SARC: The Catalyst Turning Rare Sarcoma Research into Real Trials Transcript

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Podcast Introduction and Guests

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. I've been looking forward to today's episode for a while.

I'm very excited to welcome Dr. Scott Okuno and the president of the SARC, which is named Stephen Young. The SARCs mission is to connect individuals and organizations from around the world committed to discovering, developing, and delivering the latest and most promising treatments for sarcoma.

As a sarcoma patient, this means everything to me. SARC stands for Sarcomal Alliance and Research Collaboration. And I'm very excited to welcome both the president of the organization and the chief medical officer.

I think you'll find this episode very instructive and useful, and I hope you're as excited about it as I am. I am delighted today to have two guests. This is exciting.

Usually we just have one guest on the podcast. Today we're going to highlight a wonderful organization called SARC, which stands for the SARCOMA Alliance for Research and Collaboration.

Is that correct? Have I got that right? So, correct. Wonderful. We have Dr. Okuno, who is the Chief Medical Officer for SARC, and we have Stephen Young, the CEO of SARCs.

Why don't we start with you, Dr Okono. Would you mind introducing yourself in detail to our audience and how you got started in SARc? Thanks for the invitation, Dr.

Crane. It's a great privilege to be on your podcast. And from my role, I am a sarcoma medical oncologist. I practice at Mayo Clinic, Rochester. So I support the organization at SARC to make sure from the medical standpoint that we are doing things appropriately.

Dr. Okuno and Stephen Young Introductions

I am also what we would say the Medical Monitor or the Medial Officer, and I oversee the clinical trials that have. When I got involved with SARCs very early on, when it started, there was a big need for us to have a group of researchers collaborators that were interested in sarcoma research and we pulled together and started SARC and Stephen will tell you a little bit more about the organization but it was a small group of people that initially started Mayo Clinic was part of that group and then over time I had the opportunity to become more and more involved with SARCs and eventually became medical monitor officer and now chief medical officer.

Thank you. Steven Young is the CEO of Sark and a similar question. Stephen, tell us your journey. How did you get involved with SARK and what was the vision when you first started and, what is your vision now as you've been into it for a while?

Again, I echo Scott for thanking you for hosting us. This is a great opportunity to spread the awareness of who and what SARK is because our mission is to help rare and ultra rare cancers for patients that are impacted by this.

I joined SARC about five and a half years ago. It was recruited in to step into the rather big shoes of my predecessor who was part of the founding group of leading and directing this organization.

My background is as a non-scientist is facilitating and establishing collaborative research consortiums in cell tumors

and blood cancers. And so my role here at SARC is primarily to run the organization to be the facilitator, enabler, catalyst to allow doctors to collaborate within academia and also critically, we also bring the patient, and we'll talk about this more later, I imagine.

We also ensure that the patient's voice are included in our study designs, et cetera. So what SARC does is handle a lot of the business aspects, and I'm in charge of that.

Dr. Okuno and our chief scientific officer respectively are responsible for setting our scientific mission along with our various committees and clinical mission and to oversee our clinical trials.

And SARCs is the operational sponsor of these trials. So think of us as the word catalyst. We catalyze, we allow scientists and clinicians collaborate more effectively.

And it's my job to make sure Sark does the best you can in that space. Well, like I said at the beginning, I'm actually really excited to have both of you on the podcast.

I learned about Sark just earlier this year, had a diagnosis of solitary fibrous tumor about three years ago, at I guess at end of 2022, beginning of 2023.

And at beginning that journey, it's just so overwhelming because it is a rare cancer, most sarcomas are rare. And it's hard to find really detailed information.

And at some point in the dark hours of the night when you're worrying, you wonder, is anybody even researching this? How far can this go? Is there anybody that actually knows about such a rare cancer?

And so to found out about other researchers has been really wonderful. To find out that there's a whole alliance that's organized around rare sarcoma research and designing clinical trials and making sure that we actually put the pieces together and connect all the dots was really exciting.

I was so excited to find that. So I wanted to ask you, Dr.

