Living with Metastatic Solitary Fibrous Tumor Transcript

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Podcast Introduction and Host's Diagnosis

Welcome to the Doctors Making a Difference podcast, where we help physicians to be empowered with the tools they need to successful in medicine, in finance, and in life.

Join us as we highlight doctors and other professionals around the world who are making a difference. Today's episode is just a little bit different than ones I've done before.

This podcast is primarily for physicians, and most of our guests are physicians. Today, we have the privilege of having Steve McBee, a person who I have communicated with before, Steve and I had the same disease, which is an unfortunate thing to have to share with somebody.

And it's an episode I feel a bit vulnerable recording because I'm talking about something that I am fighting and appreciate Steve being willing to talk about his.

journey. I, as many of you have listened to this for a while, know that I have a solitary fibrous tumor. Had a large 28 centimeter tumor, surgically resected and treated with radiation two years ago.

And then I haven't really shared on this podcast prior to today, but I'll share now that over this last few months, unfortunately I've discovered I had some metastatic solitary fibers tumors.

So I'd have to deal with the consequences of solitary fiberous tumors in a metatatic form and have medications that make me feel terrible and I don't really enjoy the metastatic portion of it.

But Steve and others who have had this disease for a long time have been warriors on this front. And Steve is one of those people who is inspiring because he just takes things and doesn't just talk about the negative parts of what he wants to fix it Steve, would you mind introducing yourself to our audience?

Dr. Crane, thanks for having me on with you today to talk about solitary fibrous tumor. About 19 years ago, I was having some symptoms and I didn't recognize it at the time that it was after a 100 mile run trail run out near you.

in the Bighorn area, and I thought it was just fatigue from that. I was tired, sleeping a lot, my mood had changed. What I didn't realize is that I started to have waking seizures.

And I on the way to see another client one day and ran a stop sign and had an accident. And everything, everybody was fine. And the accident was just a minor vendor.

At the end of the day, after talking to some people and nonchalantly telling them that they had an accident, they suggested that I go see a doctor and get an MRI.

I did and next thing you know, rounding up the troops, the family and looking at scans and something that was just unbelievable.

Steve McBee's Initial Symptoms and First Surgeries

I had a tumor in the left temporal lobe and so my first approach to that, was my approach, to all of my challenges and adventures and let's go. How do we fight this?

I jumped into surgery right away, it was a few days later, didn't start with second opinion or anything, felt competent with my surgeon. He discovered that when the.

Tumor was wrapped around the trigeminal nerve and went into the skull base and inner ear. So it was a little more complex. Unfortunately, wasn't able to take everything out.

Did what he could and closed me up. Then I was on second, third, fourth opinion, referral circuit. And I went, met with a lot of great surgeons and ended up at MD Anderson.

And so January 2007, I had my second surgery. and had pretty much a full resection and preserved the trigeminal nerve, preserved my hearing. I was thrilled and then followed that up with some proton beam radiation for six weeks.

And then I was pretty much clean and free. I would go in and have scans every three months, moved it to four to six to a year, and then graduated to the magical every two years.

The other one had my scans and that was unbelievable, thrilling. just almost forgot about the disease. I, in 2021, just a few days after running a three-day hundred mile trail run.

Back to the trip, back to 100 mile trial run, you had finished one of those, the original diagnosis. Couldn't give it up. Yeah. It was part of one my many types of adventure.

yeah, I was going to back down to have my checkup and. I did well on my 100 mile run, so I'm feeling Superman. And I walk in and go through my scans. I go in to see the doctor.

If I have questions or if it's important, I usually presend those and I hope to make our time together as efficient as possible. And so I had an eight, I think it was eight thirty appointment follow up after my scans with my doctor.

had a plane flight out of Houston scheduled for right after that. So I was going to go in as typical, spend five minutes with my doctor. He's going walk in, tell me everything's good and then get on out here.

This is a two year scan, right? This was a 2 year interval. Yeah. And my doctors were hour and a half-ish late coming into the room. Yeah, at eight in the morning, I didn't, or eight 30 in morning.

I did make much of it until they walked in and said, Hey, everything in your skull is fine. But they discovered a tumor in my pancreas. So they said you need to extend your stay.

