Rare Cancer Breakthroughs: How Tissue & Data Donation Saves Lives | Barbara VanHare Transcript

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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 unique. We're going to talk with Barbara Van Hare.

She runs an organization, a nonprofit called pattern.org. Pattern. Org, part of the Rare Cancer Research Foundation. And they have this unique role of trying to be at the very center of collecting information and trying collect tissue samples so that we overcome institutional barriers and make sure that Hopefully thousands of patients with rare tumors across a variety of different types of cancer can collect information into a central repository that researchers worldwide can access.

I do think this is just the tip of the iceberg and there's a ton of information that can be collected from this. And instead of having rare cancer rely on just a very small subset of patience, you can get to the place where we try to collect the information for the very large majority of these cancers.

And I think this is an exciting time to be in this world. You never want to have cancer, you never wants to either person has that diagnosis. But if you must have it, I'm thankful for those who are doing research and trying to find answers.

I really appreciate Barbara taking the time do this. So stay tuned. I'm pleased to welcome our wonderful friend, I want to say doctor, but she talks like a doctor.

Barbara Van Hare is a wonderful person who heads an organization called Pattern and she works for Rare Cancer Research Foundation. I think you're going to really enjoy this and I wanted to introduce Barbara.

Sure. As Peter said, I'm Barbara Van Heer, and I am with the Rare Cancer Research Foundation. And I Am President of Pattern.org, which is an initiative of the rare cancer research foundation that we'll be talking about here today.

That's wonderful. So we're going to talk a lot about this. This episode, as my long time listeners know, I have a recurring series called living with metastatic cancer.

And we focus a little on doctors, doctor stories, the doctors making a difference. We also talk about some of the things that are available and useful for physicians and for patients who are dealing with.

rare cancers like solitary fibrous tumor. And so we're going to talk about that a little bit today. But before we get into the specifics, I want to hear a bit about your story.

How did you come to work for Rare Cancer Research Foundation? And specifically, how did learn about solitary fibers tumor and some of these rare cancer that you are working with?

That's a great question, and my path was a little different probably than most getting into the rare cancer space.

Barbara Van Hare and Rare Cancer Research Foundation

After spending 30 years at home or cards, primarily in sales and marketing, there had been a long history in my

family of rare cancers. My dad was diagnosed in 1959 with a rare oral cancer.

And my brother, my only sibling, was diagnosis in 2009 with glioblastoma multiform. The deadliest brain cancer there is the good news is he is still living, which is a miracle.

His eldest son was diagnosed with ocular melanoma at age 28 in 2012. and that my nephew Mark is the one that started the Rare Cancer Research Foundation.

And the reason why he started it is as he approached treatment for his disease, he found that literally nothing had changed in the previous 25 years for this rare cancer.

He set about trying to figure out why that was and during that journey he learned that It wasn't just atypical for his cancer that not much progress been made, but it was typical across rare cancers, that basically there wasn' t the infrastructure in place to allow researchers to get access to what they need to find new discoveries, to help find therapies.

So he created the Rare Cancer Research Foundation in late 2013. to do that to help patients and advocacy groups and researchers across the US and actually across make the research go faster by getting those researchers what they need.

So in 2014, I joined the organization. Initially, my position was to reach out to patients and patient communities to tell them about the work we do and fast forward 12 years later.

And I am president of pattern.org, which is a key initiative to help bring patients, and researchers closer together. Thank you so much for that synopsis.

I think it's important to state the problem. Just like you said, all cancer needs attention, but there are so many different subtypes of cancer. And really, when you look at the sub types of the cancer, it is almost like everybody has a rare cancer because there is so different genetic variability.

The more we learn about it, the more realize how unique and rare each cancer is. It is so important to be able to connect all those pieces that overcome some of the regulatory barriers that make it so people can't get tissue samples or do proper research.

And it's going to so frustrating when you say, look, we pushed the timeline forward 15, 20 years and very little progress made on some these rare cancers.

