Bridging the Gap in Multiple Myeloma Survival

What is the gap in myeloma survival? Currently the National Cancer Institute reports a life expectancy of just over five years, whereas, myeloma specialists at myeloma centers of excellence have reported a life expectancy of over ten years for myeloma patients. This five year difference is the gap between what is and what could be! A simple explanation for the difference is that only 15-20% of patients actually see or have a treatment plan from a myeloma specialist. Patients may want to see a myeloma specialist, but the wait time is excessive. The only way to close the gap is to provide education, coaching and specialist's expertise for myeloma patients and local hematologists/oncologists.

Multiple myeloma survivor and advocate, Gary Petersen talks to the CEO of HealthTree, Jennifer Ahlstrom who has been building a comprehensive platform and organization to help to close this gap. Jenny will provide her perspectives on how the HealthTree platform can help bridge the GAP in myeloma survival and how it may become a template for many other hard to treat diseases.

Full Transcript:

Gary Petersen: Hi, This is CureTalkswithGary and I am discussing, bridging the gap in multiple myeloma survival with Jennifer Ahlstrom, Founder of the HealthTree Foundation.

I'd like to open the meeting by saying that they're at least when I was diagnosed, I had looked around and there wasn't very much data on life expectancy and being an engineer I thought that was pretty odd but I did find a couple and one of which was Mayo Clinic said that from for about 13 years, prior to 2003, it was, the average life expectancy was 33 months and that hadn't changed in that 13-year period. At the same time, only one other place I could find had life expectancy that it published that was UAMS- University of Arkansas for Medical Sciences and Dr. Barlogie and he had seven years. So, I had decided that what I do is I would opt for live in seven years versus just 33 months. And so, I went to UAMS and when I was there well, I read an article that Dr. Barlogie had written, it said the people with my type of myeloma with which had dialysis dependent kidney failure, I think it was like, 248 people that they looked at the average life expectancy was 33 months. So, now, here 17 years later, I feel pretty confident that I made the right decision in going to Arkansas from.. right next to Mayo clinic. And so, what I wanted to say is that I had thought and I started my website because I thought that and I wanted to see whether or not different places had different results. And so, I went about doing that but most people like I said, don't do that. So, I asked them to do that for me and a number of them did and I find that they had average life expectancy in the 8-to-10-year range or even greater and that the National Cancer Institute only had data that showed that people lived at a maximum all that time about five years. So, there is a gap of about five years between the two. So, my thoughts were that if I could just tell people, who these people were, who these myeloma professionals were that that Gap would close but unfortunately, what I have found is that gap is not closed, it's still about five years and so I'm frankly very disappointed and a little bit saddened that, now you can see people do agree on where you go that the life expectancy is a 10 year range for a myeloma specialist. But unfortunately, that isn't represented for the entire population, which is still five. And so I was just trying to find why that might be and I had published an article some years ago that said myeloma specialist don't grow on trees and it was because 15 to 20% of the patients went to one and the other 80% didn't, perhaps that difference was the reason. So how do you fill that Gap? And my thought was well like I said I was quite disappointed, but I thought perhaps the way to do that is with what Jenny has been doing and that is she developed this HealthTree and with HealthTree you can kind of follow along with what the Myeloma specialist that she has on her team would recommend for various types of chromosomal abnormalities or gene expression profile. So that's one of the reasons I wanted to kind of highlight Jenny's HealthTree organization that she can help

to fill that gap because she too has experienced a lot of the same things inadequate care, slow to be identified as a patient, there's always that. And so, I was just wanting her to go through some of the things that she might think her HealthTree format would allow to help close that gap. So, Jenny kind of a wide-open subject and I know you've got all kinds of things that you can talk about, and I know just even doing this putting a lot of hope on your organization's program. So, if you could touch base on some part of it?

