Podcast Introduction and Episode Overview

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 part of the Living with Metastatic Cancer series.

Longtime listeners know that I wear both hats as a physician and a patient. So I'm excited to share this resource today. I've been able to contact a person who is developing a large language model that can help with information that's cited and has a lot more credibility than some of this stuff people find when they just Google something on the internet.

And also an excellent patient who's been at this for a lotta years and is really engaged with research. The question I had asked at the beginning of this or had thought about when we developed this episode is what information resources could I turn to as a physician where I could find out really relevant information for these rare diseases?

And if I'm a patient, how do I prepare for an interview or a discussion with my doctor so that I can actually be prepared for this? I think you'll find this fascinating and I look forward to having you listen.

I'm excited today to have two guests with me. And this is one of those episodes where we try to share insights, resources, and information as part of the Living with Metastatic Cancer series.

Those of you who are long-time listeners know that I get to wear both hats as both a physician and a patient with metastetic cancer. Not really a fun road to walk, but it's a club that nobody wants to be a part of.

But here we are. And so one of the resources that we've found to Be really helpful is to try to get information. So when you go to your doctor, you have information and if you're the doctor when somebody comes to you, want them to looking for your clinical experience.

And so today we have two people who I consider experts on this, and I'm excited to talk with both Steve McBee. You can go back to the August 13th, 2025 release when we recorded an episode with Steve and then Mike Wysoon.

I'd like to have both of you introduce yourself briefly. Steve, would you mind introducing yourself to audience? Yeah, Dr. Crane, Steve MacB, I am a 20-year patient.

We're dealing with SFT, solitary fibrous tumor. had gone through just about every experience possible searching for knowledge and answers to help me deal with metastatic disease.

And so here to share some of my experiences. Excellent. Yeah. Mike, do you mind introducing yourself to our audience? Yeah, thanks for having me on Dr.

Crane. My name is Mike Wysoon. my background is in technology. I started a company up about 21 years ago as a tutoring marketplace called Wyzant. And about four or five years, I left that we sold it and started up a academic literature search engine.

Why Patients Need Better Medical Information

and about 40,000 academics use it a month now. And as a result, and from that, we've moved into using that as the core and matching it up with large language models to try to help patients ask questions and better understand

their own medical history and their health.

So through that I met Steve and we'd been working on some fun stuff together, which I think we'll get into later. Oh, yeah. No, this is exciting. And so I can say this podcast has quite a few listeners who are physicians and then some who also patients because of that dual role that I get to experience.

But what I would say is this opportunity to highlight a resource and maybe an approach that patients can use and physicians can us as we approach it. Let me just give a little bit of preface as a doctor.

I love it when patients come well prepared. They come to the clinic visit and they say, I have specific questions about my disease and not because I think I know better than you and I'm going to try to get a gotcha moment.

If you don't say this right, then I got you. I like it. When patients say I've got information and well researched. And I'm here with a little bit of humility, seeking for information so that we can match clinical experience with good information.

And then the magic happens because you're taking a well-informed person and you are guiding them through the process. At the end of the discussion, you make a tailored decision to that person.

This is what we're going to do based on what you know, where we are at. You don't spend the entire visit just educating somebody about what the disease is.

you get into that next level where you say, what are we going do? And as a patient, I love to go to my doctor's visits where they honor and respect the information that I have, that i've been given.

And, but together, you know, we're not, it's not one person talking down to another. It's two people looking at an information set and trying to come up with a really good solution of what works for them.

and I'll give one more example before we launch into it. I said it before, hit record. Some of the search engines are the AI type resources can lead people to do things that are crazy.

You are not too long ago and it was late in the evening and I was working and this gentleman came in with a script that he'd gotten from chat. GPT and chat GP T says I need to be here and here's the list of questions I'm supposed to ask you.

And basically if you don't answer all my questions, then I needed to go find another doctor. Cause obviously chat, GPTs got it right and you might have it wrong.

