Hope for Patients with Solitary Fibrous Tumor: Advances in Sarcoma Care With Dr. Robin Jones Transcript

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Introduction and Guest Background

I'm pleased to share this podcast recording with you. This recording is with Dr. Robin Jones, a really kind and helpful person who is a medical oncologist and sarcoma researchers, spent time in the United States and grew up in The United Kingdom, is now back working in London.

He provides some excellent insights on treatment of sarcoa and the specifically solitary fibrous tumor. He also talks in detail about the challenges of accessing medications in Europe and his work in the United States.

A person who's worked in lots of different areas in this field and delighted to meet Dr. Jones. This is an interview I've been looking forward to for quite some time and I'm really excited to present this to you.

I think you'll really enjoy it. Today, I'm delighted to welcome Professor Dr. Robin Jones. Dr Jones comes to us from England, and I am so excited that he's taken the time, despite the times old differences, to join us today and talk about his work as an oncologist and a sarcoma specialist.

Doctor Jones, would you mind introducing yourself to the audience? Yeah, well, thank you so much for the invitation and likewise, it's a pleasure for me to join you today.

So my name is Robin Jones and I'm a medical oncologist at the Royal Marsden Hospital and the Institute of Cancer Research in London. And I treat patients with sarcomas, including patients, with solitary fibrous tumors.

Oh, thank you. That's a humble introduction to a long journey to become a sarcoma specialist. And people who have listened to my podcast know that I am a patient with solitary fibrous tumor.

I also work as a physician full-time and I feel really blessed to be able to continue that important work. But I enjoy working with talking to other physicians and patients who've dealt with this.

So walk us through a little bit of your journey. You started off in United Kingdom. I know you spent some time in Seattle and now you're back in London.

Tell us a bit about your career journey, how you became a sarcoma specialist within oncology and how your careers led you back to England. Yeah, so thank you.

As you said, my medical training was in the UK. I trained at Skye's and St. Thomas's hospitals in London and then did my oncology training at the Royal Marsden.

And essentially during my on oncologic training, I became very interested in sarcomas and I was struck by the fact that there were so many different types of sarcoomas and that they were all treated with the same chemotherapy drugs in the metastatic setting.

And that led me to think that we surely can do better than just using the Same treatments for all of these different diseases. and that coupled together with The unmet medical need for better treatments, for patients led Me to pursue a career in sulcoma oncology.

Career Path to Sarcoma Oncology

I was fortunate enough to take up a position at the Fred Hutchinson Cancer Research Center and at University of Washington in 2010 and spent five very happy years with my family in Seattle.

It was a difficult decision to move back to the United Kingdom. I think being so far away from family can be really challenging, particularly if parents are unwell, which ultimately led to a decision to move back to the UK.

But we were very happy in Seattle and you may have heard me say before that I'm American really, but I just need to work on my accent. But I would then meet back to the Royal Marsden and for the last 10 years have been working on the sarcoma units here, basically working clinical trials and working with collaborators including Paul Wang on tree translational studies as well.

So that in a sort of nutshell is my story in terms of my employment as a sarcoma researcher. Well, I think it's interesting. I remember the, in medical school, going over all the different sarcolas and thinking, wow, there's a lot of sar colas.

That better memorize that for the test. But I took that back in my memory and I'm a primary care physician. So I see everything, you know, so many different things.

And so I feel like I have this broad set of knowledge, but you saw that subset of Sarcolis and said, well, if there is work to be done, we surely can't be treating this variable group of diseases.

that some of them are rare, some are a little more common, all with the same disease, of the exact same kind of treatment protocol, because surely even though they have some related characteristics, they're all unique individual diseases.

And now as we come into the more genomics era of medicine, we realize there are specific mutations on every one of those that is different and unique.

So I'm so thankful that you recognize that early on, that's you have that interest. And the second comment on your statement is sarcoma affects people all over the world.

If we concentrated all of the people who have the same interest in only one country, we would be remiss. I am so grateful that, you were able to return back to the UK for family reasons, but I think it's a large benefit to folks who are in the United Kingdom, who also suffering from various types of sarcoma.

to bring someone of your expertise and to have you be a part of a great institution and continue to offer those services. And take that interest you had in medical school and take it into real world applications.