SARCu2019s Mission and Role in Sarcoma Research

Okuno, as you've gotten involved in this, and you're a medical oncologist, you have this experience, a broad variety of cancer knowledge. As you got involved with SARC, what do you see specifically as the role of SARCs as opposed to other organizations that are in the space?

Yeah, that's a great question because part of the evolution of SART has been to use and leverage the local expertise of major sarcoma centers. Our job is to say, if you are doing solitary fibrosis research, how do you connect and collaborate?

If you're interested in a clinical trial that crosses multiple institutions, How do you do that? That's where CIRG steps in. So our job is not necessarily to set the agenda of all the cancer centers out there and doing their circular research.

We love this decentralized approach to say it's, you guys do the research, You do these activities. Well, we are there to help, as Stephen said, to be a catalyst to connect researchers.

and to hopefully develop clinical trials based on that research. And SFT is one of the more rarer types of this, but we have done multiple studies where we are able to get world's experts together to design and develop critical trials from their institutions, and also work and collaborate with industry.

Industry is very important with what we do in Asia is because they have resources and expertise as well. And that we help guide them into the diagnosis of sarcoma, where the big institutions that do the research.

So we're as the catalyst. Part of our job is not to own all that space, but to allow people to thrive and develop and collaborate. That's what our name C stands for in the collaboration in SARC.

No, that's really good. And like I said, I was just so excited to find that earlier this year that there is an organization that puts money behind it and puts information behind.

One of the things that we all know is that when you pay attention to something, it tends to get a little bit better. When you measure it, It gets better and sometimes it can feel like several disparate organizations that are doing work, but don't necessarily have big funding or they don' availability of just trying to get all this information together.

So I love that, like you said, you coordinate with industry. You coordinate. With different institutions, not by telling them what to do, but by being able to collaborate and facilitate this research.

And it's so the mission is really noble and it, it broad cause. There are, I think you told me over 70 different types of sarcoma that you address and it is quite a few different diagnoses.

They share some similar features. It's really kind of a broad mission, but it's an important piece of the puzzle that I suppose was missing before SARC started.

When you first got involved, what was the problem that SARCs set out to solve or what the missing piece that, you saw SARc as filling? I'll highlight it and then we'll have Stephen tell the history of how, what we're still trying to solve right now.

Back when CERC was there, there was a big reorganization of what would say the cooperative groups. This is the National Cancer Institute or the NIH. And at that time we probably had 11 different cancer organizations doing multiple clinical trials, but no one was focused just on Cercoma.

And during that re-award, we wanted to make sure that sarcoma expertise of running clinical trials, designing clinical trial was done by sarcoma experts.

That was not available 20 plus years ago. And we said we need an organization to help coordinate and focus on sarcoma research developed by sarcoma researchers, developing from real expertise and those that actually manage saricoma.

So that's how the loose-knit affiliation went. We realized fairly quickly that each institution brings a lot to the table. However, if you bring four or five different institutions together, you can really design trials better.

You can do a resourced commons core group better, and then you can answer questions quicker because you're hitting circled centers that have the volume of patients that can actually execute on the design of the trial.

And we're very fortunate that all of our trials have approved very well. We published on every single one. Bigger cooperative groups, when you do these trials, they linger on because there's not enough people in these bigger groups.

So that's how we've developed. Now, to sustain this, we need support. And as we have grown, so has the cooperative groups. They've learned their operative groups that do research as well.

Many of us are also part of those big cancer center, NCI, or what we call CTEP. And I'm using the lingo and we can probably get into this alphabet lingle that we kind of throw out there, but it's really important.

that we understand that in order for us to continue to move forward as an organization, we do need collaborative research with industry, with NCI government and grants.

And that's been a huge change in our world because the space is greater than ever before. We have more and more industry people, more more researchers interested in sarcoma.

So it's actually a great time.

Why SARC Was Needed and How It Works

to be in this research field, when in the old days, we were in back alleys trying to pull ourselves together. But now, Sir Kolob, based on a lot of great individuals that we have been able to come across, has been helpful.

And that's where Stephen has involved with Sarkozy, is how do you take an organization that started as a small little group and continue to be relevant as we go forward in 2026 and beyond, not only for the big so-colmas, but also the rare so colas.

