgery, and most people would understand they want to avoid a whoops surgical procedure. It describes a contaminated resection of a sarcoma, and that occurs in about 30 percent of the patients that we see.

**Andrew Schorr:**
Whoa.

**Dr. Conrad:**
If it occurs in a patient with a high-grade, fast-growing tumor it can cause problems with local control and compromise our ability to achieve local control. If it occurs in a less aggressive tumor, then the consequences are not as dire. So it's important—the adequacy of the surgery is critical. It's just as critical when I'm doing it as when somebody else is doing it. It's the greatest reason to have a tumor board in your hospital to review the adequacy of surgical excision because being able to satisfy the opinions of your nonsurgical partners is what keeps you honest as a tumor surgeon and helps you make decision about the need for adjuvant, what we refer to as adjuvant therapies, which is chemotherapy and radiation therapy. Surgical margins and the adequacy of resection are really an enormously important detail in every sarcoma patient's care.

**Andrew Schorr:**
Now, couple questions. So if somebody listening has a diagnosis of a soft tissue sarcoma, how do they know how urgent it is that treatment begin?

**Dr. Conrad:**
Mostly by the size of the tumor. If you have a large tumor, a tumor that is larger than four or five inches, then you are in a riskier ball park than if you have a tumor that's just an inch in size.

**Andrew Schorr:**
Are we saying, you know, start treatment in weeks or a month? And you mentioned that there are some low-grade tumors that may not be any big deal even though it's a malignancy.

**Dr. Conrad:**
Yeah, that's a great issue. Most of these tumors are lower grade tumors. If you assume that and you don't do an MRI and you don't do a biopsy, especially not doing an MRI and just assume that that's a lipoma and never have an MRI on it, you're assuming some risk that you might be wrong, or your doctor, usually it's a primary care doctor, is assuming some risk for patients that have larger tumors. So you have to—the patient has to participate very carefully in that decision because occasionally that will prove to be a malignancy, and patients start to have problems because they never had an MRI or they never had a biopsy.
Andrew Schorr:
Okay. Now, I'm often impressed as I talk with folks like you and you talk about these debates in medicine among very smart colleagues around the country and around the world. How do you feel about somebody diagnosed with a sarcoma getting a second opinion because whether you turn left or turn right, do this first or second, do this or another modality, those are real questions and of course may affect their life. So how do you feel about that and people—do they have the time to ask expert one and also see expert number two?

Getting a Second Opinion

Dr. Conrad:
Well, we almost always encourage people to have second opinions, especially a second opinion with an experienced—somebody who is experienced with sarcomas. You asked earlier, I never answered the question, about what's a real delay of significance for a patients with sarcomas, and if you have a high-grade sarcoma then a significant delay a longer than six or eight weeks. We think delays in treatment more than a couple of months—because it takes a couple of months to see a change in the growth rate of a tumor. But we try to never discourage patients from having other opinions and try to encourage them to have other opinions. It's getting more difficult now to have opinions. If you live in the Tri-Cities and you're a farmer and it's that time of year where your cash flow is low, you have a hard time driving to Seattle for extra opinions, and a lot of patients now are having difficult times to get to other expert opinions in the big city. And for sarcoma patients who are having problems, that's a real challenge.

Andrew Schorr:
Yes, it is. Now, who can help them identify sarcoma specialists? Obviously there's your whole team at the Seattle Cancer Care Alliance. There are advocacy groups that are devoted to this, aren't there?

Dr. Conrad:
There are and it's a great phenomenon in North America and even in Europe now, I think. These groups are becoming more and more opinionated and more and more available to people online. And if you just look up sarcoma groups online you'll see that there are several major national groups and there are several regional groups who will actually offer cash to patients so that they can drive for an opinion, and they have grants to patients to seek out expert care. And it's a wonderful phenomenon. They're offering now research grants to some of the institutions. They want a return for their dollar, they want some bang for their buck, and they are demanding that these groups deliver some research results that are positive for sarcoma patients with the funding options that they have. So it's a very good, positive movement around the world, especially in North America, especially for patients who are sort of cancer orphans a little bit like the sarcoma patients because they have a cancer that is pretty unusual compared to the big three or four subtypes of cancer.
Andrew Schorr:
Right. It's not on the tip of everybody's tongue at all when they talk about cancer. For the families touched by it then, it sounds like there's support. Now, you're right at the forefront of research and talking with your colleagues around the world. There are lots of questions you mentioned to be answered, but are you optimistic?

