



What's a Myeloma Clinical Trial Like? Patients Share Their Experiences

Cherie Rineker
Myeloma Patient, Host, Author & Blogger

Brian, Barb, Matt and Eric
Myeloma Patients

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

Cherie Rineker:

My name is Cherie Rineker, and I will be your host today. Today we will be discussing what it's like to join a trial, how we got in one, and what it takes to be part of a trial. We have a lot to cover, and we have four guests that were kind enough to take time out of their busy days to share their experiences with us. So having said that, I would like to start by asking you, Brian, where are you from, when were you diagnosed and what were some of the trials you were part of?

Brian Helstein:

I am from Southern California I'm one of the five people you will ever meet who was actually born in Hollywood. I was formally diagnosed in February 2011. In retrospect, symptomatic throughout most of 2010, but that's with 20/20 hindsight.

At the time that I was considering undergoing a stem cell transplant I was offered one clinical trial through City of Hope which formally is identified as BNTCTN0702. It was a three-arm stem cell transplant trial where one arm would get two stem cell transplants, one arm would get a single stem cell transplant and go directly to maintenance, and a third arm would get the stem cell transplant, go through consolidation therapy and then go to maintenance. And I was in that third arm at the time that that was offered to me—I work in higher ed, and at the time that that was offered to me I said, certainly. If I'm going to be sick somebody besides me needs to learn from this. So I signed up for that.

And when I was going through the consolidation therapy they asked me if I wanted to participate in another trial that was—that was attempting to monitor my maintenance and so that they wanted me on a specific maintenance regimen, and I signed up for that one. So I was on maintenance from that from spring of 2012 through September of 2017.

Cherie Rineker:

Excellent. Thank you, Brian. What about you Matt? Where are you from and what year were you diagnosed? What studies have you participated in?

Matt William:

Hi, Cherie. I grew up in Santa Cruz, California, but I was diagnosed in 2011 in Anchorage, Alaska, and then eventually moved to here in Kauai. I live in Kauai now.

And I have been in four different trials. The first one I don't remember. It was pretty minor, just a different combination of drugs that were common drugs. And then my second one was my cells with radioactive antibody isotope injection and then followed by an allotransplant. And I had a stem cell transplant before that, so that was my second one within a year. And then I wasn't given much time left, and I was sent to City of Hope for a study on an agent to help with deletion 17p, and that was followed—let me look at my notes here. Idasanutlin and ixazomib (Ninlaro) with dexamethasone (Decadron), and that helped bridge the gap. I wouldn't have made it to my CAR-T trial without that. And then eventually just recently finished up a CAR T-cell trial in Seattle.

Cherie Rineker:

Excellent. Thank you. Eric, can you tell us where you're from?

Eric Wolf:

Yeah, thank you. I'm from Southern California also, grew up in Pasadena, California. Was diagnosed in 2012 with a vertebra collapse. That's how my disease presented. I have been on four different trials. Post-transplant in 2012, I was part of a shingles vaccine trial. Don't know if I got the placebo or the vaccine. It was one of those types of trials.

Since then I was on a drug trial that did not work. And then most recently I am currently on a trial. It's an antibody-drug conjugate trial through City of Hope, and as part of that I did a gene sequencing trial. So four different trials, and currently on an antibody-drug conjugate trial.

Cherie Rineker:

Excellent. Thank you. Thank you. And last but not least, Barb, could you tell us a little about yourself?

Barb Hansen:

Hi. Thanks, Cherie. This is a great opportunity, I think. I am from Morrison, Colorado, which is a small town outside of Denver. I was diagnosed in 2006, December 6. This was after breaking a rib back in March, so it took quite a while to get my diagnosis. And I had been in a clinical trial, the CAL GB100104, which was the trial that helped set the protocol for stem cell transplants now. That happened back in October of 2007.

And my doctor had talked about a stem cell transplant for me, and then later I found out, like two weeks later I found out it was going to be part of this trial and didn't want to participate. And when they said it was going to be a 15-year trial I said, yeah, sign me up. So I had the stem cell transplant October of 2017, and then was given the maintenance drug the following February, and then took that maintenance drug for five years and have been in remission ever since then.

Cherie Rineker:

Excellent.

Barb Hansen:

Thank you.