So Stephen, your thoughts on this, we've moved along. Yeah, interested in your thought because like you said, the goal is to a catalyst in all this. Stephen what do you think?

Yeah, I think to build on the other side of the coin. So Dr. Kudo touches on, the criticality of team science, multiple investigators with great ideas and what SARC does and drives is eliminate some, not all, some of them barriers to multi-sector vibrations.

SARCs rather uniquely is the regulatory sponsor of a trial. They can't underline that much, how almost unique that is. It's not easy to do. The NCI, National Cancer Institute, Corruptive Group Models, et cetera, grew up out of the need to drive team science, primarily across academic centers.

the upside to that as the federal resources, and there are centralized aspects of that. The downside, and I don't mean in a negative way, the downside is, as Dr.

Okunov said, Sark is focused only on sarcoma. As he said to me once years ago, a sarcooma doctor trying to convince a committee of multiple specialties, breast cancer, endocrinology, whatever it might be, that this trial makes sense.

It's a bit swimming upstream because that's not what they live, breathe, and eat. As Dr. Bruno said, is SARC aren't us. We're all metricoma. And so the logistical aspects of writing a multi-center trial is not MITRE.

So SARK exists almost like a central clinical trials office across all these major centers around the US and also globally to facilitate and turn these ideas into action.

turn potential energy into kinetic energy and translate in a relatively rapid space, an idea into first patient enrolled in the trial. And we, SARC, handle all the logistics, contracting, regulatory submissions, database collections.

We bring in biostatisticians that work with the doctors on designing of studies. I can go on and on, but the bottom line is we don't invent these studies within SAR.

Those are being invented by Dr. Ushakuno, So with all these doctors around country, around the world, our job exists, as I said, is to effectuate their vision and to handle all the multi-center or logistical aspects.

Fundraising, there's Dr. Kuhn, who said we do need funding support to support this. There's not a lot of money available in the sarcoma banks, if you will, financial banks of the whole world.

And I'll close by saying, Dr Kuno said something also important. Drug companies, the biopharmaceutical companies these have these compounds and they could take them in multiple directions.

They could go after the big cancers like breast cancer or lung cancer, but it also biologically may work in a small subset of the 100 or 120, 150, I hear of subtypes of sarcoma.

And if we can make it easy for a biopharmaceutical company, say we'll also study this in sarcooma, it's a win, win win around the table because we're encouraging compounds or drugs or agents that may not have come into

sarcoma, the existence of SARC and the cooperative groups makes it easier for a pharmaceutical company to justify taking this drug that costs a lot of money to develop and to also add on or even primarily target sarco.

So that's what SARCs does. We reduce the barriers, not only, of course, collaboration across academic centers, but also the barrier between the biopharmaceutical industry and the investigators then actually have the ideas of how to take these drugs and study them and publish and hopefully eventually get these drug approved by the FDA.

Oh, thank you both. That's a doctor. I love it. And I think it's really interesting. As a patient, as a solitary fibrous tumor patient. This sounds amazing because if you look at the studies on solitary fibers tumor, a rare type of sarcoma, the sample sizes on any of our, not the meta-analyses, but just our regular studies that are done at a primary institution.

Sometimes the enrollments are fewer than 20 people. So you're trying to get actionable data from just such a small subset. And it's really hard to really say, we've got sample group here, sample groups here.

You can't really do treatment arms very well with those, with that small number of people and so one of the things that I'm really excited about SARC, like you say is you can help collaborate and catalyze, I like your word, trying to get some of this research done across multiple institutions in the United States and abroad.

Dr. Okun, I wanted to ask you, can you give us an example of, are there times when you have done that with other research, maybe not necessarily solitary fibrous tumor, but times where you've collaborated across several institutions, in United State or abroad, and how that went?

Yeah, that's a great point. And when you start to have rare tumors, and there might be less than 500 total across the United States, you're going to need an elaboration.

Sark has been able to do multi-institutional, multinational studies. I'll just highlight one right now. We're running a clinical trial with four institutions on clear cell sarcoma.