So you saw a problem, your nephew saw problem and started an organization so we can try to overcome. tried to eliminate some of those barriers and move the field forward is a really noble and really cool initiative.

So thank you for what you're doing. Great. It's very motivating to work with patients and advocacy groups as well as researchers to try to bridge the gaps that are there.

As you mentioned, really all cancers at some point probably will be classified as a rare cancer because the more we learn about each cancer and how it reacts differently in different individuals.

But our primary focus right now is what people consider to be The rare cancers, the pediatric cancers the sarcomas, solitary fibrous tumor being one of those, penis cancer, all the different ones that maybe people have never even heard of.

And the key is as we say, these cancers are rare. So that means by definition, there aren't that many patients with them. And when you have a small patient group and it's spread out across the country, any given institution, even the largest academic centers, may not see enough patients in one year to be able to get the clinical data and the tissue that they need to study those cancers.

So we work across the board with patients and with institutions to try to bring those two groups together. So, we've mentioned pattern.

How Pattern.org Collects Tissue and Data

org, and what that does is it allows any patient, regardless of where they're being treated in the US, whether it's a small community hospital or a large academic center, if a patient wants to contribute their excess tissue, so tissue that's not needed for their individual care, and or clinical data, their medical history, they can go on to pattern.org, consent to give us access to that tissue or that data.

And then we'll take it from there, de-identify the tissue and, or data and put it either in a biorepository so that researchers have access that that issue or send it directly to researchers that are utilizing that issues today.

and de-identify that data and share that so that the researchers and bioinformaticians can find what's called patterns in the tissue or data. Hence the name pattern.org is because really what research are looking for are patterns that help them make discoveries to lead to new treatment options.

So walk me through it for just a second. So I have shared with my listeners that I had solitary fibrous tumor. If I end up having another biopsy and I say my treatment institution needs that sample initially so they could do the testing that needs my care, but now they have a little bit of extra, how do I go about getting that information pattern, both the specific tissue sample and the information associated with it?

What are the steps? How would a person with a rare tumor go So if you have a rare tumor and you're having a procedure, whether that be a biopsy or a surgery or even a fluid drains for some cancers, fluid will build up in the abdomen or around the lungs.

The patient can go on to pattern.org, put in some basic information about themselves, like their name, what type of diagnosis they have. And then on pattern dot org, after they put that information, they'll be matched to a study or to our biobank.

If we don't currently have a steady in need of that tissue or if there's a state that needs a certain amount of tissue samples before they can start, we'll temporarily store them in our bio bank.

And so the patient will go through the process online on pattern.org. There's a consent that they can go though page by page, take their time reading through it, and then they actually consent online.

After they consent, we'll get a little more information about where their procedure is going to occur. And even if they don't have a procedure coming up and they just want to share their medical information, that's great too.

They go through the same process. Once they finish that consent, we're immediately notified and then we'll start to work on what we call their case. So if they are having a procedure like a biopsy or a surgery, then will reach out to their clinicians at that particular hospital.

It can vary by patient and by hospital in terms of who we talk to, but usually it will involve potentially a surgeon, an interventional radiologist, the pathologist.

There can be lots of people depending on the situation. We'll tell them who are that the patient has consented. we can send them a copy of the consent and our protocol.

that of how this work is overseen by a regulatory body. And then we will send in, if they are interested in donating tissue or fluid, then, we'll send overnight a kit with all the components that they need.

We try to make it really easy for the clinicians there to just put in the tissue into the kit. we may also ask for some blood if blood is being collected.

and then they seal up the kit. It's got a prepaid address sticker that goes on the box after they sealed it up. We even include the tape in the Box. And then it goes off to either the research center that's going to study that tissue immediately, or it go to temporary storage in our biobank.

Then we'll notify researchers about the ability to access that issue for the studies where they're working on these various rare cancers. So it sounds like you've addressed both sides of it.