Cherie Rineker:

Thank you, Barb and everybody. Well, many of you know me. I was diagnosed in November of 2012 after six months of much back pain and severe fatigue and was diagnosed with multiple myeloma while in the ICU. And they found three tumors on my spine. One had gone into my spinal cord, and they were surprised I was still standing. And then I did nine induction therapies which only brought my counts down to 80 percent and my bone marrow.

But they went ahead and did a stem cell transplant followed by another, and then I went through a total of 13 lines of therapy. And when the 13th wasn't successful, relapsed again in December of last year, I told my oncologist that—who wants to put me on four chemo drugs instead of the usually three, I said I want to try out the CAR-T.

So very, very sick, I started making the trips to Sarah Cannon, which is about a 14-hour drive from our house. And was accepted into the trial and received my CAR-Ts on the 12th of March, and a few weeks later I showed no myeloma at all in my blood and then also none on the PET scan and none in my bone marrow. So what 13 lines of treatment were not able to do over 65 months, CAR-T basically gave me my life back within weeks. And I've become a big proponent of trials ever since.

So what's a myeloma clinical trial like? The experiences are probably as vast as the amount of patients that are in it. Matt, allow me to start with you. What made you decide to join a trial, and how did your experiences compare to the actual expectations that you had?

Matt William:

Gosh, with my most recent trial I was at the end of the road. It was the last house on the block, so I was eager to get in and did everything I could to do that. I was turned down all over the place. I was on the list in several places including China, and I was told that I only had a couple of months to live and that I probably wouldn't—there was a—I had an allotransplant so I was being turned down because of that.

And then Seattle Cancer Care Alliance came up with a study that I heard about just through word of mouth. Although I was a patient there I was not aware of it. Somebody told me on social media about it, and I got my name on the list. And my doctor told me I wouldn't make it, that it wasn't going to open in time for me, and he was kind enough on his own time to do some searching for me and found the City of Hope trial that targeted my 17p deletion problem.

And so I was willing and eager and trying to get in everywhere and was continually disappointed being turned down, and I thought it was going to happen again there for sure. And I was lucky, there was a doctor, the Dr. Green there was—opened it up a little bit. There was many reasons for him to exclude me, but somehow I just squeaked in there, and my story is very similar to yours. Shortly after, in 28 days, I had no sign of myeloma in my marrow or my blood.

There was a little bit left in my PET scan, but I just got back last week from Seattle and there's zero sign of myeloma now after my 90-day test. So I'm just so grateful for clinical trials and to be able to finally get into the CAR-T trial.

Cherie Rineker:

Yes, Matt. We've gone this journey together, and I'm so, so thrilled to hear about your results from last week. Brian, you can you tell us about why you decided to join the trial?

Brian Helstein:

Seriously, I really have spent my entire working life—I'm getting ready to retire, and I've spent 50 years in higher ed. I really, really had no clue at the time of diagnosis life expectancy or anything along those lines, and I figured, you know, that I was going to learn how to deal with this, that or the other infirmity the treatment was going to cause, and other people needed to know how to do that and do it better. They needed to learn from my experience. It wasn't—it just wasn't something I was prepared to take with me.

And I must say I'm somewhat rebellious about things. I have a dermatologist at this point who does not like me to go running out in the sunlight without a hat, without a long-sleeved shirt. If he had his way, I would also have ski mask and tights on. No exposure to sunlight, and I have been known to go for a long run in my running shorts and shoes.

This was not going into a clinical trial where I was going to be told you're going to take these drugs on this day, you're going to show up at such and such a time on that day. I knew that I was going to have to be disciplined, and I was going to have to follow exactly the protocol of the trial if it was going to be of any benefit to other people. So I made that compromise. I'll go running without a shirt once a month or whatever, and I will be at the doctor's office at, you know, 10:15 if that's the time I've been summoned for.

I don't know any other way to put it. It was a matter of being disciplined, so I could share so that others could benefit from this.

Cherie Rineker:

Very good reason. Very good reason, Brian. Thank you for sharing. Eric, why did you decide to join a trial?

Eric Wolf:

Yeah, I think in some respects they are easy, right? So the one that I did having to do with—what is it, the shingles trial, it was there, it was offered to me. It didn't require much of me but calling in and reporting once a month on what—if I experienced anything. It was really easy, and so in some sense there's those types of clinical trials that are just sort of tag-ones to what we're already doing. Same thing with the extra marrow that was collected to do my gene sequencing. That was not really a big deal.