Now, for those that don't even know anything about clear cell sarcoma, it's probably very similar to thalagery fibrosumera. It's rare. But there is this very specific translocation that's important.

So there's an immunological type of a study that being run with two collaborators, one from Memorial Sloan Kettering, as well as one Royal Marsden in London.

And we're very fortunate that we did have support from industry and expertise. on both the Memorial Sol Kettering side and the Royal Marsden side to go develop this study.

But in order to answer a study that is only about 200, 400 total patients a year, we needed to do cross-pond across the multi-national study and because of that we've had two sites up and running and then we brought two other sites in the United States on board.

And this is how we as an organization can help get a study, get industry involved, and get the expertise. of clear cell and run a clinical trial, not only in the United States, but also in England at this point.

Now, the hope and goal is that we will have more of these.

Multicenter Trials and Rare Sarcoma Collaboration

So if we have a solitary fibrous tumor investigator that's interested in doing a new novel approach and needs to pull together resources, they will approach SARC.

Sarkin will work with that institution and or industry and pull together all the clinical places that have solitary fibrous tumor and then run the critical trial.

That's how it is. As a patient, you don't know where the big sarcoma centers are. Now you as a physician, Dr. Crain know that, but Sark has done a great job of developing what we would call sarcooma centers.

And maybe you can ask Stephen Young about that because I think this is a good resource for patients of where high volume sarcomas are being seen. Yes, a lot of it is done in the community with the local oncologists, but ultimately, just like your journey, you do need that expertise and where do you reach out if you're not a physician?

So we have developed on our website and a lotta work and lotta collaboration, the Sarcoma Center, what we call the MAP. I really appreciate that answer and I know I echo the prayers of hundreds of people with solitary fibrous tumor.

We hope that as you coordinate with people in Florida and across the United States and in Spain and England where they're studying some of these rare cancers that eventually that will turn into a clinical trial and that would just be an answer to so many prayers like I say to be able to say that like what you're doing with clear cell sarcoma, that eventually that comes into solitary fibrous tumor and really all of them.

What a cool thing. Let me echo what she said about the Sarcomas Center. I'm a primary care doctor in a rural area, which means I see a little bit of absolutely everything.

There's some stuff I thought I would never see and I'd see it and like, oh, good thing I studied that in medical school because I come across everything because one day I'll be delivering a baby and the next day, I am taking care of somebody in the nursing home.

and the next day I'm taking care of somebody in the intensive care unit, or sometimes all those things are the same day, and I work in an emergency room as well.

So I get a perspective of a lot of different fields of medicine. With that in mind, I am spread a mile wide and an inch deep, hopefully more than an an.

But the concept is that you can't have the really in-depth working day-to-day knowledge of every single disease if you treat a broad variety of stuff.

And to that end, if I see someone that does not see these rare types of sarcomas, ever or extremely rarely, they're going to have some working knowledge but not the depth of knowledge to be updated on the latest and greatest research in those spaces.

And so having sarcoma centers of excellence where we know that they really have a very deep knowledge, maybe not a mile wide, but a mild deep, a really deep on something has been really important for my own personal journey.

I wanted to turn that over to you, Stephen. Would you mind talking a little bit about that? What has SARC done to to collect all that information across sarcoma centers and where could patients, if somebody's listening to this or if you're a physician listening saying I need to refer someone to a sarcoma center, how do people find that?

What have you been able to do on that You know, while the two of you, two physicians were talking, the word access kept coming up, access to expertise.

And you mentioned Dr. Crane, that you're a primary care doc in the rural community. You could see something that, you don't know what to make of it. As you said, your mile wide and a couple inches or couple feet deep.

They say, You've not seen it, but it's seen you. you may not recognize it so exactly that. Go ahead. So therefore, the Sarcoma Center's directory grew up by the fact that we were finding out that patients and patient advocacy organizations around the world were steering their patients to what we then called the SARC member centers map.

These were centers that were done trials with. And we rather quickly realized sort of the emperor had no clothes

because the map was who were collaborating with on trials did not necessarily equal a center that had multidisciplinary care across and breath in depth.

They may only see five patients or 10 patients, 20 patients a year. You both as physicians know it's experience. I'm not a doctor, so I am just extrapolating here.