I'm a busy physician. And if a patient comes to me and says, I want to do this big, long, extra thing, and I'd like to spend several extra hours researching this on my behalf.

Sometimes we don't have the capacity to. To do it like, to ask the staff. We'll try to accommodate what the person needs, but that is useful from the clinician side to say, there's just a box here it is.

Here's the mail and you even have to tape in the box. So you have that part is easy. And then the second is that the patient can sign their forms online and the kit is sent to their institution, to the clinicians so that they can get it.

So it sounds like that parts relatively easy to send the tissue sample to get into pattern. Is that correct? That is correct. We've tried to make it as easy as we can to the point that our kits even have a self-cooling technique.

So when we send the kit out, there are little tubes with media in them. That's basically a liquid that has nutrients for the tissue when it's collected to keep it kind of refreshed as it takes its less than 24 hour journey to where it's going.

And so there is a freezer pack on the way out to keep that media cool that the tissue is going to be put in. But we know that hospitals don't necessarily have freezer packs there on hand and we don' want to require extra work for them.

So at the top of the box is what's called a nanocool. It is a self-cooling mechanism that basically will cool to 4C. And for those that don't know, that's basically refrigerated temperature.

All the person putting the tissue in the kit has to do is literally push a button and that automatically keeps the at that refrigerated temperature for the tissue journey to the biobank or to research lab.

And we overnight those tissues because we want them in the hands of researchers or them to be processed into the bio bank as soon as possible to keep them as viable as possibly for lots of other downstream uses for that tissue.

Okay, perfect. Thank you. Another question they have, I guess this is partly from my work as a physician, is sometimes we do a biopsy and maybe I haven't even sent the person to a big cancer research center and we get a tissue sample back or they did a surgery at the local facility and Hey, this was a rare cancer.

We didn't know until we did the biopsy and now we have that tissue in the facility or we forwarded on to a cancer center. You know, so is there a way for people who have already had their biopsies performed and everything's in block or it's informal and formaldehyde?

How do they, is their way, for that type of tissue to get to the bio wig? Absolutely. Last fall, we changed our protocol so we now can accept stored tissue.

Historically, were really focused on the fresh living tissue because that's what's needed to make things like living models of cancer tissue that drugs and things can be tested against.

But they've made so much progress now in the lab on things that they can do that we're getting lots of requests. for stored tissue as well. So if a patient has tissue somewhere stored, even if they don't know how it's been stored they can consent on pattern.

Stored Tissue, Institutional Barriers, and Biobanking

They'll mark the box that they're interested in giving stored tissues instead of having a procedure coming up and then we'll reach out to whatever institution that tissue is stored at.

and work with the pathology or other group there to see if there's any excess tissue that they're comfortable releasing to us that might not be needed for the patient care in the future.

We want to make sure there is always some tissue in case a patient would need it for something in future, so we'll work the group at individual hospitals to do that on the patients' behalf.

And then, of course, we'll always let the patient know if we were able to secure the tissue, whether it be fresh or stored tissue so that they know what's happening with any samples that may have granted us access to.

So the regulatory environment is complicated in every institution and so I imagine part of your work with Pattern is trying to go through some of those barriers because you're working with literally hundreds of institutions.

They each have their policy, they each a historical thing that they've done and some that's based on individual policy, some of it might be based on state regulation, and some might just be individual preference.

How do you navigate through that? Because getting all these samples into a biobank, into essential repositories that can be accessed by researchers is really important.

It's a big deal, but it's hard. There's lots of barriers that I think an individual institution would have trouble overcoming, or an individuals person has trouble doing so.

So how do approach that. That is a great point and exactly the reason why we were founded is Mark, our founder, realized that the way to navigate through all of these institutional and regulatory barriers that exist, and many of them exist for good reasons, but they are barriers, that are preventing research from moving faster, is by going directly to the patient.

So having the patients sign the consent online and us being able then to go to whatever institution it is and saying the patient has asked us to collect this tissue on their behalf allows us, we have about a 95% success rate in getting the tissue out when indeed there is tissue available.