Jennifer Ahlstrom: Yeah, sure. I kind of think about it in 5 Steps because when we were both diagnosed Gary it was longer ago, right? I was diagnosed in 2010 and you before me and as we came into like trying to navigate our care for ourselves, we saw gaps that needed to be filled. You saw this outcome gap. I saw other gaps that really have an impact on the outcome gap. So, I think I'd like to talk about it in 5 Steps, you touched on the first step. But if we meet with other myeloma patients that are newly diagnosed, the first thing we tell them is find a myeloma specialist. So, you mentioned the Mayo Clinic, there was data from the Mayo Clinic and the University of North Carolina, they both showed that if you have a myeloma specialist in your corner that you live longer. And that could be from 2 to 5 years longer, in my opinion that might be much longer than that based on the kind of myeloma that you have, the kind of treatment that you get, but there is actual data showing that myeloma specialist is really key. So, when I was diagnosed, I was baffled why isn't there an online directory with myeloma specialist where you can go and connect with them or learn more about them and see more than just their name. Because there's not much to a name. So, what are the gaps that I wanted to fill in getting that better care was to build the myeloma specialist directory. So, on the HealthTree website and you can go to healthtree.org/myeloma to find all these tools. The first thing we did was create that directory because there's data around it and Gary very nicely talked about why having a specialist on your team is so important and it is whether you get treatment on going because that's not always that easy to do. You don't live close to an academic center, you live in a rural area or transportation is difficult, you can still go to that myeloma specialist, and you can have them consult with your care when you're making treatment decisions. So that's the most important time whether they give you your infusion your weekly infusion or every other week infusion or whatnot, that doesn't matter as much. Just so you make sure you have somebody tracking your care and they can help you make key decision points because I was think about it like this that we are playing chess with our lives. So, every move we make on a treatment option is an important move and it should come from a well-educated decision-making process. So, step number two, in my opinion, is to educate yourself. Because the more educated you are, the better questions you are going to ask your doctor. The more aware you're going to be about your own Labs. The more aware you going to be about treatment options. And so, we started filling gaps in that education space. We created HealthTree University to build a complete platform for classes taught by myeloma experts. And now we have over 40 classes, we have over 600 video lessons, all taught by myeloma experts and newly diagnosed patients say they'll binge-watch their way through HealthTree University, and it goes from the basics to more complex topics. Doing that empowers you, educating yourself powers you, you can attend webinars, you can go to live meetings, you can start with myeloma basics, articles, we have news on our website, which is why I started reading and everything was really the scientific papers that was being shared, so I didn't totally understand how this as newly diagnosed patient. So, that's why we built the news website, we try to explain things in patient-friendly language. I think the third thing is to get involved in academic research and consider joining clinical trials and Gary you, and I could probably talk for more than an hour about clinical trials, and I don't know if there's anything you want to highlight about them, about the importance of them before I continue.

Gary Petersen: Well, I think that an academic center is the place that really has most all clinical trials because for one thing, they have the resources in order to follow up on it because I think it's probably much more now, but I think it was eleven thousand dollars per patient in order to do that. And, that's a lot of follow-up and a lot of paperwork and a lot of things like that, then you have that on staff in order to follow it. So, you don't find clinical trials all that often anything other than large institutions or academic centers and so my belief is that that's one of the key reasons that you want to have a myeloma specialist on your team some place, maybe not as treating physician, but maybe it's somebody who has come up with a plan that local oncologist can follow, if he's smart. So, that's part of it. And I wrote an article some time ago and it was keeping one step ahead of the reaper. And it had to do with when I was following a young lady a while ago, it seemed like every time she relapsed, she found another clinical trial. And it was always that step that saved

her.

Jennifer Ahlstrom: It's true.

Gary Petersen: That's saved her much like somebody I know like Jenny Ahlstrom who might have had one of the most significant new developments and that's the CAR-T and seems to be doing pretty well for you and you wouldn't have that opportunity if you didn't have a myeloma specialist kind of focusing.

Jennifer Ahlstrom: Right.

Gary Petersen: Yeah. That's part of it.

Jennifer Ahlstrom: Right, and when I was newly diagnosed, I kind of I had, I don't know why but I assumed I would relapse quickly, I don't know why I had that feeling.

Gary Petersen: A relapse feeling?