Anyway, the person didn't need to be in the ER. The diagnosis was incorrect and the questions were kind of irrelevant. And so you have to kind be really careful how you use information to make sure that you actually use it so that it's fruitful and helpful and instructive and not something that gets in way.

So I think as we highlight InsightfulMed, this resource, and we talk about how to approach that. This becomes a really important conversation for both clinicians and patients.

And so I wanted to start with Steve first. Steve, you have been an example of having a disease for a long time. and showing up prepared with information so that when you go to a clinic visit, it's not just saying, tell me about what this disease is.

It's saying we both understand what it is, we've both looked at the research. How does this apply to me? I wanted to give you a chance to reflect on that experience as you've worked with clinic visits, both good and bad.

I have to tell you, I felt like I was walking into the meetings with my doctors very informed and having the right questions. I realized early on or actually late after discovering InsipilMed that my list of questions might've been 10 deep.

And that was a little bit overwhelming when I would walk in the room and expect my physicians to answer those questions. Reliable patient education relies on input that is correct.

Steve McBee and Mike Wysoon Introduce Their Work

and often my input was biased because I was looking for specific answers. You know, walking into the room with even a sarcoma specialist, they're learning alongside you if they realize that a Sarcomas specialist Dr.

Brotto or Dr D'Amato were probably about 10 to 20 percent of their focus, meaning SFT is 10 to 20 percent. They are seeing so many other rare diseases at rare sarcomas that walking into the room with the right questions can make all the difference.

So I think it's important to go into that with proper information. And then the other factor that I kind of wish it was a little bit more transparent for patients.

People don't realize that when you show up, like when somebody comes in with, you know, they have a notepad with three pages of questions, my heart starts to race a little bit because they don't know that I have 20 minutes and it's not because I don t want to pay close attention but I've got three patients that are waiting and I ve got a baby that's about to be delivered and somebody from the ER checked and so-and-so is having an emergency at home and wonders whether they should come in.

And so you want give all your attention, but you also want make sure that that time is fruitful, that you have 100% of my attention during those 20 You know, don't plan on an hour unless you're, you know.

If you have know that, if you had that transparency, like I've booked an hours, I booked 15 minutes, You would know but in most patient interactions, really, especially if it's a follow-up patient, not a new established care, a lot of times the system allots you 15, 20, maybe 30 minutes if your lucky.

And so you want to make sure that it is useful and show up with relevant questions and as a patient you don' want say like, oh I'm so disappointed, but I didn't get to answer all my questions.

But you also want to kind of have a little bit of agenda setting at the beginning so you do get to those most important questions. So, Mike, I know you talked a bit about your background with education and research and large AI models.

Obviously, this led you to this process to start InsightfulMed, which is Maybe just to like what you shared with me a little bit more than just algorithm driven or something that leads you to the answer that you want.

We talked on before we hit record, we live in a world where you can sort of create your own reality. You can make it so all the media you take in fits your worldview and you click on one thing and it leads to another thing that.

Leads to some similar information and pretty soon everything around you can give you the answer you want and Maybe that's not really the most scientific inquiry method really we should be looking to wherever the data leads is wherever The science leads us and so tell us a little bit about the development of insightful med And what makes it different than other AI or large data model search engines?

Yeah, I guess I'll start with the Second part first, which is what? makes It different Than other large language models. So large-language models, at their core, the way they're trained, is you put in a ton of different text and as much text as you can possibly get your hands on.

That means, in some cases, downloading all of the books ever written and digitized, legally or illegally. But at its core it's just a probabilistic association between words.

There's no centralized idea of a fact. Right. If you think of it as like just a giant auto complete and literally this is how they work. You put in your prompt, it puts out what it thinks should be the next token.

Then it put your prompts back in along with that next and spits out the nest. It just keeps on doing it. This is really complex auto. Okay. There's no facts in there.

The facts that it does spit out just happened to come from the fact that those words are associated with each other. Interesting. Yeah. And then there's like training on top of that where that get people to get it to act like a chat bot.

Okay.