There are times when the institution will say no, but that has become less frequent over time. We've been doing this now for about eight years, eight, nine years in terms of collecting tissue.

So we're pretty successful in getting it out when there is tissue available to share. And I guess one thing I would say that maybe even when I started in this role a number of years ago is I didn't realize how important, I knew patients should be at the center and I know they were very important in the whole process, but I didn't realize that the hole crux of the research and where things can get stopped is patients have what researchers need.

And in simple terms, that's the tissue that comes from a patient's body, and data that's associated with how their body has reacted to drugs, when they were diagnosed, environmental factors, which all of that is contained either in their clinical history records or if they have sequencing done, people may have heard of genomic sequencing, all that type of data also is very beneficial to researchers to find out why patient A is responding differently to the exact same drugs for the same exact disease than patient B is.

So if you think about, patients are the key that is needed for researchers unlock new discoveries to help find new ways to stop that cancer from continuing to grow in patients' bodies.

So we're trying to intersect at the point where patients can help control the future therapeutic options for the disease by donating what they already have when they're willing.

I can imagine, like especially rare cancers, solitary fibrous tumor, for example, my understanding is there's 300 or fewer patients in the United States of America that are diagnosed with this disease per year.

So it's a small group. And if we're scattered across 50 states and 20 or 30 big research centers that deal with a lot of cancer, but it is just really hard to get all that information.

And so every institution doesn't necessarily have solitary fibrous tumor tissue samples in their bioblade, but pattern probably does. Like you said, you created a bi oblate for specifically for solitary fibers tumor and this could extrapolate to other cancers.

One of the questions that I have is. If I say I went to my Cancer Institute institution, they do research and development. Why should I, as a patient or a clinician, want to have all this information in a central repository versus just in trusting or just relying upon the team at my individual institution to do that research?

Because I think there's a real powerful thing here that we've hit it around. I want hear your description of that. Sure. We always want to support research wherever it's done.

And we think it is incredible when institutions are doing research, particularly when they are research on rare cancers. The problem is a lot of institutions aren't doing on research rare cancer because even if they have a few samples, they may not have enough and they a real hard time accessing tissue from other institutions.

Not to say that it can't be done, But in many cases, it's a very strenuous, long, drawn out process. So the reason why we created our biobank, and our Biobanks is fairly new.

We just opened it last year, was because continuously we kept hearing from researchers that even if they had some samples in their own labs, they needed access to more and or ones that were in a lab at their institution weren't available to them.

Every tissue is precious. It's just making sure it's getting into the right hands so the research can be done. So by putting the tissues in a biorepository such as the Pattern biopositories, we are basically what we're saying is open source in that we allow researchers to come to us regardless of where they're trying to do their research so that they can get access to those samples and breaking down those barriers.

I don't know if I want to say it's a funny story or a sad story. We're literally working with an academic institution now where a researcher is trying study a rare cancer.

The pathology group at their institution is actually in the same building, but like on a different floor, they cannot access any of those tissues from surgeries that are done in their own hospital because of institutional barriers.

So actually what we're working on is they're going to have patients that're being treated in there institution, consent through pattern, so this research lab can actually get access to those tissue.

It sounds crazy, but this is a true story of what is going on today. You would think it would be easy for them to just walk upstairs and get access, But that's not the way it's set up in that particular academic institution.

So they asked if we could help. That same lab also is gonna start a section in our biorepository. to try to get other groups to send tissues of that particular cancer into our biorepository so it can be accessible not just to them from the academic institution, from this researcher that wants to pay for it, but so other researchers will have access.

So even researchers in academic institutions that are doing great research realize that there are still so many obstacles within their own and other areas that they are raising funds to put samples in our biobank, just so that's there's greater access to all.

I know it sounds crazy, but you describe it like that. You think I, yeah. Yeah. How are we ever going to win? But I do think that there's a place for what, like what you just described to have a biobank, a repository of information.