So go buy a t-shirt and whatever you needed to spend a couple more nights here because we need introduce you to another team. They had you do a CT chest, abdomen and pelvis, and then imaging of the brain as well as part of your follow-up routine.

Yeah, not pelvis. It was caught on the CT of a chest. Gotcha. Yeah, just at the bottom of it. So that pretty lucky that they caught it while it was there.

And the interesting thing about this disease is that you may have it for a long time and not have any symptoms. And I didn't have symptoms at that time.

They started to surface shortly after that. It became more obvious that there was an issue with my pancreas. I was able to delay my. pancreatic whipple surgery for a period of time, had a little bit of chemo prior to that.

So more, they were taking a, now that it metastasized, taking it a systemic therapy approach, Timzolomide and Avastin. And then, then I had my Whipple Surgery and that went well.

Took that out and complicated surgery. It's a big surgery now. Fortunately for each of my surgeries, I've gone into the surgery in really good shape, very fit.

And I think that allows me to recover fairly quickly. So that was in June of 2022, August, 2022. They took out a solitary fibrous tumor in my quadriceps.

And then in 2024, took a tumor on the left lobe of my liver.

Metastatic Recurrence and Ongoing Treatment

So here we are today. still have some areas that they're monitoring, unfortunately. Everything to this point has been in a place that could be resected by surgery, which is the standard for this disease, because there aren't a lot of other therapies that work well.

But where the tumor is currently long in pelvic area, they're in some touchy, more sensitive spots. So I'm on watch right now. This solitary fibrous tumor, some people listening to this may have heard of it.

Some people hadn't, I've been a physician for enough years. I'd heard a lot of tumors, but I had never heard solitary fibros tumor because it's so stinking rare.

You look at the statistics and it, it is hard to even get the proper statistics on it but from what I understand for most studies that most people agree it about one case per million individuals, which means in the United States, if you have 350, to 400 million people, you're going to have 35 or 40 people max.

And worldwide, there's just really not that many of us total. So when you get these orphan diseases or rare tumors, most of the studies are just quite small.

The centers of excellence that deal with a lot of sarcomas have certainly heard of them and have some experience, but it's not like they have a panel of 10,000 people.

They've got a 10 people or 12 people panel. And so it leaves you with this dearth of information, hard to know what to do as a patient. And then on the physician side, I walk both sides of that fence.

I think if I was the doctor, how do I properly recommend something that is both safe and effective when the information we have is so sparse and you don't want to give somebody a treatment that's going to cause them lots of side effects if you really don' have a lot of proof that it helps.

It's a challenging road to walk. Yeah. Let's add to that the fact that there are variations, at least 13 variations of a solitary virus tumor, which, and they can, some may be denied or in some maybe more aggressive.

And so it adds another layer, complexity to understanding the disease. Yeah. You know what I love about your story though, Steve, more than just a story, but the way you've experienced this and dealt with it was rather than, I'm sure you went through all the steps of grief and shock and betrayal and frustration, like everybody that gets a real unfortunate diagnosis does it, me included.

But the thing that I love about this is instead of hiding your head and saying, well, it was me, I guess that's the end, you've continued to run. You've continue to be passionate about life and just live life to the fullest.

And even after you had the misfortune of being diagnosed with metastatic solitary fibrous tumor, You have continued both your physical endeavors, being outside, doing the things you love, and you've done work with advocacy and trying to really help move things forward on this, not just for yourself, but for everybody that has this disease.

So that's one of the next things I wanted to talk to you about is some of that advocacy work and the work you have done to try to connect all these dots.

If you don't mind, share with us that part of your story. Yeah. One of things that I want. to be able to put future SFT patients in a place where they have the assets and resources that they need to understand the disease.

share it with their doctors, their team so that they understand the disease better. And I've been very fortunate that from early on, I was able to develop and bring in some really good people to help support me on my care team.

Started with my wife, Natalie, she's been. Very supportive from day one and I was fortunate that my mom was a family practice physician and just a continual learner.

I think that's where I got it from. And basically they teamed up with my doctors and we just built out a really good team. Very diversified group of people that had an interest in learning more about the disease and helping me as much as possible.