But like yourself and Matt, there are other clinical trials that we seek out on our own part, because we need those to manage our disease, and that was the case with the other two trials I've been on. You know, the one I'm on now is because, as much as we don't like to admit it, our options are limited, and so this is a trial that's there and available and the timing lines up, and so you do it.

Cherie Rineker:

Excellent. So anybody else besides Matt and I has had to travel long distances for their trials? And then Barb, I'd like to ask you the same question as well, so maybe you can answer that.

Barb Hansen:

Well, I certainly didn't have to travel. I'm right here in the Denver area. I think what really helped me make the decision, and my family helped also, is that I really felt confident with this new doctor I was seeing. I had seen someone for five months, a hematologist-oncologist who was not a specialist in multiple myeloma, and then after attending a stem cell seminar and this doc answering five questions in like five minutes I just felt very confident with him. So I started, I transferred my records and just felt very confident with my healthcare team, and it was his recommendation.

Also, I have kind of a science background and my son does cancer research, and I know that the new science isn't going to happen without clinical trials. I'm a real advocate for clinical trials and did—I volunteered for Colorado Cancer Research Program, which coordinates all the trials. So it's been a rewarding experience.

Cherie Rineker:

Thank you, Barb. I see you wrote an article at one point about to trial or not to trial, that's the question. And I was very surprised in my research how few people actually participate, grownups versus children. And I found it wasn't just the grownups fault, or not wanting to do it, but it's actually not as easy as Matt and I found with the CAR-T, and maybe some of you as well, to get into a trial because there are so many requirements in order to get into that.

Did any of you have that issue or an issue of travel, money, or health that made getting into a trial challenging? Matt, start with you. I know you had to travel very far.

Matt William:

Yes. When I was diagnosed I was in Alaska. There wasn't really a myeloma specialist, and we got online right away and found the Seattle Cancer Care Alliance, and we're really happy there and found a great doctor there. But we had—for my first transplant we relocated down there for 10 months. Luckily, they had a little school and some—for our kids and some housing. But it was expensive. It wasn't free. They had a social worker that helped us a lot, and we did some fundraising. Lots of really great friends that helped out and just really streamlined our finances and our bills and sold a lot of stuff to fund it.

And, yeah, it was very expensive, and yeah, over time it's really taken a toll on all of our savings and investments and all of that stuff. But it's worth it, you know. Money can be remade and we can live simpler. And so it was very much worth it. If I wasn't flexible with that type of stuff I wouldn't be alive, so I had to do it. And I would go to any lengths to find help and an answer to my problem.

Cherie Rineker:

Right. Right. Thank you. Thank you. I totally understand what you mean, having a young child in my family myself. We have four beautiful daughters. So thank you. We're glad you chose to hang in there.

Can anyone tell me about how they found out about the trial they joined? Eric, can we start with you? Today, online offers a tremendous amount of resources. Which one, if any, did you use, and how do you stay informed about the latest trials?

Eric Wolf:

A little bit like Matt. I made the decision to move to an area where I knew there would be good support when retired from the military, so I moved up into the LA area near City of Hope knowing that they had fantastic care and availability of trials and other things like that. So I get most of my information through them.

Also, of course, read blogs and read information from the IMF and other things that are coming out. And that all leads to trying to make the best decision. So in the case of my current trial it was a matter of talking with my doctor and look at actually three different trials that were available, any of which could have been a good fit for me.

And then it's a matter of which one—then it's kind of a matter of timing, right? It's just are you sick enough, ironically, to meet all the qualifications for this or that particular trial. And so that's kind of how I made the decision in concert with my doctor looking at the options available.

Cherie Rineker:

Right. Thank you. Thank you for sharing that. Brian, what about you?

Brian Helstein:

I was on the fence about having a stem cell transplant, not on the fence about joining a trial. And the—my caregiver, my darling wife, basically pushed me off the fence and said, you will have this. I've heard your doctor say that you will have a much better opportunity for long-term survival if you go through with this.

So at City of Hope, as I was being interviewed and prepped for the stem cell transplant, they gave me a list of options which included amongst other things the participation in a trial. And I was impressed with what they were looking at. I was impressed with what the options were. Unlike Eric's comment about the shingles trial where he might have gotten a placebo, there was no placebo involved here. There was standard of care treatment, there was standard of care plus and standard of care plus plus, which was what was going to be offered.