So now where you individuals come for a consultation and they meet someone who has a broad variety of experience and you can take and make it a real-world application for your patients.

I think that's wonderful. Yeah, I think you put it in such a nice way. So I'll have to listen to the recording and use the way that you say that. I thinks you've hit the nail on the head.

Well, so I wanted to ask specifically about solitary fibrous tumors. Of course my interest, because it's something that I live every day and have treat.

And then sarcomas in general are a little bit more of a rare type of cancer in some ways. What would you, say when a patient comes to you and says, okay, sarcolla or specifically solitary fibrous tumor, how do you take that as an approach?

Because I think this older model of, well, everybody gets the same kind of treatment to now where we do more of a genetic study and try to tailor that.

How do approach that with your patients when somebody arrives at your clinic with those kinds of questions? Yeah, that's a good question. Initially, I try and give people some sort of perspective on the rarity of the condition that they've been diagnosed with.

So, tri-fibrous tumors are trying to give some perspective in terms of all together. Sarcomas are counting for about 1% of adult cancers, but that 1 percent is made up of 80 to 100 different types of sarcoma, and that unisolatory fibrous tumor is a small proportion of that one percent of adults cancers.

And the other thing to highlight is because sarcomas and tumors are connective tissue that they can arise anywhere in the body so they have a wide distribution in terms of the primary anatomic site of a tumor and those three things the rarity.

The heterogeneity and certainly the fact that they can occur anywhere in the body can make them very difficult to diagnose and to treat and perform clinical trials.

And that's just to give people some sort of context and perspective as to how rare the condition is.

Understanding Solitary Fibrous Tumors

I think one of the things with solitary fibrous tumor in particular, even during the time that I've been practicing oncology, that the diagnosis of solitary fibros tumor has become much more robust over the last 15 years with the identification of a characteristic molecular abnormality, the NAB2-STAT6 rearrangement, because I remember doing retrospective studies 15 years ago where the diagnosis of solitary fibrous tumor was essentially a diagnosis I think, you know, things have moved forward a lot in terms of the identification of this disease and what we need to do now is to refine that further in term of treatment approaches and more precise treatments for this type of sarcoma.

Well, it does really help to know exactly which mutation is. There are many sub mutations within that, but that STAT6NAP2 mutation, is a big finding because instead of just saying this is Maggius parasitola or things that are diagnosed as an exclusion.

Now, like when I had my tumor, that work had been done. So the diagnosis was made and the molecular studies were done right then. And so they could say, Hey, you haven't solitary virus tumor.

Now once you have something you can actually research and define, then you could try to get subtypes figured out and figure out what works. But that was a really big challenge and thing that missing prior to that, the characterization.

One of the biggest things in this whole thing is almost definitional or looking back on what are we defining it as a solitary fibrous tumor. And it's crazy that it has taken so long to arrive at that conclusion, but we're now at an era where we are all reading from the same sheet of music so to speak we all know what this is and then hopefully can devise ways to come up with treatments that are a little bit more specific to that mutation or at least there's many different mutations on that but something that's a bit specific than what we had available prior to this.

Yeah, again, you put things in such a nice way. The fact is that prior to the identification of this rearrangement, here, all of the studies that have been done, it's very difficult to know, well, was that, were all those tumors included in those studies?

Were they actually confirmed as solitary fibrous tumors? Would we now change the diagnosis to something else? it is such an important point to make that molecular confirmation of the diagnosis really really does help us so much and helps us moving forward in terms of performing clinical trials but also forming other retrospective studies so yeah very important.

One of the questions on this, I know a lot of people have got quite excited about the FAP site directed studies and there's a trial enrolling right now in the United States, but I there is quite a bit of work that's been done in Germany for fibroblast activated protein is a site-directed area within the support of tissue that can be, now that there's a way to direct a theragnostic or an antibody mediated side directed therapy, you can attach ligands to that to be able to the direct therapy to, that has a bunch of promise and had a lot of people talking and are excited.

Do you mind describing that? Many of the listeners or physicians that describe it as if you're describing it to. an eighth grader so that people can understand what is side directed therapy and what does a ligand and so the folks who listen to our medical treating understand.