Collecting all of that, Over two decades, I want to be able to give that back to the SFT community. And they're working on multiple ways of doing that, just sharing information that I think could be helpful in getting that other patients in a position where they can walk in the room.

and talk to their doctors confidently and know as much as possible about their disease. And starting with our disease is very small. There's not a lot of us out there.

I think it's very unfortunate that there, and I knew this 20 years ago, there's one thing I regret that didn't happen 20 year ago is to build the community.

Understanding Solitary Fibrous Tumor

To build a community of SFT patients and doctors and researchers and care teams so that we could better communicate with each other. There is, there are a couple of Facebook groups and I think that's been very effective in sharing information, trying to build out and grow that into an actual organization that can help us researchers.

positions as a hub so that the information's there, the communication can be there. The collaboration can happen there or be, or coming out of that is the goal.

Solitary Fibrosis Tumor Foundation is a project. It's not something that I intuitively do. I've got a good background and I've owned a marketing firm for 30 years, but my background in graduate school was biochemistry and physiology.

I can read a research paper and understand the basics behind it, the molecular foundations of medicine. But. I want to be able to translate that over now and use some of my marketing skills that will help our disease and rare diseases in general kind of lift up and so that there's an outlet.

So people know what the disease is and can take that, whether that's helping push forward research and the interest in the disease, or again, just helping a patient build their brand so that they can be a better advocate of themselves and speak about the diseases and ask good questions when they walk in a room.

Yeah. One adjacent question I've been thinking of as you've talking about that. What have you found as a patient? You're an educated person, you have ability to understand biochemistry, can read studies, and some patients have that fund of knowledge, some don't.

And what have found to be effective in communicating with your physicians? Because I think, again, most doctors really want to help. They start out the process trying to and they really and then you get constrained by time and documentation and prior authorizations and stuff that sapped the joy out of medicine a little bit.

And so one of the things that I found really helpful when a person wants to know more about their disease and they study it and ask questions. Sometimes you don't have time to sit and address a lot of stuff ahead of time, but you want that time be really useful when you've got that.

20 minutes or 40 minutes, or whatever the length of time is, you want that to be a constructive period of. But as a patient, You don't want to take more than the time you've been allotted, but you do want make sure that your disease gets the proper focus.

I've wondered how you balance that as the son of a physician, as person with a science degree, and then as patient. Yeah. It's taken me a while, but over a couple of decades, I've developed kind of a playbook.

And it starts with who I am and basically building my brand as an SFTA patient. I know it sounds odd, It's been very helpful and very effective in establishing a relationship with everyone on my team.

And that's from. my wife so she understands where I'm coming from, or my local family practice physician because they're a very important person on my team, to my sarcoma team.

To the surgeon that I may be seeing for liver surgery as an example. And so I go in and I basically, I pre-send my playbook to my doctors prior to every meeting.

Patient Advocacy and Building a Community

And I, basically will give them formatted so that it's, there's a reminder of how I work, how do I communicate. So that they can better understand me.

I just tell them right in front, this is me, how I'm going to interact with you or I interact best. And it might be something as simple as asking the doctor to come in and sit down with me in the room.

Sometimes you go into a research center of excellence. It's also a resource facility. A doctor walks in, and there might two or three fellows and two nurses and it's a room full of people and is overwhelming.

And I will just ask at least if the doctor can just sit down and communicate with me eye to eye that might be in my playbook as an example that helps.

Then I'll go in and if it someone that I've already seen, I won't go over my history with them and the questions that we talked about last time or the answers that they gave me.

And then I just list out my questions and I'm pretty clear that I understand that there, we're not going to have time to answer 10 questions, but here are my top three.

And, then, I asked them also, what do they feel is important to convey to me in this meeting? And what are their top 3 questions of me or the information they want to share with me that's most important?

So that's my plan as I go in. And again, I presend usually about a week out and I always send pictures of me. doing something. So that again, it's building my brain so that the doctor knows I'm interested in paragliding or rafting or running a hundred miles or here's a picture of my wife and I hiking.

Totally humanizes you. Yeah. And I think that not only works for primary person in the room that I'm speaking with, but the rest of the team sees. I've walked into the surgery, not walked in, rolled into a surgery suite before and team and the surgeries suite say, Oh, you're that guy.

And they'll mention one of my pictures and like, at least they know who I am. That's great. Let's go. Feel good about this. So that's my approach to developing and establishing relationships with my team and.