How InsightfulMed Anchors Answers in Medical Literature

Part of training and kind of going back to what you were saying about making our own reality. A large part of the training is making sure the user is happy.

That's true. Right. So happiness and what is quote unquote happy, I shouldn't even say happy engage. And so as like you, like even the way you ask a question to a large language model can affect the, way it answers.

Right. So like, you can essentially lead it. It'll try to pull itself out sometimes, but like. You can, essentially, lead into the reality that you expect.

And that's where hallucinations come in. That's, where if the person brings in the prompt is immediately adversarial with their doctor, it'll respond as an ad, in a way that like encourages that adversariel nature.

which is not good. And that's why, I mean, there are some things that it is good at. So there's been a bunch of studies out around helping with diagnosis.

Okay. Cause you got to go back to that probabilistic nature. You've got a. Bunch of symptoms. Right. And these symptoms are all probabilistically associated with an outcome.

So it's really good at giving a list of like 10 things that might be going wrong. But as soon as you ask it, why it thinks those 10 are there, there's no underlying why.

It's just probability. And so it starts generating facts and it's starts hallucinating. So then that's the big problem with large language models, just as they're built.

For us, what we do is we like anchor it in truth and fact, and that truth in fact comes from medical literature. Every factual statement we make is cited.

And, so you can see not just like the. Paper that we pulled the statement from, but like the paragraph from the paper we pull the same from. So as a physician, you can verify right there that what we are saying is true.

Or I shouldn't necessarily say it's true is is anchored in medical literature because the basis of science is proving the previous person wrong. Right.

And like improving upon knowledge. And then no matter how much like meta analysis you do on the authority of the patient, the physician, be journal or whatever, like our tool will never catch something like the beta amyloid crisis.

Like the reproducibility crisis, right? It was a giant. You guys familiar with that? So the beta amyloid for long decades, a lot of research for Alzheimer's was focused around like beta-amyloids proteins in the brain and for decades.

And it was like, everybody was focusing on that. Then they realized that the foundational studies that it. All of that research was built on were fabricated.

But there's this entire body of medical literature around supporting that hypothesis. there are systemic problems

with medical literature. So like we as a society have to deal with, but anyway, so what we try to do is make sure that every statement we make, every claim we made can be tied back to the medical.

I think it's great. Yeah, that's awesome. And so when, and you can share it with your physician so the physician can actually look and like validate and verify everything.

Like you are not let astray. via like you're in the way you phrased your prompt or something like that. And so that's the core of what we do. We've added other stuff onto it, clinical trials, allowing you to upload your medical records or like integrating with like the FDA APIs and like affairs database for adverse drug reactions and stuff like.

So we can bump up all of these different like authoritative sources and provide the patient or the physician with valuable medical insights that they can come prepared to their doctor with.

But all answers are given in the context of you preparing for your doctor's appointments, right? It's not an adversarial thing, it's just like, how can you be as informed as possible coming into your doctors appointment so that 15 minutes that you talked about is as high value as productive as That's excellent.

You know, I think we, we talk a lot about the information age. We live in the Information Age, but in some ways we are transitioning into kind of the next step of that large language models, AI type stuff.

It's here to stay. it's going to be informing the reality for a of experiences. And so the old model of Well, the doctor has all the information, and the patient doesn't know anything, so show up and shut your mouth and just listen to what they say.

I think we're exiting that and going to a place where people hopefully have educated folks have access to the same data set. The doctor, or the patients, anybody the researcher, anyone along that chain.

And what you're looking for is a conversation just like you said. It's informed, informative, it's useful, but you are all looking at that same information and as an educated informed Patient, when I show up, I want to not just be talked down to or have that information just given to me like I'd never heard it before.

I wanna talk about what this study said or how's that relevant to. What is your clinical experience? Tell me that this is how does this apply to meet so we can come up with a plan at the end of that that I'm happy with and the doctors happy within.

Hopefully that's not adversarial, but cooperative as you mesh those to a clinical experience plus what these large language models teach us and what the patients own experiences so that it's really kind of a tailored approach.