And I like the word you says open source. I say, no matter where you're at in the United States, you can donate tissue. and I think what we shared before you hit record, You shared that But you can only take samples from

within the United States, but you share those samples and that data with any institution pretty much anywhere in the world.

Is that correct?

Why Centralized Rare Cancer Data Matters

Correct. Correct We just are limited right now because of regulatory reasons that we can collect right from anywhere else in US. And that includes Alaska, Hawaii, But we cannot collect from other parts of the World.

Tissue or data right. Yeah, there's this wonderful opportunity to do this. I guess another question I had is, so are most of these collections through a pattern being initiated by the patient saying, hey, doctor, or hey institution, I want my tissue or my information sent?

Or can a clinician at an institution say, we recommend putting your information in a central repository biobank? And because sometimes patients haven't heard about it or you feel like you've got a ton of bricks dropped on your head because you heard the word cancer.

So it's hard to think long-term. How often are these samples being initiated by clinicians or institutions? How else has it happened by a patient? Historically, it's primarily been through patients, although over the past six to eight months, we've been working trying to let more clinicians know about our work.

And we are more than happy to provide information that they can put in their waiting rooms or they hand to a patient. It's just a simple card. We can even make it with their institutional logo if they want.

They don't have to have that. we try to make really easy where there's a QR code where a patients can just scan it. and they can be taken directly to learn more about pattern.org and what the Rare Cancer Research Foundation is about.

So we are starting to work more with institutions, with individual clinicians, as well as still working with various advocacy groups and individual patients through Facebook groups, et cetera.

We're happy to get the word spread out about us in any way, any ideas that people have. Were more than open to talking with them on trying to let more cancer patients and clinicians know about the work we do.

One thing also, I'm not sure if your listeners are aware that your typical rare cancer patient is misdiagnosed three times. So one of the values of when we're sending tissue out, we have the ability that's IRB approved, meaning we that if during the research that's being done with the tissue, an incidental finding is found, let's say something is showing up in the lab with a tissue that doesn't seem to correspond with what's known about that particular rare cancer, we now have the ability, the researcher lets us know, and we can go back to that patient's clinician and say, hey, in that lab, this was what was found.

You may want to take a look at this or do further investigation to see if really the patient has XYZ or potentially there is a new treatment option because of what was found, et cetera.

Again, that was changed in our protocol about a year ago so that we have that capability just as one thing that may help clinicians as well as patients in the future.

The audience for this podcast mostly are physicians and there's some patients who have solitary virus tumor or a small club. So some of my fellow solitary, fibrous tumor patients listen along, but I think this conversation is relevant for both physicians.

And patients listened to say, this is an opportunity to. get these tissue samples so they can be used in research and overcome institutional barriers of just so we can share data.

And you can make a tremendous difference when you have larger data sets. A lot of the studies for solitary virus tumor have the number of patients being studied is a number fewer than 20, those studies of 10 or 15 or maybe 20 patients.

There's some meta-analyses that will look at looking at a bunch of different studies and you try to collect and group. But an individual study where you ran something on a group.

It's really hard to get significant numbers of people. So I can see tremendous power coming from organizations like Rare Cancer Research Foundation at pattern.org so that you can actually do really useful studies and aggregate a lot of information.

I do think that's a really important step that your describing. Also, if you don't mind me telling a personal story in terms of the value of data, which those that have not really worked with data may not realize.

So as I mentioned, my nephew started the foundation. He had ocular melanoma, a rare eye cancer, and unfortunately in 2020, his became metastatic. But as he had different lesions, so his different tumors popped up in different parts of his body, he has them sent off to different companies for what is called genomic sequencing to see what was happening with the cancer, so what at a biological level was happened.

And he had sent out three different, over a period of eight months, three tumors to different companies and it went to a third company and all of a sudden when he got the report back, it said that he has what is called an inherited mutation in a gene called POT1.