So finding where to send patients. Neither to find yourself or a loved one or your own patient that you see something you don't recognized. So this tool grew up out of the fact that we realized we needed to put some form and function behind it.

What we did is we created this questionnaire where centers objectively identify how many patients they see per year in sarcoma space. Do they have a multidisciplinary team with monthly tumor boards focused on sarcooma?

Do the publish? Did they drive research? All these end up into a factorial calculation of objectively determining, do they get on the map or not? And it's not a subjective decision.

It's objective. Do they meet this objective criteria so that at the end of the day, the three of us as human beings would feel comfortable sending a loved one, for example, to any one of these centers.

And yeah, there's a strong concentration in the United States. We've put a big push to ex-US as well. So this is a, so Coldwell obviously is not limited to the united States, and so we do have approximately 25 centers outside of United states and within the US, about I think 85 or 90 at this moment.

And the reality is as a human being would be comfortable sending myself or a loved one to any one of those dots on the map. So this is a tool that you can find centers.

And as I said, it could also help frontline clinicians who doesn't necessarily can't pick up the phone and call someone at Morrill Sloan Kettering or the University of California, San Francisco, or whatever it might be.

They can pick the phones. All the contact information is included in this. patient navigators, the physician that's in charge of the sarcoma program, email addresses, that key in today's world.

So access is key on that. As I said, The Sarcomas Centers Directory was ideated to help patients, but it also can help frontline clinicians or even oncologists or surgeons that don't necessarily know how to escalate this for their patient and help them get to the center.

Sarcoma Centers Directory and Patient Access

And timing is everything, as you know, personally and professionally. every month, every week that goes by, it decreases the likelihood of having a positive outcome.

So speed is the essence. We're very proud of the Sarcoma Center's directory, which we were able to get funded for the first two years. Were actually quite frankly seeking additional funding support as we speak so that we can expand and grow it even further.

And the last thing I'll say is we also included in part of this process developing a patient advocacy directory. of all the patient advocacy organizations.

Many of them are subtype specific. And as we mentioned earlier, there are more than a hundred, whoever you ask, is more that a 100 types of sarcoma out there and not all, many of the, some of have foundations that are set up specifically for that histology.

That's what they live, breathe and eat. Lyo myosarcomas, whatever it might be. And the last thing I say, we also added a clinical trial finder matching tool to help patients and frontline clinicians identify clinical trials that their patients may or may not qualify for.

And I'll stop there. No, it's a wonderful collection of resources. Just tell people, some people are going to access on a computer. Others are just listening to this while they're driving to work or exercising or something.

Where do they go to find that? So if somebody says, I want to go Sark's website and I wanna know where can I find sarcoma centers of excellence or contact information, or I'm a frontline physician.

I have a patient with some sarcoma I've never heard of. How do I. Find information on that. Our website is sarctrials.org, trials.or. Sarc is S-A-R-C, Trials, like clinical trials dot org.

And in there there's a menu, there is a patient resources tab that will allow patients to access all this information. We also have a researcher facing us, a medical, scientific facing work tabs with all these committees and structures, et cetera.

So one stop shopping, sarctrials.org, and you can find what you're looking for. Excellent. Thank you. Dr. O'Koon, I wanted to ask you a little bit as we go into this.

Again, you mentioned alphabet soup. There's lots of acronyms we use and I have to be a bit careful with my patients. I try to tell them I speak doctor and patient.

It's important to make sure that we speak both languages. We throw around the words CTOS, ASCO, and SARC and not everybody knows what those mean, but there's a meeting that SARCs has every year in preparation for these large cancer meetings.

Do you mind defining those terms and talking a little bit about what SARCS does in relation to some of these larger scientific gatherings and how that might affect patients and researchers who want to get involved?

Yeah, that's a great point because we learn because, we live and breathe it every single day, but the two major mediums. that we and the sarcoma realm really track up, and there are many others, is ASCO.

ASCo is the American Society of Clinical Oncology. It is a yearly meeting typically in June, the first weekend in the junior realm at time in Chicago.