I love sharing that playbook with other patients because I'm seeing it work for me and I've been told that it's worked for them. And so that's my approach.

Yeah, I'm just reflecting on that as a physician. I think that's actually helpful. In the information age, especially where people can instantly have pretty good information with some of the AI tools that are out there, it's nice to not spend all the visit just relaying information, regurgitating facts and information because certainly that education piece is very important and needs to be done along the way.

And sometimes the very first visit you are really just conveying information and statistics and this is what to expect.

But in subsequent visits, when you're dealing with chronic disease management, it's wonderful when somebody comes in and they're not accusatory or I saw this thing on Reddit, and it must be true.

But rather than that, they are saying, based on the information that I have, here's what I know and here, instead of taking a, I'm not going to add these zingers at the end of the visit.

Here's the top three or four things I want to get to. That agenda setting is both helpful for physicians and for patients. I'll just one example just to deviate like I had a patient recently that came in had A whole list of things that needed to be talked about and they were all important and it was great and we were near the end of the visit running a little bit behind on the Visit in fact and As we're just about to go out the door.

He says oh by the way I've been having crushing Substernal chest pain every time I go and work. I'm like what that should have been? That should have been item number one.

And just, of course, take care of it. We'll get all the appropriate testing and see what's going on. But it would have really nice for that agenda setting thing to say, okay, here's three or four important things that are happening to me right now, and I want to make sure we get to those three of four things.

If we have time, I'd like to address some of the others, but if not, we'll schedule back in a period of time or I'll communicate to you offline and we will make these answered.

Or maybe that's something I can go to an educator or a nurse and get it I think that agenda setting preparation that you have exemplified and found to be successful, it works for patients and doctors most of the time.

One of reasons I thinks it worked for me is because as we talk about as patients, especially if you're have cancer like SFT and you are going and following up every three months or six months, or whatever it is.

It's the stress of the scans. Scans-iety as they call it. Yeah. And then the stresses of going into the room with the doctor post scan and waiting for the news.

It's hard to share all of the really important information when your patient's just catching that and remembering that that's something important he needs to tell you when he's about to walk out the room.

That's me. If I don't have that playbook and presend that kind of information, The stress overrides just my, that thought process when I'm in the room.

And so it's been very effective and conveying all the important information upfront. and now let's get into the pertinent details when the doc walks in.

And I think it's helpful to write it down. Like I've been on both sides of this.

Communicating Effectively With Doctors

Sometimes you have someone come in with their little notebook and they've got lots of notes and you can just see three pages of stuff they'd written they want to talk about.

I know that, boy, we are never going to have time to address all those things. On the other hand, I've found that when people do have stuff written down, and I'll notice you have a list, why don't you tell me what's on that list and let's pick the things that are most important to you so we address those things first.

And as we have time, we can address some of the others. It is helpful. When I'm a patient, same thing. You walk in, had all these thoughts in my mind, then I got so focused on talking about the scan or whatever that I forgot to ask the important question I was going to.

I can relate with you, Steve, on both sides of that, both as a physician and as What other things? Just switching

gears for just a second. Think about rare tumors, rare diagnoses like this.

I don't think when you're a medical student or a resident or fellow, you can possibly know everything. In fact, it's one of the best things about being a professional is learning how to find information, not necessarily that you have every single thing at your fingertips, that your ready to be an expert on every thing, at all times.

But you have this framework or this construct that allows you to say I know everything around that adjacent to it. When I add three or four details, I can connect the dots and make sure they know what I'm doing.

Or I could connect you with someone who is an expert at this subcategory of medicine. What would you suggest for other patients or clinicians who are dealing with these super rare diseases?

You've been walking this path off and on for almost 20 years. So what advice would give to doctors and to patients on that? Yeah, that's a good one. I think my advice for doctors is just off the cuff is probably listen and then collaborate.

And I'm amazed at how open doctors are in sharing information and collaborating. If I didn't have access to a center of excellence in sarcoma center, of excellent and doctors that know even know what solitary fibrous tumor is, and I couldn't travel to the center like that, I would at least ask my team to reach out to other experts and ask them for advice.

So I think that that's what you were saying is that you know where to go. You know, where do you go to get the information? I guess a little more difficult for a patient.