What that is. Yeah. So again, this follows on from our previous discussion in a way in terms of making treatments more precise and directing treatments to the tumour rather than a sort of overall sort-of blunderbuss approach where we're destroying not only the tumor cells, but also causing damage to normal cells.

Fibroblast activation protein or P is expressed on various tumors, but notably solitary fibrous tumor. And that basically opens up an avenue for therapy in terms of using treatments, so using in a way to FAP-directed treatments, for instance, chemotherapy, we did a trial of FAT-activated doxorubicin so that the doxyruvacin is activated when it's actually in contact with Fap, resulting in theoretically greater tumor cell death rather than normal cells.

FAP-Directed and Radio-Ligand Therapies

And similarly with radio ligand, so which is basically combining a radioactive isotope with acting compounds to latch onto the FAP and again directing treatment to the cells rather than damaging normal cells.

So I think everybody in the sarcoma community is very, very excited about L-FAT directed therapy as a potential option in solitary fibrous tumor in particular.

You know, doxorubicin is known as a challenging medication. Folks who have been on doxxoribicine know that it has a large amount of cardiac toxicity and other things that are challenged, but it's also very effective for stopping the propagation of abnormal cells.

And so if you can direct something that effective so that doesn't have to go to every cell of the body, doesn´t really target the heart or other places, You can really get some mileage from that.

And then, like you said, similarly, if you can attach it to a radioisotope, it would also be damaging to other tissues that you really site directed to the tumor.

Think about the potential for restricting that growth. One of the things that I've reflected on as I dealt with this disease myself the last two or three years here is I'm thankful that even though it causes lots of challenges, I think that it's a relatively slow growing tumor that makes it challenging to treat in some ways, but it also gives us time.

You know, and so if you do a site directed therapy and it can really precisely target those cells that are expressing FAP, it has at least theoretically a tremendous opportunity to slow the growth of those abnormal cells, maybe more so than other therapies that we've explored in the past.

Yeah agreed and you highlight in a way one of the challenges of solitary fibrous tumour that there's such a spectrum of disease that sometimes the disease can be relatively progressive but other times can beat relatively slow and indolent so that you know there is a real spectrum with disease behaviour.

That's true. Yeah, some people have a very aggressive form and some have less aggressive for and it's interesting because while we know that there's a genetic mutation that's pathognomonic for solitary fibers tumor, there are many different subtypes and their characteristics of behavior are still being described and the more we understand that the, more, we can get it.

So I do think if you have to be a cancer patient, it's a better time to, be, a, cancer, patient. Now that it was before there's never a good time. But I'm thankful for the opportunities that are coming down the pike, so to speak.

Agreed. And again, I think you put things in a really nice way. That's kind of it. Another question I wanted to ask you with all these exciting areas is vascular endothelial growth factor treatment.

There's been a lot of work done on bevacizumab and pesilpanib and others that are targeting the growth factors that propagates the gross of blood vessels.

And while it's not specifically directed to solitary fibrous tumor or maybe any specific subtype of sarcoma, it does stop the propagation of blood vessels or slow it down and has shown to at least slow down the growth of these tumors.

What are your comments about that class of medication and how do you approach that with your patients? Yeah, so again, another fantastic question. You know, this has been a promising approach in terms of treating solitary fibrous tumor when it's spread elsewhere outside the primary tumor to other parts of the body.

And these drugs work by blocking the blood vessel growth, impairing the growth of tumors that way. There have been promising results with a number of these agents, including, as you mentioned, bevacizumab, vasopinib, but there are a whole range of other drugs as well.

We've treated patients with Carbosanthinib and another one of these anti-antigenic agents, anti blood vessel agents that has worked really, really well for patients.

I think one other challenge is that for some patients, with solitary fibrous sheath, these drugs can work really For other patients, unfortunately, they don't work as well.

But I'd say that they're an important component of treatments and very important that you discuss this with your oncologist if the solitary fibrous humor has spread elsewhere in the body.

One of the things to highlight, particularly in terms of, the fact that I previously worked in The United States, but now work in London, drug access and drug reimbursement can be very challenging in Many of the patients we have with solitary fibrous tumours, if we want to use these drugs, we'd have to try and use them on compassionate access programmes, or if got a clinical trial, will try to offer a clinic trial.

So drug access in certain parts of world can be really challenging.