Dr. Conrad:
I'm very optimistic that we're going to have a breakthrough in some of the basic biology, understanding some of the basic biology and be able to solve some of the drug resistance problems. Even in the next five or six years I think we'll have some new drugs that will help patients. We have some drugs in clinical trials now that help patients who either have a very high risk subtype or have failed what we think is the current good therapy for these tumors. And those clinical trials are really an essential part of trying to make some advances with sarcomas and being on the cutting edge.

Andrew Schorr:
Here's some questions I just wanted to ask you that came in. And Sylvia from Seattle wrote in and it's a tough question. "What are the fatality rates" she said, "associated with soft tissue sarcoma in adults?" Now, I know it varies. People must ask you that. Is that a very personalized answer we need to give, or how do you approach that?

Dr. Conrad:
Well, every patient in their subtype and the size of their tumor and the extent of their tumor determines their five-year survival, if you wanted to boil it down to brass tacks. So every patient is different. But if you wanted sort of basic survival statistics for sarcoma patients, as I said earlier, in adults with a high-grade soft tissue sarcoma that's not spread to the lungs, which is the first place it usually goes for the basic sarcoma, the overall survival is approximately 50 percent for highgrade, fast-growing tumors. For a tumor that's a little less high grade, then the survival goes up right away to a higher number. But it's a 50/50 ball game, in these patients who have the serious sarcoma that we determine by biopsy and by PET scan.

And that extrapolates to other kinds of cancer. Unfortunately, it's a 50/50 game when you have a high-grade tumor. We're trying to crack that egg, and making that survival 75 percent for adults I think is our biggest challenge here in this next decade.

Andrew Schorr:
I hope so, but again I'm a leukemia survivor 12 years now, and I know there's been progress in that and I see it in other cancers too. We just wish you well with all your research.
Here's a question we got in from Gavin who actually listens in to our programs from Nashville, Tennessee. He wants to know then, "What questions should I be asking my provider prior to treatment?" What are just--if you wanted to rattle off just some key questions. Obviously, what are we dealing with, high grade, low grade, but what would you say?

**Dr. Conrad:**
I would say one of the first things we do is image the lung to make sure there are no lung tumors that have come from the primary site of their sarcoma, where the tumor begins as the basic staging. And then what's being done to biopsy the tumor? And what's the experience of the treating team? Do they see sarcomas routinely in their practice or do they not see sarcomas? And who do they refer to for expert advice when they need expert advice?

**Andrew Schorr:**
Great questions. We've covered a lot of ground, Dr. Chappie Conrad. Is there anything else you want to add before we wrap up as you lead the sarcoma effort both at the Seattle Cancer Care Alliance and play a key role nationally and internationally?

**Dr. Conrad:**
My greatest advice to patients is to champion their own care and not be bashful about do that. That's their own care or the care of their loved ones. They should be getting reasonable conversations from whoever is taking care of them. Given the pressures of life and practicing medicine these days, communications are a great challenge so I always tell patients to be aggressive about championing their own care and getting communications and answers from the people that are taking care of them.

**Andrew Schorr:**
Well, that's great advice, and of course that's what Patient Power is all about. Dr. Chappie Conrad, professor and co-vice chair of the orthopedic department of the University of Washington and director of the Sarcoma Service at the Seattle Cancer Care Alliance, thank you so much for joining us once again on Patient Power.

**Dr. Conrad:**
Thank you.

**Andrew Schorr:**
Well, this is what we do on Patient Power. And I want to mention in two weeks we will be back with another program where we help people with unfortunately the most common cancer, lung cancer. We'll be visiting with Dr. Doug Wood to give you guidance on how there can be the best care for lung cancer. Please always send us your questions and comments and thank you for joining us today. I'm Andrew Schorr reminding you that knowledge can be the best medicine of all. Thanks for joining us.
Please remember the opinions expressed on Patient Power are not necessarily the views of Seattle Cancer Care Alliance, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That’s how you’ll get care that’s most appropriate for you.