Hopefully we will have more information available that is current and usable for patients. better understanding of the disease and current up-to-date because it's even over the last two decades seeing just a massive shift when you talk about a disease that was two different diseases and then renamed under one disease.

It has its own It was hemangioparasitoma and solitary fibrous tumor, and then they got recategorized into one disease, which is solitary fibers tumor.

So for patients or doctors who are listening who might have heard hemangio-parasitomia, we're talking about the same disease. Yeah, exactly. And that happened in 2013, World Health Organization chose to bring those two together.

I think it's pretty clear now. That's the way it was presented in research papers. It's not clear to me that the weight's coded is separate, but it is just another layer of complication.

Yeah. The kind of the tip that I would offer them is there is a community here that are the rare disease and that is very giving of information and wants to help, although it can be a little bit isolating because it is rare.

And there's not a lot of. You will have a long support. And probably one of the healthiest things that I've done for myself is to reach out to others in our community with the disease and just to have conversations.

I have regular conversations with patients from all, from anywhere, all over the United States, different countries, just talk about our disease. Because it is so rare.

We have to communicate worldwide to try to get enough people. I'm thinking about other rare diseases I've encountered as a physician. I'll come across something and not necessarily solitary fibrous tumor, but I will say how interesting this person has this disease or maybe I'm the one making the diagnosis.

I say these things suggest that you have this diseases and this is on the differential. Even though I've never seen this thing, I have seen thousands and thousands of other things like it but not that specific one.

And what I found, number one, is it's really helpful to reach out to a center of excellence or collaborative care and

even if it's on the phone or getting the person to travel to that center to have another person look at it and we can decide together what's going on.

But the second thing, and I can't think this sort of plays into what some of the work you're doing, Steve, is there are a lot of really excellent information websites on rare diseases.

If you go hunting for it, you'll find the Such and Such Rare Disease Foundation. And you can read about it and it might be more comprehensive and instructive than if you just Google it.

Those foundation things were started by individuals, usually a collaborative effort between patients and outpatient doctors or research centers.

Advice for Rare Disease Patients and Clinicians

all that stuff together and you know what you're starting with this foundation and spearheading is something that's likely to become an excellent resource for patients worldwide when they get this and then also a great tool so if you are the first doctor to discover that for a patient even though you may not be familiar with it you need to look and say oh here's solitary fibrous tumor I went to the solitary fibers tumor foundation I found out a little bit more about it and I find out some centers that are reasonably within my region that our centers of excellence that know about this and I'm going to connect you with one of my colleagues at this other center and anyway that grassroots work that you're doing to start it really does bear fruit and i'm thinking about lots of other patients that i've worked with that have that and now a patient myself in this disease that we both share iIm anxious for that information every new study that rolls out on that that gets shared in our group iI'm like all right I want to highlight what those researchers are doing because it makes such a tremendous difference and is such, a highlight and a blessing for those of us who have the disease and are working and trying to live life amid the uncertainty of this rotten disease.

Yeah, and it is definitely not a me effort, it's a we effort. There are a lot of patients and caregivers, support-frame researchers and physicians to prove this effort they see the benefit and I'm really impressed that everyone that wants to put in A little bit of time because we don't have a lot or not.

I work pretty much full time. Still an adventure athlete in between my downtime. handling my own component of this disease. But when I can take a little bit of my time, carve out just a tiny bit my of time and give back to this community in this way and work with others to make this happen.

I think it's going to have a big impact on the interest, the knowledge base for the patients and then driving more interest for research in the near future.

I Think so too. Like I, think there's a lot of things happening and it feels to me like that we're on a cusp of a of the things that are really likely to move the needle, not on just telotary fibrous tumor, but a Because we're down at the immune level, the molecular level on a lot of the things of why these genetic abnormalities are happening on these mutated tumors.

And when you can get to that level you don't just blast people with chemotherapy that kind of works on every cell of a body. You can be a little more targeted.

in immune therapy. I'm not an oncologist by any stretch of the imagination, but I find it really interesting and fascinating to read. My bachelor's degree was in microbiology, molecular biology, so I share some of that same background, Steve, and I found the molecular understanding of disease to be fascinating.

We don't always have molecular solutions to everything, And then you say, okay, this is actually what's happening. And that's where we're at. That's what we are headed in cancer of all types.