And the old model of how we were trained as physicians and patients is sort of changing a little bit with these, especially if you can get respected data sources so it becomes informative.

Steve, what's your impression? What's you're insight on this? Well, Dr.

Preparing for Doctor Visits with Focused Questions

Crain, when I discovered Insightful Med and I talked to Mike about this, one of the first things that I did was reflected back on my 20 years of dealing with this disease and each phase that went through, starting with discovery of a disease.

So I had a car accident and headaches and some waking seizures. And so I took that information and just typed it in as a basic prompt into insightful meta basic question.

I just had a headache. Had a car accident. What should I do? And so it directed me towards going out and seeing a doctor. That went in and had to see T and the doctor told me I have a brain tumor.

I'm looking at the input or the output from InsightfulMed and the questions that, what I really like about it is that it will give you a basic overview.

It will get you some questions you need to be asking yourself. Questions that you probably should be ask your doctor, three or four questions. And when I am looking that I thought, I wish I knew that.

at that moment, when that happened, I wish I had this resource to plug in. And I carried that through to brain surgeries and pancreatic surgery, liver surgery and ablations.

This is such a great tool for me, especially going forward now. Any new patient that is introduced to a rare disease, I just hope that they can find this tool and utilize it in the same way that I have over the last couple of months.

It's just been game changing for me and how I've seen my disease learned. Even though I spent the past 20 years going to medical libraries and searching through PubMed and looking for answers, it's been the easiest, most clear path for Yeah, I'll talk to Michael about this and I think that this is how the sharing the whole patient path from discovery of the disease to going to a sarcoma center to different types of treatments.

And then Michael took that and ran with it and created the SFT, the insightful medicine patient guide, which was just a fabulous new tool. It's awesome.

So Steve, when you go to a doctor's visit, again, some of the folks listening to this are going to say, I just got diagnosed with solitary fibrous tumor and I searched up something in this podcast popped up.

Cause it, you know, just it. I don't know anything about it but I know I'm listening. To a guy that's had this for over 20 years, how do you prepare for a doctors visit?

Like what's your process? And again you have a finite amount of time. How do prepare that? So when show up you can kind of strike this balance between well-informed and inquisitive.

Curious and inquisitive and how do you know what's your process? Well, I've developed a there's a method to my madness and it seems to work for me I did all to playbook for me as a patient, I preach this to my doctors and just on one page I tell my team what my expectations are in the meeting, what expectations for my life is, my quality of life and what I want to do.

So let's help me get in for Go that direction, stay healthy enough to go that. Make decisions so I can go in that way. I tell my team how I communicate and some kind of my way of working.

And then I asked them to tell me their way working and then in addition to that, and again, this is really all on one page, so it's not overwhelming. I'll put down my 10 questions.

Overwhelming amount of questions, but I tell them. If you are the expert. Please reprioritize these questions of what you think is important for me. I'm not going to walk in the room as an expert, But this is in general what I want to know.

There are probably some questions and this was where insightful Matt has been really helpful. I can put in 10 questions and say, given my circumstances today, what are the three things that I need to ask my doctors?

What is, they may be, and what needs to go in the parking lot? And I've been really impressed at how it can re-prioritize those for me so I could be focused on the right thing when I walk into that meeting with my doctor.

That's cool. That is a nice tool. Like I would say, every single day in my office, I have folks who come in with a large list of medicine. I'm not bugged by it.

What we do at the beginning of those visits is we a little bit of table setting. Okay, well here's your questions. And just like what you described, Steve, let's focus on these three or four because I think those are most relevant, most

important to what's going on right now.

And then we'll meet again at whatever time we will talk about the next. I'm going to give you some resources so you can answer these others. And it sounds like, you know, with these large language models like insightful med, You might be able to have some of the just basic nuts and bolts of factual statements answered through that.

But it is really helpful to go. If it was a one pager and the patients come in and say, look, I am ready to answers to these questions, but help me prioritize what I really need to know based on your experience.