Jennifer Ahlstrom: Yeah, I had a high-risk feature not on my FISH but on gene expression profile test. And when I went to join clinical trials, first, I looked at clinicaltrials.gov, which is total mess of a website, in terms of navigating. It's great for a listing, your clinical trials, that industry has, our investigators have or whatever, but it's terrible search experience for the user. But I ended up calling about eight different trial sites, and I got a call saying, hey, I would be interested in joining your trial or learning more about it. I got called back from two and it just made me think this is very challenging so that's why I started the podcast about the HealthTree podcast because I didn't understand what are these trials all about. I didn't understand the drug names. I didn't know how they went together. I didn't know why I should be interested in this clinical trial. So just tell me why is this important to me? Why should I be joining clinical trials anyway? The more advanced you get in myeloma the more you realize, how myeloma is really special because there's so much development being done in multiple myeloma right now compared to other blood cancers and compared to other solid tumor cancers or other types of diseases. There is a lot of development. So, when you think about going into clinical trial, it's like getting very promising therapy early and that's why when I relapsed, I was looking at options and I met with multiple myeloma specialist, missed several myeloma specialist, I got different opinions from each specialist which is not uncommon, but still confusing for patients and I really had to go and do my homework. So I searched all the clinical trials to try to find what was available for me and I found a CAR-T option, I already made because I wasn't educated patient because I had already done 10 years on homework and doing the things that we do at HealthTree, I understood I could gauge relevance, I could see oh, this one had great survival compared to this one and it's all this logic that goes through your head, right? So, what's my time in clinic, is this a one-time therapy or what's the progression-free survival and or how long can I go without falling out of remission? And so, you put all those things together in your mind, you kind of add your personal desires to that, am I working, am I retired, what's my physical status? And then you hopefully jointly make a decision with your doctor, and I decided to join a CAR-T trial, it happened to be miraculously open at My Center. I don't know how I lucked out with that. And then there was a 50/50 chance, I would get into the treatment arm because it was a two-arm trial and I did get the CAR-T arm, which may not have had have happened. There was a risk in not doing that but I probably would have went gone on to look for different trials, have that not happened and to me it was much earlier access than I could have accessed that particular treatment years earlier than it would have been approved for me as a patient with the prior lines of therapy that I've had. So, clinical trials are the way that we as patients can get involved and push research forward. So, whatever tools you can use to find a clinical trial, I would suggest you use them and look at that as a treatment option whether you're a newly diagnosed patient or whether you are relapsed/refractory patient, doesn't matter. Clinical trials are always a really good option. That's why using a clinical trial finder is a really important thing to be able to do. So that's kind of like step number three, consider, joining clinical trials. Number four is kind of why you invited me to talk about this. But I want to share a story from my brother-in-law. So, my brother-in-law, David was 33. He and his wife were pregnant with their sixth child. Their oldest was eight at the time. So, they had a very young family. He was diagnosed with acute myeloid leukemia and it was very well progressed. He had many side effects that were ignored

that he didn't understand. He went into treatment at a general oncology center, and they said you could do transplant now, or later, turns out, you can't always do that. It had passed the blood-brain barrier, so transplant was out as an option for him. In the AML space at the time, this was 19 years ago. And there was very little development in the AML space, comparatively to anything else. But in specially myeloma and about six months into his treatment, he was in the ICU. His heart rate was going crazy, and the doctors said, he has 48 hours to live. You should really let him go. And you're being mean for keeping him alive. We had done some research showing that he had Cd-33 protein on his AML cells and my husband asked the doctor, can't you give Mylotarg to him? Which was the first antibody drug conjugate. It wasn't approved for his indication at the time, and they said well you have to call the inventor and ask him for permission. So, Irv Bernstein at the hutch was the inventor and my husband was stereotype A. So, he found his cell phone and he called him in a restaurant that night and got him on that phone with the head of oncology enhancement and said, will you give this to my brother? He said it should be fine. They gave it to him. 72 hours later, David was riding a stationary bike out of the hospital for another six months until he passed. And that six months was really meaningful to his family. Obviously, his daughter was born in that time frame. And it was a tragic, very emotional experience for our family. So, when I was diagnosed, we have had this idea for HealthTree Cure Hub back during that time before I was diagnosed, why did David's experience get lost to his peers? Why did that drug not get approved for another 14 years for that indication? Can't we move research faster? I mean, yes. We should be joining clinical trials, yes, we should do consider doing that because that's how things progress in a disease. Is if we do that, not just get treated on standard of care, which is good. But what's better, but it just didn't make sense that something like this as basic as this didn't exist. So, when Gary was diagnosed, when I was diagnosed, we're all looking for data. Like, the myeloma experts are disagreeing on the treatment protocol. When I was diagnosed at that time it was single versus tandem transplant. Well, show me the data, like, show me, somebody who has the similar genetics to me, show me what they did for therapy, show me their outcomes and I want you're telling me that this is my most important decision. You're not giving me any tools or data except I just trust you as a myeloma specialist, my specialist had come from, UAMS also. They were very well entrenched in the tandem transplant and doing induction transplant, consolidation and maintenance, which really nobody else was doing at that time. And so, they were Really kind of yours. Yeah, they were kind of pioneers in the field and now everybody does induction transplant, consolidation and maintenance which really nobody else was doing at that time so…

Gary Petersen: There were 61 combinations.