So it was at that point a fairly easy decision saying, okay, I have made this commitment to go ahead with the transplant, so let's see about going ahead with the trial and, as I say, being disciplined enough for follow directions. But it wasn't—there was no hesitation about it. It was not something where there was a specific start date, again, like Eric, where I needed to fit in or I needed to be so sick or so healthy. It was very much you're going to do a stem cell transplant, and then beyond that we're going to put you into one of these three arms and we will monitor you from that point.

Cherie Rineker:

Right. Right. Thank you, Brian. Barb, I'm not sure. Did I already asked you this question, or do you have anything to add?

Barb Hansen:

Well, my stem cell transplant was part of a clinical trial, and when my doctor said to me with a stem cell transplant you might be able to take a drug holiday. That was appealing to me, so that combined, you know, being part of the clinical trial then was a bit of a driving force. I hated being on dexamethasone. I did not sleep well for, well, a long time.

And then, you know, I just can't encourage people enough to find a multiple myeloma specialist who really knows this complicated disease and treats people individually and just knows what's best for the patient. And I was very glad that I joined the clinical trial, and I certainly advocate for them whenever I get a chance to. Thank you.

Cherie Rineker:

Excellent. So what advice do any of you—do we all have for those myeloma patients that feel overwhelmed now and through the entire process, what they can do when they feel they're running out of time or options? What is it that you would like to tell them? What has helped you on the internet? I know Brian at SparkCures really helped me to find the trial that I got into, BB2121, a Celgene CAR-T trial that ended up giving me my life back. Just like Matt, I only had a couple months left. What would you tell others? Eric, do you maybe care to answer that first?

Eric Wolf:

Yeah. So this disease of course is real science-e, and we're always thinking one step ahead, what's the next thing, what's the next thing? So part of that calculation should be clinical trials, and so you have to keep up with what's going on with those. There's a lot of information out there in different blogs on Cancer Care Network, on Sparks, and those types of things.

Of course, if you're fortunate enough to be associated with a Cancer Research Center like City of Hope, then that's a great opportunity. They have posters throughout the campus about different trials that are going on, and of course I can reach out to my doctor at any time and look at those things. But I think that all goes into our calculation of how we're going to manage our disease and what's the next step for us.

It's—different people have—and I've ebbed and flowed over the years about how much I want to be involved, and sometimes you just want to take a break. You just want to just do whatever my doctor says, and I don't want to think about this disease for a while. I just want a couple of months off. We have that option, but it always comes back and comes to the forefront.

So I think as—the advice is to look ahead, think ahead, keep up with what's out there, but don't let it overwhelm you. At some point you have to live your life and just not—you can't live for the disease, live every day thinking about the disease.

Cherie Rineker:

Right. I think we all agree with that, Eric. Matt, what would be any of the advice you would give?

Matt William:

Just going back to how I accessed some of the trials. It started with me, just through my doctors. I had three trials that were just recommended by my specialist, and then it led to—once I got to the CAR-T cell therapy it was a little harder to find. And I started with The Leukemia & Lymphoma Society (LLS), and they were very helpful, and they actually taught me how to do a little searching myself.

And then I got into some Facebook chat room type stuff where I was getting more information, and that's where I met you. And you recommended SparkCure, so it kind of led to that. And I was doing my own stuff, and I met couple other people that kind of were like Brian, helping out.

But ironically, it turned out to be, you know, I like sending little messages, private messages to people and making acquaintances, and I became friends with this guy, Grant, from South Africa. And he's the one who told me about the trial that I finally got into, and it was at the very hospital that I was at, but I was unaware of it. And he told me so early I got my name in there.

So I think, leading up to your question, persistence, you know, and don't give up. And just take it one day at a time. And I like the advice of don't get overwhelmed with it and just keep a good attitude. And then ultimately be flexible. There's a lot of help out there and I'm continuing to be helped with my air fare and stuff like that, I forgot to mention before.

And so there's a lot of—don't get overwhelmed by the money. There's some help out there for that, too. And just one day at a time and don't give up and just try to reach out to other people and get—the personal information, one patient to another online probably ended up being the most beneficial to me.

Cherie Rineker:

Thank you, Matt. And I completely agree with you. I'm pretty busy on Facebook myself, and I had people pushing me when my body and my mind could not handle any more and I wanted to give up. And there was one lady in particular who just kept nagging me about it, and just to quiet her up I started following her advice and stuff. And then one thing led to another, and I'm sitting here today because of these personal experiences.