I actually like that quite a bit. And then because it sets the idea of what is a priority for everybody. Mike, it sounds like you've used Steve as far as kind of your guinea pig on some of this stuff for solitary fibrous tumor.

Using Medical Records and EHR Data with AI

But I wondered what you know, as you develop this, you mentioned being able to upload in a private HIPAA protected way to your own information, your medical records as a recent development.

And I wondered about that step and then how do you envision this going forward? Because it seems like this has a lot of potential to be really helpful for everybody in the medical decision making.

Yeah. So let me start. We are, for physicians out there, we respect all of the security practices of HEPA, but we are not HEEPAA certified right now. That is not something we've gone through, but like we have all of the logging, all the verification and everything, But we don't assign BAAs or anything right now.

We're, we're patient focused. Just, I wanted to kind of clear that up. But yeah, what we actually just released yesterday is the ability for you to export your information from an EHR and import it into our system.

then our agent can, as you ask questions, selectively go fetch relevant records from your past history. So if you asked something about like, make sure Steve's 20 year history of SFT is going to come up with a lot of stuff, but it will go selectly fetch the pieces of your record that are most relevant to answer your question.

Michael, what gave us an example? So that is what type of records are those? That's pathology, histology. Yeah, so it's all text based stuff. So like actual, like primary imaging, we don't have like foundational models to read images, but the interpretations we pull in.

It's. All your vital records, all your notes from your doctor, All of your tests, be it blood work, he scans all like anything that is available to you.

And let's say like my chart. When you export it is. Available to us. Right now we just have a one-off import and you can, you do it as much as you want.

We will in the near future allow you to essentially like do an OAuth or like a single sign-on so that we could pull your records for you. Yeah. But the idea there is like in.

when we're talking about like getting prepared for doctor's appointments, we can help you prepare in the context of like your historical appointments with that doctor or the labs that that Doctor has ordered previously that have just come back that you haven't seen them since.

And yeah, the idea of being essentially patients don't necessarily always know what is the most relevant thing to give to BLM. like social determinants of health, history of smoking, drinking, weights, that kind of stuff as well, which all oftentimes like matter, but they are not necessarily input.

So it becomes a lot more powerful. I could see the value in that and that as a patient, you're in the room with a doctor, it's sometimes a little bit overwhelming and you don't absorb or hear everything that the doctor says.

And then you get the report and no offense, Dr. Crane, but sometimes physicians write in a language that we as patients don't necessarily understand and insightful.

Then once you've uploaded that can interpret that and give you the record in the context that you understand as a patient. And I've tested that a couple of times, and it's been a lot easier for me to look at that report from my physician or from a treatment that I received or the scans or pathology.

And it kind of drives it down into some more basic language that understand. As I like to say, it is on a 10th grade level. I can read that. That's great.

I'm sure you can read much higher than 10th grade level students, but I just thinking about this. So when I went to medical school, I graduated in 2008 and it was just in that transition where things were becoming electronic health records for everything.

We wrote everything on paper at the beginning. And then it became EHR based, which has its pros and cons. But it's interesting how that's appreciated your comment.

And I think it is relevant for this discussion about insightful med. Doctors have traditionally been trained that the notes were primarily to communicate to other physicians or to give a reminder to yourself of what your treatment plan was for that patient.

Prior to the EHRS, it was never really something that was patient directed. The notes where primarily for Other clinicians like, hey, cardiologist or other specialist, here's what's going on.

Here's the test I've ordered. And it served as a medical record for record keeping for the patient's best interest, but not necessarily a patient facing sort of thing.

Now with the HRs, it's become very much insurances want to have all that information. They want everything said in such a way. and the patients have access to my chart.

And there's a lot of positive to it. Folks can get information to their access, to the records. One of the challenge I find as a doctor is that you're recording stuff and you doing it in real time.

You're also seeing 20 or 30 people that day. Do you have to go home and see your family that night? And how do you get that all in a way that's properly represented is so that it factually represents everything and now I worry about like what if I say something if i make some comment about some word that's going to offend that patient you know because they're going look at it and you want to make sure that its information now is kind of high stakes on those records because everybody looks at and so what I think you just described on insightful med Again, you want to make sure that things are privacy protected and stuff like you said, but it is interesting to be able to say, how do I take this data down to a level where I understand it and can read it?