Jennifer Ahlstrom: Yeah, they were kind of pioneers in the field and now everybody does induction, transpant, consolidation, maintenance, everybody kind of does that now, but at the time they didn't do that. So, I feel like I lucked out by finding a specialist and then doing a protocol because like David I went to a general oncologist to get diagnosed and they said the same thing. They really hadn't even done a bone marrow biopsy, they're like, okay, we're going to start your treatment on Friday, and we can save transplant for later. And we're kind of thinking, oh, we've heard this story before. We are not doing that and then he kind of made the mistake of saying don't call Huntsman because they'll have you doing tandem transplants. So of course, we hit the parking lot and we're on the phone with a specialist at Huntsman, who is treating 600 cases of myeloma versus 5 at the general oncology center. So, if you can imagine just the patient experience that they have under their belt in treating that many patients is so different. So, we asked ourselves when I was diagnosed and we kind of went back to this idea that wouldn't it be amazing if patients were willing to share their data together so we could come to faster conclusions and Paul shared this with his brother he have got this great idea. It's called HealthTree and he said, you already had this idea. He said, what are you talking about? Yeah, few years ago, look at your email and he looked in his email and he looked and found this pitch deck called HealthTree. So, we had done that even before I was diagnosed. And interestingly, so we pursued it. First we helped build community and we created those tools that I felt like I had an immediate need, the specialist directory, the news website, the podcast and HealthTree University, and things like that. In 2018, we decided it was time to go after this data idea. So, we went on a 50 City Tour and asked patients, we met with, we slept in our beds, I think five days that whole summer, and we went to 50 cities, we met with support group, we went with a single person, we met with a group of 10, we met with a group 75, we met with all sorts of patients from all walks of life, all races, all age ranges, City, Rural and we

showed them a potential tool and said what do you think? Would you use a system like this? What are your potential objections? and they always ask like, who are you? Why are you doing this? And what are you going to do with my data? Because we've all been conditioned from HIPAA to protect our data and it's so important and so it needs to be so secure, we forgot that the P in HIPAA, one of the P is for Portability and it was for the portability of data and not privacy of data. Because my data by itself is not that valuable, my data combined with Gary's, combined with 10 of our other myeloma friends or now ten thousand myeloma friends is much more valuable because now we can see patterns in care. And so, we started that journey, we kept iterating over that whole tour and really people understood that as a patient myself, this is how we change the way research can be done. So, all of a sudden patients cannot just join clinical trials, but they can add answer common questions the researchers have. So, we went to the recent IMS meeting, that's a myeloma meeting with specialists. And one of the big controversies was do use, daratumumab, revlimid, velcade, Dex or do you just use revlimid, velcade, Dex for induction therapy? And the Europeans were saying well we really needed a phase 3 clinical trial to study this with hundreds of patients and the U.S. folks were kind of saying we already have enough data in some of these early trials. It's showing to be really good. We should just start using it earlier and for newly diagnosed patients. So, we went back to our database that now involves 11,000. myeloma patients to say which one is better. And they were presenting results from what was called the Griffin trial, which was testing that do you do Dara RVD versus RVD and our data results showed similar outcomes. So, in the real world not just in the clinical trial, it was better to use the quad combination. So, how many years of a clinical trial would that save? How much cost, how much time and how could the investigators better prioritize, what they choose to spend their time researching. Same thing for Investigator questions, for example, one of the doctors at Huntsman wanted to know what a patient think is a myeloma cure, what does that mean to you? Because it's kind of what more well-established, maybe what a functional cure means in Lymphoma. But in myeloma it's not really well defined. So we were able to send a survey out, 1500 patients responded to it and they told the doctors, this is what it means, and in priority, does that mean going off therapy forever, but maybe not maybe a functional cure is staying on some kind of therapy where you're not experiencing a whole bunch of side effects. And that's kind of like number one would be, no more disease, no more treatment, right? But no more disease or controlled disease on low level treatment with low side effects, that's number two. Being on therapy forever with lots of side effects patients, don't think that's called a cure So, hearing from the patient community, I asked the doctor how long would that have taken you and how much would that have cost you? And he said that would have taken me over a year and a half because I have to go get agreements now. I can't get 1,500 patients at my own facility to answer that survey. So now I have to go do a multicentre kind of study. So, I have to coordinate with the research coordinators at all of those different centres. We have to have somebody create the survey, send it out, capture the results, do the stats analysis on it and then publish on it potentially. We have that finished for free for him in about six weeks and it was because patients are so generous. They want to get to cure faster. Same things like Maury Gertz is wondering why are patients getting such a delayed diagnosis. You can get it's kind of like a different thing that can happen with myeloma, and you can get these protein build ups in your heart or your liver, or your brain. And these patients really struggle to get an accurate diagnosis. So, why is that? How many doctors do they have to see? We can facilitate that survey for them, for him and we're going to be doing that for free.