There are roughly 35,000 other oncologists and then learners and everybody go to that meeting. And that's where typically the education of all oncology and in part, hematology there.

They also have groundbreaking research presented there and that is a great opportunity. Not all sarcoma, by the way, but this is great avenue. If you want to know anything about oncologist, ASCO is the place to go.

It has multiple days in Chicago. However, It is a huge meeting. It's in multiple buildings, multiple venues, and where did the sarcoma fit into that space?

And it's hard. So we decided to have our meeting before ASCO, American Society of Clinical Oncology. And we have a meeting there. We have it before the start of an ASCo, that allows all the Sarcomas people to come.

We have a scientific part, we also have more of a patient-facing part. And then we kind of share what we are doing as an organization. That gets everybody in the mood, if you do Cercola, to kind start the week out there at ASCO.

Then we hopefully have some highlight of what WE do at an to share groundbreaking research that Zircoma does. And fortunately this year at ASCOL, we were on the plenary session.

Now, what is the plenary session? That means of the 35,000 people there doing all research, they select four studies that they want to present, not a bone marrow sarcoma.

And we're fortunate that Sark, Dr. Dixon and SARK-41 in a study using a bemucite clip in the different sarcoma called D-differentiolagma sarcooma was one of four plenary session.

So we were very excited and we're very grateful for Dr. Dixon and his team, and the research team at SARC, in the multiple centers that participated in this study to do this studies.

Again, that is that part. The second major meeting that it is there, it's called the Connected Tissue Oncology Society called CTOS. Now, CTOS by design was done several 20 plus years ago as well, and it pulled together all disciplines of all people only focusing on sarcoma and started as a small little group with pathologists, radiation oncologists surgeons, medical oncologist.

And now it's quite big. This is where also major publications, research, and gathering that education only for sarcoma is. And then this year, it is six months different than ASCO and CTAS is now in Seoul, Korea later this fall.

And there, because all the Sarcoma people are there we at SART also have a meeting before they start the whole several-day journey of learning everything about Sarroma, but we also a session there as well.

So those are the two major meetings that we physically go to ASCO, American Society of Clinical Oncology, and CTAS, Connected Tissue Onchology Society.

Major Sarcoma Meetings: ASCO and CTOS

And Steven and his team pull together, along with our chief scientific officers, some great meetings. We also have patient advocates that come to these meetings, maybe you'll ask our patients and family members invited to the meetings and we can share.

Yeah, Stephen, do you mind going over that? Because if I'm a patient, if i'm, a family member, If I am a general oncologist or someone just anybody, how do I sign up?

If i said I want to go to one of these meetings and actually in my case, like I said, I've never met somebody with solitary fibrous tumor. It's just like in person I met online.

I have several friends that have the, uh, social media connection that way. But if I wanted to actually meet somebody else that's in this space and meet some of the researchers, would I be welcome?

And how do I go about registering for that? So if anybody listening, how would they go First, it's a big yes if patients and family members and loved ones are more than invited to this meeting.

We actually go out of our way to make it have an element of patient centricity to these meetings. It's primarily about medicine and science and studies, but we, for example, our meeting that we just had in Chicago at ASCO.

included the keynote speaker, the closeout speaker was a patient survivor, a very well known communicator, podcaster, etc. So we make sure we get the patient voices incorporated in this.

Secondly, when our presenters present science and medicine from the stage, from a podium, they also go out of their way to not only use acronyms. They might explain, I don't know, gene therapy, then they probably will have a sentence after that explaining what we mean by gene-therapy in relatively lay language, which I appreciate because I'm a lay person.

So they do a great job at, if you will, not, I wouldn't say dumbing down, but to make sure that the audience in the room, no one is saying I don't understand what they're talking about.

They may not understand every subtle detail of the science, they understand the gist of it and that's what would we do. We also, as I said, highlight other patients throughout the three-hour meeting at ASCO in Chicago.

And then during CTAS, a number of patients and advocates do go to the CTASE meetings, which I don't think Dr. Kuno mentioned is usually alternating years within the United States and then outside of the And due to vagaries of scheduling, et cetera, outcomes probably from our COVID era.