Anti-Angiogenic Treatments and Drug Access

And even for drugs such as Przopnib, which is reimbursed in many other parts of the world we currently can't use that drug within the NHS which is really really challenging and means that we have to find other ways to get access to these drugs for our patients.

Every country approaches this a little bit different. Like the NHS, are they choosing not to cover those because they don't have detailed enough efficacy trials?

Or is it because the manufacture of those drugs is done outside of the UK, so they have a more difficult time getting the medication in the country? What do you suppose the reason is that they do not offer that for patients?

So in the case of Pezopnib in sarcomas, it boils down to the cost-benefit and the randomized trial in pre-treated advanced metastatic soft tissue sarcombas of pezopenib versus placebo showed a benefit for pezzopenab in terms of the progression-free survival.

So the time that it takes for the cancer to regrow compared to placebo, but it didn't show a benefits in term of for all survival And the reimbursement agency in the UK analysed the trial, analysing the outcomes and deemed that the cost benefit wasn't good enough to be reimbursed within the NHS.

With patient groups and other organisations have been trying to sort of push back at this in UK, but it's been very challenging. One of the things that we have been working on is to try and find a way to identify people that are more likely to benefit from presopinib to see if there are any markers within the that can help us identify patients that have a higher chance of responding to presopenib and other similar drugs and that's a work in progress, but

that is the situation that the reimbursement agencies sometimes can be very black and white in terms of their interpretation and judgement on clinical trial results.

Yeah. Well, I do understand that they want to look at real data and try to see efficacy and not paper things that are not going to really offer the person the potential to improve.

That being said, like you pointed out, there are so many subtypes and things, that really need to be characterized in this realm. And it's all like, you need the medications first so that we can design the trials, but it sort of a catch-22.

If we don't have the medication, we just can't design trials. We don' have those trials and we cant design medications. does require funding. And I think this is a worldwide problem, no matter what country a person is from, is how do you get funding for rare cancer research?

It's very challenging. So you recently went to the ASCO meetings in Chicago that happened this last month, and you talked to people that are studying cancer sarcoma all over the world.

How would you say people, I guess countries, but just individual cancer groups, how are they securing these medications for research And how are they obtaining funding for research on rare cancers?

Because it is challenging because there's not that many of us. Yeah, well, again, that's a fantastic point that you make. Taking a step back, rare cancers are probably between 20 to 25% of all cancers and are impacted by a lack of funding, even though essentially they account for about a quarter of more cancers.

So much more funding goes to more common cancers, and a disproportionate amount of money goes all of these rare cancer that make up 20-25% of all cancers, so you're right, it's a real challenge all over the world.

I'd say that in terms of obtaining research funding, I'm sure that all of my colleagues in North America, Europe, Asia, Australia, Africa all over the world will say that it's almost you have to get funding in terms of getting different funding from different sources.

So from grants from philanthropy, from national initiatives. And I think, you know, we just become adaptive trying to. Pieces from all, over any option that we can apply for successfully.

I think there isn't one funding source, but that we just try and get funding from anywhere that can in order to move forward with research and clinical trials.

In terms of your first point regarding access to drugs and funding for drugs, I'd say that the fact that there's Opnib is not available in the UK is a real challenge for us in UK, Other countries around the world, I'd say that Pozoknip is available and is reimbursed.

There may be exceptions, but I think the UK is unique in that respect that we won't access Pozochnip routinely. Well, I do think, like we said at the beginning of this podcast, we're entering this era of genomic identification on most every cancer specific to Fasolifer terifibros tumor.

Understanding those specific mutations that are causing this, i think we'll make a more specific research and antiangiogenic agents. or site-directed FAP treatments or other things that are still on the cusp of the horizon.

Funding Rare Cancer Research

I have to believe that's going to continue to really create a tremendous impact because instead of blasting everything generally, now you are site directing a laser focus on something that is much more specific to that cancer.

So as a cancer researcher, as an oncologist, where do you see the field going forward over the next decade? I

think moving forward, as you've alluded to, treatments will become more specific and more tailored for an individual person.

My great hope for SFT is that we will be able to use FAP-directed therapy to bring benefit to patients. And I'm really optimistic that this approach will Be successful over the next five years.