And just the other day there was a gentleman who just basically said, I'm at the end of the line, can't do no more, and I've been working really hard today and yesterday to write letters and talk to my doctors and to try and get him, because I know when we're that sick sometimes it's really hard for us to do it ourselves. So absolutely there's support you can get online...

Matt William:

...one more thing, Cherie. I forgot to mention, it's so important, Patient Power has been amazing with their videos and these interviews, and it really helped get me pointed in the right direction as well and some hope about CAR-T cell and a little extra information and got me excited and added some hope to my journey.

Cherie Rineker:

Absolutely. Absolutely. We owe a lot to Patient Power. What about you, Barb?

Barb Hansen:

I'm very pro clinical trials, and I do have a couple of venues where I'm able to encourage people to check out that option. One is our multiple myeloma journey partner program, and because I tell my story there having had a stem cell transplant I also include the clinical the trial stories. And so when I'm doing that I encourage people to check out the possibility, the option of going through a clinical trial. And here in the United States we really need to encourage people to do that.

And then the other avenue I have is through The Leukemia & Lymphoma Society first connection program. The Patti Robinson first connection program where I get calls from the society asking me if I'm available to talk to a person who is in another part of the country or here in Colorado. And so it's a person who just wants a call. They're either newly diagnosed or they're going to go through a stem cell transplant or they're considering a clinical trial, and so we chat and talk and I, you know, point out what I've been through and what has worked for me.

Always encourage them to talk to their doctor, and I don't give medical advice by any means, and it's encouraging. Very rewarding to talk to people like that.

Cherie Rineker:

Thank you, Barb. Yeah, you just taught me about two things I'd never heard of, so that is wonderful. And I really think when patients talk to each other we can tell other things that the pretty pamphlets that are sent along with our Revlimids or our Velcades doesn't always talk about all the things that we really experience. So it's wonderful to hear a person who's been there explain things to us. You, Brian?

Brian Helstein:

What I would tell somebody, first of all, is take a deep breath. It ain't going to kill you today. And then the second thing, as we move forward with this, after you've had that deep breath, start evaluating what's important to you, how hard are you prepared to fight this. This goes to what Matt was talking about, the kind of thing that Eric was talking about. What drives you? What motivates you to keep going, and to keep those things in your mind? It will make a tremendous difference in how you approach your various treatment options, the people you work with.

Barb was just talking about talking with, working with her doctors, and one of the things that I think all of us will agree on is you have to feel comfortable with your doctor, and if you don't, it's time to find a different doctor, a different treatment facility, whatever. You need to be comfortable as you're working with these people.

And, again, I think it was you, Eric, said sometimes you want to turn your mind off and stop worrying about this thing for a little bit. I find that that's fairly easy to do as long as I keep in front of me why I'm prepared to keep fighting, to keep going. At that point, having made that decision, having put that focus on, it makes it easier for me not to focus on being sick. And that's something I would tell somebody, is why are you here? What do you want to do with the time you've got left?

None of us are getting out of here alive. Seriously. All a diagnosis of multiple myeloma does is say, okay, you've got something that can kill you, and now you can put a name on it. That's bringing home in a very visceral way something that we probably intellectually knew but were not emotionally prepared to deal with. And so focusing in on what's important becomes very important part of moving forward.

Cherie Rineker:

Having a purpose in life is so very important. I always tell people that even when you have cancer you can beat this disease if you keep in your mind you can, like you said, know what's important, why you're fighting to stay here, and then just do what you have to do. Absolutely.

I would like to ask one final question of all you, all my guests here today. How is life treating you today? How are you feeling? How are the drugs doing? How are the side effects? How are you sleeping? And what is motivating you? I know, for you, Brian, it's your running, correct?

Brian Helstein:

Well, I'm working on the retirement actually. Running is just like you brush your teeth in the morning. That's just a normal activity that I do. Yeah, it's just something that is part of my daily life, but, no.

I've been running a program for the University of Southern California, for example, that enables access to all of our licensed electronic resources, books, journals, databases, for the last 13, 14 years. And I'm trying to clean up my sloppy programming, document my work, and train the people who will be my successors. So that's my real daily operational motivation at this point.

I'm not doing anything other than looking forward to some silly things in retirement. I want to be on the Champs-Élysées one day when the Tour de France ends. Okay? It always ends on the Champs-Élysées. That's one of my goals in life. It's not a major driving force. I have five adult children. I would love to see some grandchildren. That's something you can't control.