This year, in two months, it's going to be in Seoul, South Korea. Next year it'll be Vienna and Austria. The year after that it will be back in the United States.

So there's always an opportunity for folks that people travel to either Chicago for ASCO or also alternating years to CTAS within or without the U. S. And I guess the only, what was the other point you asked about?

I apologize. I just wanted to know, like, how do people actually sign up? So if somebody listening to this says, Hey, I actually want to go to. And, and I think that would be useful information to collaborate work.

How does somebody sign. So for ASCO, we actually have a formal registration process. It's completely free to all registrants with the exception of those from the biopharmaceutical industry.

That's just the way we structured it. So patients can register, they go to our website, or they can click on meetings and there they could find the links to register for.

For a CTAS, we're actually within the meeting envelope itself of the connected tissue oncology society. And there's no fee to get into the SARC session.

There's not pre-registration part of this SARCs session, but you do have to be technically having registered for the connective CTOS meeting itself. Just to clear on that.

Thank you. So I wanted to ask, Dr. Okuno, I want to another question as it was kind of our last segment here. We live in the era where the information age, instead of treating the what, we're trying to get to the why.

In most cases, where understanding what genetic abnormalities actually exist within the cancer, or understanding the microenvironment around the cancers, there's just so much being done in this space.

If a researcher or a patient wanted to get involved a little bit more with SARC, or specifically we're talking about solitary fibrous tumor in my case, how do people get involve in that?

Because we would want to do everything possible to help design clinical trials around this information that's already known because there's a lot of primary research, but trying to a clinical stage trial around some of these sarcomas is very challenging.

So what can an individual physician or patient or researcher do to support the work of SARC or to take the next step if they wanted to get involved. Here's, I'll just put a plug in for the cures.

The organization that you were involved with, which is called the, these patient advocacy groups do have medical advisors that really work well together to help drive science.

But if you are an individual researcher interested in solitary fibrous tumor, you probably know the community of other doctors, physicians, and scientists working in that.

And at SARC, we're very fortunate. We have Dr. Jonathan Fletcher, who is our chief scientific officer who chairs the Discovery Translation Committee. He and his team, the board, and the committee work extremely hard to engage and collaborate science, the basic science core science group together.

How Patients and Researchers Can Get Involved

And they hold meetings called SAG that are really bringing in different researchers, not necessarily researchers for clinical trials per se, but during the basis core research.

So if you are an individual that has a great idea, has concept for a clinical trial, they just reach out to me and our group and we have a committee that reviews it.

We're very fortunate to have two individuals. Dr. Greg Cote from Mass General Leads our what we call clinical trials development committee and the vice-chair is Dr Libby Davis at Vanderbilt.

And they help support individuals and industry develop the trial. If you want to do basic science research, they reach out to us and then we can connect them with the Discovery Translation Committee because there are other people in the circle of the world doing that work already.

So we are the conduit to get people there. And if you're a patient that's interested, I would probably start out with, you can reach out to our group as well, but you do at the solitary fibrous community have CuresSFT, which is an organization that is designed to bring together researchers for specifically SFT.

And hopefully if guys come up with a trial concept, You'll want to come to SARC and we will develop that study. No, thank you so much. Let me just plug that again.

Curesft.org is a recently launched foundation specifically for solitary fibrous tumor. I strongly encourage you to, if you're a solitary fibers tumor patient, family, researcher, anybody, that's a wonderful tool that has recently been launched.

Our friend Steve McBee has done a lot of the work on that and I just want to call that out. as we wrap up our time here. Before we do the wrap-up, Dr.

Crane, I want to go about something else back to the patient centricity and the meetings that you're asked about. We have a two-hour breakfast that leads into this meeting, an hour and a half breakfast.

The opportunity for patients to be eating a bagel, talking to a field leader, and just say SFT research is built into that. Another thing I wanted to build in is in each of our clinical trials, we actually embed trained patient advocate insurer So we make sure the patient's voice is in the room and respected and incorporated into the study design and some of the patients' reported outcome tools and go on and on.

But that's rather unique that we made sure that the patience are embedded in that. So, we have a group of trained research advocates that are being embedded into each of our trials.