And I guess one other question on that is, I don't know if there's a great standard of care of it. If you're on the standard care therapy, which would be antiangiogenic agent, and maybe, you know, a classic chemotherapy type agent that if somebody has been on, that and they say, well, my disease is control versus someone who says my diseases no longer control.

When would you encourage someone to access a clinical trial? Because sometimes people, they will, I'm not really curing this, but I've just in a holding pattern.

So you hate to upset what is working for something that may or may not work. But that's always a challenge for people to know when to switch therapy just based on, you know, the availability of technology as it develops.

Yeah, really good question. I usually tell people about clinical trials at any point for treatment of metastatic disease. And I'd almost say that clinical trials are part of the strategic approach to treating the cancer so that if we use a clinical trial early on, people can always fall back on the standard treatments after that.

So in a way, it opens up an extra line of treatment for individual patients. I'm a big proponent of using clinical trials early on in the treatment of metastatic disease in order to increase the number of options available to a patient because sometimes clinical trails close very quickly and if somebody goes for a standard treatment and then you know the clinical trial has closed the trial is no longer an option but doing it the other way around, we can always fall back on the standard treatment.

So it almost creates more treatments and it's part of the strategic approach to dealing and managing the cancer, if that makes sense. That does make sense, there's been kind of a call within the solitary fibers community, tumor community and then elsewhere, I think in rare sarcomas to Please get involved in clinical trials.

Please. Get involved.

Future of Personalized Sarcoma Care

In donation of tissue samples to bio bags and other places so that more research can be done. Because I think what I'm hoping will happen. And I. Think what you're describing is.

We are entering this area where I, think the growth of. The treatment options can grow not linearly, but more exponentially as time goes on. But we have to have the data and you need the clinical trials and I've observed on solitary fibrous tumor.

A lot of the studies have a population size of no fewer than a hundred people, sometimes fewer the 20 people. Just because they're small. So there is a real benefit for the field of science and individually to be informed about these trials and maybe even be a candidate for your self-work.

You're having a tissue sample obtained from a surgery instead of just putting it in the pathology lab to sit there forever. Go ahead and get the studies and then donate to a bio bank or someplace where that can be used as part of that research and development.

Any other comments on that? Yeah well just to say I totally agree I mean the more information we have the stronger we are and in a way even if a clinical trial is negative it provides us information for moving forward and designing future clinical trials and gives us Information that we can use to counsel patients regarding treatment options and I think donating tumor material is incredibly helpful in terms of being able to better understand the biology of these tumors and even we discussed earlier the identification of the STAT6 rearrangement.

All of this is possible through research and research improves our understanding, but also improves the outcomes for patients. I'd say it's absolutely essential and so, so important.

Yeah. Well, thank you. I have really enjoyed this discussion and I'm excited. There are things that are happening in this world. Again, when you're kind of a lonely little patient, like I was when I first heard this, I remember studying sarcova and probably red solitary fibros tumor on a list somewhere.

It just felt so lonely when first got that diagnosis. It's helpful to understand that there is a world of people working on this. We're not alone. And actually as a patient, you can get involved quite a bit by being part of trials, attending sarcoma specialists, consultations, donating tissue, and that becomes available.

So it's, like I said, there's no good time to be a cancer patient. But as the field of this board, that are warm treatment options, so I hope that results in better treatments going forward.

I really appreciate your work and your attentiveness to this bill. No, it's been a real pleasure to chat to you today. I really, really enjoyed it. And as I say, I'd really like the way that you phrase things, so I'll have to ask you for advice in the future on how to phrase it, and it was really good.

Thank you. So for folks who are listening, who may want to say I would like to follow along with Professor Robin Jones and his work in oncology. Do you have a website or a social media or professional site that would direct people towards so that they could follow on with your work?

Yeah, there's the Royal Marston Hospital website and I'm also on Excel Twitter at Robin L underscore James. And as he pointed out, meeting highlights and everything also can provide information regarding trial results and research outcomes.

So that I think there are plenty of avenues to obtain more information. Thank you again for what you're doing. I hope to keep in touch, I'll meet you at some meeting down the road in person, but it was very nice to meet virtually and I appreciate you taking the time.

Well, likewise, thank you so much again, for the invitation. Thank You.