He'd never heard of pot wine. Quite frankly, a lot of people have never of heard pot one. But it said that it was called a germline mutation, meaning he had inherited from one of his parents.

But the other two reports didn't say anything about that. So he actually hired bioinformaticians to look in the data. And it turns out it was in raw data with the companies, but it wasn't something that currently many clinicians or researchers are looking at this particular potwin gene.

As of 2021, only about 100 families in the world had been diagnosed with it. It turns out he had a mutation in a POT1G. I mentioned that my brother had glioblastoma multiform.

He also has that mutation and turns I do as well. So I have had two different cancers. I'm doing great. Life is good. But if someone hadn't looked into that data and realized there was something in there, so that was a new finding for our family and it's now allowing my brother and I to be proactive in our care.

And it was just because something was in all of that broad data files that just really hadn' t been looked at or not much was known about. And we believe that not just part one, but think of how many other potential things could be found if we continue to consolidate data so that the people bioinformaticians that know how to look through there and others can find these new learnings that can help solve the complex workings that are undergoing that these diseases possess.

And so that's just a personal example on how that helped me and be proactive in my journey and my cancer care. Because this mutation is so rare, it's actually considered that I have rare cancers, and there are not a lot of us out there.

But the more we group together like you and the SFT community have, the quicker we'll come to answers to provide a much brighter future and hope for these communities.

Thank you for sharing that. That's a powerful story. And I think it's reflective of the era that we are entering. I believe that will get to a place where pretty much all of our cancer diagnosis are sequenced and that know the genomic patterns.

that's happening a lot already. And I think the more we assimilate this information, the most of those patterns can

show up. Then you can observe, okay, we've seen the pathology, but we can tell you the what.

But maybe now we could tell the why. We've spent a long time on the What and we tried to treat. When you could get to the Why of why these things are happening, then there's a whole lot of strategies that can be made to fight cancer.

As a cancer patient, I remain very hopeful on those kinds of things.

Funding, Access, and How to Get Involved

I believe that pattern is really important. placing that to connect all these different pieces together so that researchers throughout the world who are diligently studying rare cancers can find answers that they would never be able to find without that repository of information.

I do think it's really important and I think, again, important for both clinicians to know about that and for patients. They both have an important role in this.

Exactly. One other question they have for you specifically about this is, so patients look at this and they say, well, it costs a lot of money to ship all this stuff to a research repository and have something that cools it to four degrees and keep it on storage potentially for years and how bioinformaticists go over all the information.

Who's paying for all of this or how do I have to pay for it? Does my insurance cover it, how much is it going to cost me? And an institution might have similar questions.

How do you address that as far as the financial coverage component of that? So as far as for the patient, there's no cost to their patient to donate their tissue through us.

We will handle the cost. For an institution, There is really no costs for them if they want to help support getting the the patients tissue into the kits.

Just it will take a little bit of their time, not much, to put the tumor tissue and maybe collect an extra tube of blood into that kit. We are funded from a variety of different means.

Philanthropy is one. Also, when we put the samples in the biobank, hopefully we don't have them there for years. Our goal is not to just create a big biubank where the tissues sit there years and aren't used.

We want to turn those tissues around as soon as we can. But a researcher that would be interested in accessing those tissue, they would buy like a vial of tissue or a sample from us that will help us recoup the cost to keep that biobank operational.

And then researchers, if we send tissue directly from let's say a surgical patient directly to a lab, they will reimburse us for the costs of us getting that tissue to them.

So we try to make it, we're trying to do this to help the common good. to help patient communities, and hopefully also it will help individual patients.

Right now, if a patient is getting sequencing, we can help them get that or help doctors that may not know a lot about sequencing. We can explain the program, the different companies that do it, provide the forms, help patients find out if it's going to be covered by their insurance, etc., as just a way to educate the clinical as well as patient community.

but there's no cost really to an institution to work with us or for a patient to working with. Just the researchers do pay a relatively small fee in order to access the tissues.