Just two points I didn't want to leave off the plate. We could talk for another hour and a half about other things that Sark are doing. I want make that sure patient aspect of this is underlined.

Yeah, like I said at the beginning, I'm so excited about SARC and what they're doing and the research and work. And not only is it a high-level major institution, you can get involved as a patient.

You can be involved with a researcher. There's just a ton of resources that this organization puts through. The other comment is, we're all people. No matter where we are at, no matter what you are doing, when you interface with somebody and you actually realize, hey, this person is a human being.

We share a lot in common. And you meet the researchers and the researches meet, the patients. I think there's a lot of value in that. Stephen, do you have any other places where you would guide people to, to contact you or other people if they wanted to find more about SARC?

I'd say our website is a good place to start. I should also point out, and you may have already touched on this, we have a series of podcast series that are run within our organization as well.

We'll call it the Sark Talk Podcast Series. Dr. Cronow is the host on that. we also have it Sork Talk Journal Club, which focuses on cutting edge, recently published or presented data.

And then the third one, which is also new is called the patient experience led by a patient survivor and no MDs, no degrees after the names folks sit around and talk about their disease and their experience and the loved ones and experience.

So there was also those avenues as well. And I would encourage people to check those out in addition to, of course, your podcast, Richard. Yeah. It's so wonderful.

I consume many of them already leading into this call. Thank you. Those are wonderful resources. Dr. Okuno, do you have any final thoughts as to where you would turn people or any recommendations for people who are listening to this excellent podcast?

As we say that there's a wealth of information, some of that information you have to wait through to kind of make sure where you go. But we do steer people to our website to make that if you are interested in connecting with major sort of COLA centers that have multidisciplinary high volume, it's there.

The other part too is that we really want to makes sure patients are engaged in their patient advocacy groups. SART, with the help of Denise Reitke and some other individuals started the Sarcoma Coalition, which is all the patient-advocacy organizations out there because they provide the local, boost-on-the-ground expertise of their specific disease, just like CURE's, the website that you have.

It is there as well. And that's where we don't want to own it. We say, if you want, to know about Lyme Myosarcoma, go to the National Lymyosarcoma Foundation.

If you wanna go do, learn more about solitary fibers tumor, cure solitary sft.org. You wanna know more by EHE? Go to our sarcoma coalition and go to the EEG website, same thing for Desmoid.

Patient Advocacy, Resources, and Closing Remarks

So if you are there with a rare disease and don't know anything, you can come to SAR and we can get you located to a different organization with AI and CHAP, GBT and CLAWD, and you're going to find it.

The real important part is to find out who is the right group to understand. And this is where we at SARC kind of work with these organizations to make sure that we feel comfortable with the mission, vision, and the individuals that work in this space.

Steven, you were going to say? I just wanted to put in a plug also. Obviously, I said earlier, SACOMA doesn't only happen in the United States. There are advocacy organizations around the world, And there's this great group called the Saccola Patient Advocacy Global Network, SPN.

that had a sort of a European centricity to it early on, they continued to expand and work closely with the sarcoma coalition. And so there are a lot of advocacy groups out there that can actually help patients access expertise and be answering layperson to lay person questions about the disease, not necessarily always an MD or a physician or scientists explaining it.

So I can't accentuate Dr. Okuno's point more. You said it before, as an SFT patient who felt alone, you have never met another, this is just like a pig in slop when the patients get together and realize I'm not alone and there's someone who is struggling with the same thing and I am trying to figure out what to do with my son, daughter or myself or my mother, how to handle them.

These groups are invaluable resources. I just want to thank both of you. I think this has been very useful, very instructive for people who listen. Everybody who listens to this will take something from it that's actionable and useful and realize if you're a solitary fibrous tumor patient or a sarcoma researcher, realize you are not alone.

Come to these meetings. There's a group of people that are very interested in this. And I'm excited, I am enthusiastic, and I have a better day for having this conversation.

and appreciate both you so much for taking the time to do it. We appreciate you doing this for the opportunity. Thank you. I echo. Thanks for tuning in to the Doctors Making a Difference podcast.

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