Cherie Rineker:

Right. Eric, what about you? How are you doing these days? You look really healthy. All of you, by the way. Looks like we've taken on the beast and we're winning.

Eric Wolf:

Like Brian, I'm trying to retire again. After one retirement from the military I'm trying to retire again and just kind of working on some other things. The clinical trial I'm on now, it's been very rough. It's pushed my blood counts down, so I've had trouble with bruising, had trouble with shortness of breath and just getting enough energy. So working through that, and who knows where this will lead, maybe CAR-T or something else.

But, ultimately, the things that I like to do, I like to ride my motorcycle. I like to backpack and camp, although the backpacking has been kind of cut short these days. Just have done a lot of that over the years. And looking forward to spending more time with the grandbaby. We have a 2-year-old granddaughter now, so enjoying that time. I will say though, ultimately, my hope is in eternity. And that's from my Christian faith. I'm enjoying life. I'm enjoying fighting the disease, I actually am, and I'm positive about that. But, like Brian mentioned, we're all—we're all going to die eventually, so my hope is ultimately in eternity and the joy of that. So that's kind of where I am.

Cherie Rineker:

Thank you for sharing. Very nice. How about you, Matt? Girls keeping you busy?

Matt William:

Gosh, yes. I have so much to live for. And I just turned 50. We didn't think that was going to happen. We're expecting a grandchild in December, I didn't think that was going to happen. We just found out about that. And, you know, I really like what you just said. You know, cancer hasn't been all that bad to us. It's been—we've had our share of struggles. But I'll tell you what. Our quality of life has actually gotten better. It's brought us closer together, closer to our God, and we just really don't take things for granted so much anymore.

And there's a lot more to look forward to in the future. I'm an avid surfer, or was. I haven't been out in the surf in over a year, and—because of some phone problems, but I'm thinking that's not too far away, that I'll be able to start slowly back at that. And just continuing to raise these kids and enjoying life, you know. And just one day at a time, not worrying about what's coming next all the time, you know. I feel like I have that little break right now.

Cherie Rineker:

Absolutely. Enjoy it, enjoy it, my friend. Thank you. What about you, Barb. What are your aspirations?

Barb Hansen:

Well, I'm just so thankful to be here. When I started Googling back in 2006 and even talking to my dear doctor, Dr. Jeff Matous at Colorado Blood Cancer Institute, Richards Rocky Mountain Cancer Center, you know, back then the average life expectancy was three, four years, and now it's upward of 10, and I've beat that so far. So I am just so thankful to my healthcare team and just grateful to be here enjoying my two grandchildren, who I did not think I would have either. Forest and Estelle, they are the joy of our lives. Really enjoy them.

I golf a little, nine holes. I do get tired because. Of all of back issues, the bone fractures that I had, I do tire. I love doing the volunteer work that has come my way, and now there's more work they've asked me to do primarily through our church. And I'm going to have to start saying no. You know, I'm just taking a break and really enjoying life.

Tomorrow I'm going to Boise to talk to a support group about my journey, and I look forward to those times. It's really neat getting to be with other people who have this crazy disease and just showing them I'm still here. I went through a stem cell transplant, a clinical trial, and it's encouraging to help give other people—help them with their journey and be hopeful. Faith, family, and just enjoying the outdoors, creation. That's what it's all about. Thank you.

Cherie Rineker:

Yes, thank you all. For me too it's my family. It's also I became a huge advocate just for myeloma patients. Because it took so long for them to diagnose me I always thought if my story and my symptoms are out there, and somebody is seeing a YouTube of mine and that makes them go to a doctor and find out and say, hey, I want a Kappa light chain test or a Bence Jones 24-hour urine test or anything.

Or even a doctor that would become more aware because we are putting ourselves out there with our stories, and if even just one person won't be diagnosed with stage III but maybe as stage I and have a better chance of long-term survival then I'm extremely grateful for putting myself out there.

So besides enjoying my family I really helping Patient Power and anybody else who comes knocking on my door, whether it's through Facebook or companies giving talks, giving interviews, anything like that.

So I want to thank you panel for sharing your stories, giving your advice with us today. As we all know, myeloma is a very difficult, painful disease to control, and I know without online support and things like Patient Cafe and SparkCures it would be a lot harder for me and I likely wouldn't even be here today.

Thanks also to our listeners for tuning in. We hope we were able to answer some of your questions about trials and how to get into them. Reach out to Patient Power with any questions, please. And we hope you'll tune soon in again for our next show.

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.