Cause like, medicine's its own language. I had to learn a new language when you go to medical school. And so how did you take it from medical ease into your native language?

Yeah, totally. That's part of like the prompting around RL is kind of bringing the technical nature of the language down. And like when there's like pivotal concepts around like your disease or whatever might be going on or a test or something like that, it tries to like.

use analogies and use other things to like help the patient understand what's actually happening so they have like a better understanding than just this like really complicated word that like they've never heard before yeah so it's interesting i mean people have used this medical records feature for a few different things uh we actually had someone recently report that are you guys familiar with liquid biopsies or like ctdna yes yeah basically for people listening essentially There's a new procedure coming through, coming down the pipe.

Personalized Care, Rare Disease, and Better Decision-Making

It's still being actively researched, but the idea is in the case of like a tumor that has gone away, they will sequence the original tumor and then draw blood and sequence, the DNA in your blood to see if there is evidence of that tumor's DNA circulating around.

it's very much still experimental. I mean, there's the lot of the good evidence and it depends on like the type of tumor you have to have a cancer. Well, like on how well it works and it's just not generally available, but we had a patient come in and upload their medical records and like our tool started talking about liquid biopsies as a thing coming down the pipe.

And their hospital said, no, we're not going to do it. Their insurance company said no we are not gonna do. And they had Insightful Med write a letter to the doctor outlining all of the research about their particular tumor, how it's been well researched and how effective it is.

So the, the doctors said okay we'll do, it and then they wrote a, letter using Insighful because you can have a draft letter for you using, Insightsful to be insurance.

Essentially like out lining all the benefits. And they both got approved. But it's just, again, the power of integrating your records with our cool. I got really excited when I heard that one.

Well, we live in a new time, like I said. And I've had to shift, say, to 2008, 2007 model of writing notes on paper to now it is an outward patient-focused sort of record that everybody, from the insurance to the patient, everybody is going to be seeing that and having ready access to it.

So now where we say we're entering this large language model, time where AI is going to be here and it's important to know how to use it properly because there's lots of improper uses where, like you said, it just gives you another prompt and an autocorrect and people are led to things that are foolish and crazy.

But we need to have this really based on good published data and then as clinicians and researchers, you need to go wherever the data leads you. But if you have access to all the date at once, instead of having to spend five hours in a library combing through it or in PubMed, it gives you tremendous power.

And so you'll have that at your fingertips. The hope that I have, and I know Steve has, as well, I'm sure Mike, is that with this power, that you lead to solutions that are not just theoretical or this worked for somebody or it might work, but to actually say, hey, this is the Peter Crane solution.

This might actually work for your tumor, your subtype. And then you go from in the world of cancer, instead of saying like, you have this cancer that you kind of get to the place where everybody has a rare cancer because it's the Peter Crane cancer.

You know what I mean? Everybody has the specific cancer we know, what your genetic mutation is. We know the treatment is that works for your cancer and then instead saying, oh, You have X, Y and Z cancer you really focus it down and say, it is really specific to you and the treatments can become much more tailored.

So I'm pretty excited about where this can go. it's just a matter of trying to do it right no totally i mean as like a personal story so the medicine inherently has been kind of like especially guidelines have been built around like at a population level not an individual level and a family member went in got an x-ray found something weird on the lung There's unrelated incidental findings, but they did a CT scan, found a nodule with some features that was like 17 centimeters, I believe.

And they're like, OK, we're going to wait six months. Let's do follow up imaging. The guidelines say we should do that. I hope that I was millimeters, not centimeters.

Seventeen centimeters is quite large. That would pick up most of the airway. Anyways, there's some feature on it that were clearly pointed to like doing something sooner.

And like, or through medical literature, we decided, oh, well, this is probably not something you'll sleep six months on. You should go against the guidelines in this scenario.