The data for researchers that will be in the data commons, that would be free. For researchers, biotechs or pharma,

there would a charge for that to help again cover our cost.

We are a non-profit. Well, that helps a lot to understand the funding process. So another question I had is, so patients who already know they have a rare tumor or rare type of cancer, and they don't, like you said, you mentioned that they could donate their information through pattern to look for that genomic sequencing or whatever information is there.

And so just to make sure I understand that process, a person who says, I already knew I have this, in the process of doing it, have an oncologist that treats my rare cancer.

They can go to pattern.org and it sounds like there's a process of just gathering that information. It's not the same process they go through and assign the consents and then that data is kept collected in a central repository.

Yes. So what would happen if a patient doesn't have tissue or doesn' t want to donate their tissue, but they do want t donate the medical records and or sequencing data, is they would go pattern dot org.

When they fill out their information, there is a box that they can click for medical record only. And so they can click that and then we will send them, they'll actually, They can consent online and we'll send another form to sign because most institutions they will release the tissue with our general consent but for their clinical history, their medical records they require a different form.

So we send it through DocuSign which is an electronic signature platform. a medical record release form. And then we will go to their hospital or hospitals where they've been treated, pull their medical records, extract the data and put it in the Data Commons.

Again, it'll be de-identified. So it won't be tied back to the index. When I say de identified, they'll take off the patient's birth date and their name and information like that would identify the patients.

Then that is put in what we call our Data Commons. where researchers can have access to look at that data for individual cancer types like SFT or cross-cancer types.

And I know we've focused a lot on rare cancers because that's our primary focus, but even a patient with a more common cancer, if they want to participate, they can just let us know and we're more than willing to accept their information as well.

And as you said, for an institution doing research, the information is not, there's not a charge for that for they can use these data sets, but they must, they'd have to pay a little bit to get the tissues transported to them if they're going to do that because it has a cost to refrigerated shipping and all the storage costs associated with running a biobank.

Correct, correct. You wouldn't think it was that difficult to get tissue out of an institution, but when you think we're working across hundreds of hospitals and the particular surgeon or pathologist may never have heard of us, so there are lots of calls back and forth, it's pretty time sensitive.

We do ask if a patient can. to consent at least several days, if not a week before their procedure, they want to donate tissue. Although even if they consent just a day or two, we will do our best to jump through hoops to get the kit out.

We just have to make sure the institution is willing to release that tissue to us, but we'll send a kit there in the hopes that they will. While we're working with them to reach the proper authority to say, yes, We can release the tissue, to you.

I want to thank you for taking the time to share these details and answer all my questions because it is really interesting for me as a patient and a doctor to see this really cool resource that's available for our patients and I'm excited what it means for research going forward.

So where would you direct people who want learn more about this or they want contact you and try to understand more of this process? So there are several places they can go.

If they're interested in donating their tissue or data, it's simply pattern.org, P-A-T- T-E-R-N dot org. if they want to learn more about our organization as a whole, It is rarecancer.

org If people have individual questions, they can send an email to me, Barbara at rarecancer.org. That's B-A-R-B-A- R-a at RareCancer dot org. Or even they could go to our general info at rarercancer.

org, or they go our websites and see the links to all of our social media, Or there's also a link on rare cancer dot or that they send it's the info email.

So lots of different ways for people to reach out, whether they be patients that have questions, patient communities, or clinicians that might be interested in referring patients to us, happy to talk to them at any point in time.

Thank you so much for sharing. We'll put that in the show notes. So if you're listening and you are intrigued by this and have more questions, get a hold of Barbara, ask me and I'll forward it to Barbara.

Let's just make sure we get this information out there. And again, I want to thank you for taking the time. It was really a privilege to meet you and go through this.

Thank so for what you doing. 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.

Your work truly helps so many people. We produce this content to have the tools you need to stay in medicine and to highlight the amazing work being done by physicians around the world.

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See you next time.