Then as a solitary fibrous tumor patient for both of us, I think we, we hang a lot of hope on that. On that stuff, those connections being made and we count on our colleagues and peers and other places to continue doing it.

None of can do it alone. Yeah, that is true. One other area I wanted to ask you, Steve. So you've lived a full life despite having a diagnosis for almost 20 years.

And I'm sure that you like me, we've all had days where it feels discouraging and overwhelming and you're not quite sure. how to handle it because it seems so uncertain when suddenly you are living your life, taking care of your family and doing everything you can to be healthy and suddenly, you get handed this really horrible diagnosis and all the uncertainty that goes with it.

And there's a whole array of emotions and challenges that go into receiving that sort of a diagnosis and deciding that it's actually really happening and going from I'm about to die, maybe I should just give up to there is a lot of hope.

And I wondered what advice would you give to others, even if they're not dealing with solitary fibrous tumor, but you've been a cancer patient for many years.

What have you found to be successful in dealing with those uncertainties and the challenges of being a cancer patient? What do you do to find hope? Long before I faced that first diagnosis, and it wasn't the first that was the hardest.

It was learning that the disease metastasized. That was probably a more difficult moment for me. But I've always, I'd been very fortunate in that I always done hard things on purpose.

So it's whether it then the work that have been doing for 30 years or trail running, racing, kayaking, classified whitewater, paragliding. or taking on the advocacy projects wasn't qualified to do in the first place that I'm going to find a way.

I think doing hard things by choice helps me face that involuntary hard thing with more confidence. So I can usually, as I hope, facing a really difficult decision about my disease.

Just, I think because of all of my, the way I've lived my life and the activities in my. That are hard. It's allowed me to. understand how to take it.

Like my analogy is aid station to aid, station and a hundred mile run or Eddie to Eddie and, and class five rapid.

Finding Hope and Closing Remarks

You just take a little bit at a time and not try to let everything in at one time. And overwhelm you. That's that I think that's how I deal with it, That is really helpful.

I got to tell you, Steve, when I first met you and came across your story, my wife and I talked about you like, hey, and it actually brought me a lot of hope because I had recently, a few months ago, found out that I have met a metastatic disease.

And similar to what you're describing, it was a bad day, really rough to think about that and all the uncertainty that still got kids at home and just a of responsibility and things that need to live for, plan to life for.

But when you suddenly get that, you hear metastatic cancer and you think, boy, I better put things in order because I'm not going to be around very long.

And none of us know the future, but I plan to fight the fight and be round for a long time. That's what I told my wife, Christie. I said, look, Steve's been around for almost 20 years with this disease and he's not just laying in a hospital bed staring at the ceiling.

He's out living his life and doing everything he can. Your story provides inspiration and I hope that someone who listens to this can derive some inspiration from that instead of saying the end is nigh and that I've got to just hide.

Let's do what we can and hopefully it'll be a blessing to our own lives as we're here. And hopefully, it will be move the needle forward or move progress forward so that others who face this disease Maybe don't face it with quite the same, just the sort of bleak outlook where there's not a lot of specific treatment.

But hopefully some of these things will come online and connect the dots with all these experts. And it can be a tremendous blessing to those who come after.

So thank you for what you're doing. Oh, yeah. I am standing on the shoulders of many others that have inspired me in the past. Many of those people are still with us.

So that's, I guess, one of the fortunate things about this disease is that often it is slow growing and that gives us an opportunity to dive in a little more time to assess and figure out what the best next move is.

We often don't have to rush into it. Not everyone with different types of diseases have that opportunity. So we are pretty fortunate in that way. Yep.

If you have to have a metastatic cancer, this one's at least slow. And so with the good and the bad about that, but it does give you a little bit of time to consider and hopefully to seek some expert advice and figure out what to do next.

Yeah, Steve, I, so I've learned a lot from this and I appreciate it in the show notes. I will include information about the solitary fibrous tumor foundation.

And I hope you'll allow me to put your information on there. So folks have specific information. On LinkedIn or something they can connect with you. Okay.

Thank you so much, do you keep in touch and appreciate you much. Dr. Cran, thank you. Thank you for what you're doing and sharing the message about the solitary fibrous tumor.

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