So she got a second opinion with someone who knew what was going on and they did a biopsy, lobectomy and started her on like a specific treatment. She's still here and healthy with actually no signs of the tumor, which is great, right?

But again, like that's where like the population level recommendations fall down and not all doctors have the ability to spend a ton of time doing deep research on every patient.

It's just that It's not the doctor's fault, it's just how the American medical system is structured. We're going to get to a system where it is more personalized, and I think AI can be a big part of that.

As it pertains to solitary fibrous tumor, this discussion gives me a lot of hope, personally, people in our community, but just across the whole spectrum of what we consider rare diseases.

And there are things that are more common, But I think that your particular iteration of it, each individual does have specific things and we have the ability to tailor personalized medications and treatment plans a lot more with this kind of technology.

As we kind get a little bit closer to wrapping up our time here, I wanted to give each of you a chance to kind some final thoughts. And maybe if you don't mind, share with our audience how they can communicate with you or reach out to you, or follow your work if have a website or a LinkedIn profile or something like that.

Steve, do you mind starting? Yeah, you can reach up to me on LinkedIn. I have Soldier Virus Tumor-focused newsletter on Substack. Which is really good, by the way.

Thank you. It's an attempt for me to share like all of my institutional knowledge and experiences with other SFT patients. And so that's kind of where I hang out.

Thank you, Steve. Any final words, any thoughts that you would leave with our audience as you kind of finalize your time here? You know, I think that using a tool like InsightfulMed has been very helpful for me, and that comes from having 20 years' experience of researching and thinking that I was on the cutting edge of knowing about our disease.

Final Thoughts and Where to Find the Guests

This tool has game-changing for me. And it's so easy to sign up and use. I don't have any vested interest in this, except that I think for our community, for all the questions that we see that are repeated over and over in the confusion, especially in Facebook groups, which is really the only place that have.

Our time with our physicians is very limited. Physicians don t come into our This is a tool that can be very helpful and guiding you to better understand what you're facing.

That's excellent. Thank you very much. Mike, what are your thoughts as we conclude here at Contact? Generally, I'm somewhat apprehensive. This is gonna sound weird for someone who's doing what they're doing about where AI is going to take us as a society.

There are really amazing uses of it, and there are terrible uses. And having people understand what a good use is really important. That's kind of what we're trying to do here.

How do we, in this case, rectify like an incredible information asymmetry between like doctors and patients and there's tools like ours out there like open evidence that I know a ton of doctors use but patients can't use it and they purposely keep patients away by requiring an NPI number to sign up And like all of their funding comes from like pharmaceutical companies, conflict of interest.

And so we're just trying to build something to help people and patients to the extent that like we can help. That's our sole goal here. Yeah. So I mean, for people who are interested, especially in this community, Steve alluded to it.

It's the solitary fibrous tumor patient guide. You can find it under insightfulmed.com, INCITEFULMED. COM, slash, resources. And it'll pop up there. Uh, our goal with that is to essentially create a list of resources, especially starting with the rare stuff that can help patients kind of anchor themselves and understand and get up to speed.

And there's even things, there was a feature on there where you can type in your address or your zip code and it will pull up the researchers who are closest to you who're studying the thing that you're suffering from.

part of like what we want to do is empower patients. And that's like making sure your meetings with your doctor are good, but also your meeting with the right person, which is especially important in a rare disease.

Next. Cause your average PCP is not going to understand anything about SFD. Right. No, like I, I'm a primary care physician. I don't think I'd ever even heard of solitary fibrous tumor before I became a patient of it.

You hear a lot of sarcomas, but there's so many weird, rare sarcombas and you never ever see them. So no, really helpful and appreciate what you're doing, Mike.

Thank you for taking the time to come on and Steve, you as well. thank you. Taking the to do this. And I think this episode will be really informative to those who listen.

It's been informative for me and I hope you both stay in touch. Thanks for tuning in to the Doctors Making a Difference podcast. And thank you for what you do to help your patients and your community.

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See you next time.