So, like if you think about like what Gary talks about, one of the low-hanging fruit type things that we can learn in a database like this, we can go back to CAR-T patients, we will be launching a CAR-T survey and three-year study pretty soon. Should we study what these patients had before CAR-T, after CAR-T, how many lines of prior treatment do they have before their CAR-T, who's getting better outcomes and why is it? What are their side effects before and after, other long-term things we should be worried about is the sequencing better, if you do it bispecific antibody first versus a CAR-T first. We can answer those types of questions with patients who are treated either on clinical trial or with commercial products if they join these types of surveys and studies. So, last year we did over, I think collectively we've done about 35 surveys or studies, we have will probably accomplish, we have 35 open right now and we'll probably complete I would guess up to 50 sometime this year, different projects like that, either looking at the data on the back end, we also try to share it back with patients so they know what we're doing with their data. It's all aggregated so there are no names used on the data. But we're trying to see patterns. And even if nothing new was ever developed for myeloma, again, we could improve care for people regardless of where they live by just using

this data for research. One of the points about HealthTree Cure Hub is as a patient I didn't want to say, hey just donate your data will do something great with in 20 years and we'll learn something cool and then maybe we'll share a back with you. Patients really need to get value using this tool immediately. So, what Gary mentioned earlier is the ability to see treatment options that are customized for you personally and it's based on like, let's say you're a newly diagnosed patient, you're going to see different treatment options than if you had relapsed and been on prior lines of therapy. So, we have logic in the system that kind of filters things out based on what line of therapy you've used. And with the goal Rafael Fonseca, from the Mayo Clinic is the one who came up with that benefit because just what Gary said, in the beginning patients were not getting treated as if they were getting treated by a specialist. So, he said, why don't you kind of democratize that show those treatment options so patients see how an expert might treat you and then you can go have a conversation with your doctor. Why would you do this combination versus this combination, when should I do a clinical trial either like a maybe I do CAR-T earlier in lines of therapy or do I do a bispecific right now, do I wait on that and don't use that target quite yet, or what's the whole strategy here? So, we have other benefits like you can see, you can find clinical trials also, you can find your twin so if you want to do what I want to do at the beginning, you can say I have these genetic features, I've been on these prior lines of therapy, show me all the people in the database that look like that. You can see that list it's all de-identified so you can see who that person is. But we had a chat feature and we revamped everything and so we have to bring the chat feature back to be able to connect those two patients together so you can see, I can kind of do that research now that I wanted to do when I was diagnosed. Show me everybody that looks like me, show me what they got for therapy, how long do they stay in remission, what were their side effects and what are their genetics? And that's our treatment, we have a treatment options kind of section and a twin, we call the twin machine. Go ahead, Gary.

Gary Petersen: I think that's very, very important that's available. And one thing I was thinking was, why doesn't every oncologist or haematologist or haematologist oncologist go to that site to begin with, to look at what the options are. In last year is probably because I was somewhat disappointed with that gap doesn't seem too close and what am I really doing to get that closed and is it worth the effort, then I thought well if in fact you can get that information to their doctors, their haematologists, their patients that could go a long way to fill the knowledge gap. And the knowledge gap is what creates the life expectancy gap.

Jennifer Ahlstrom: I agree.

Gary Petersen: That's kind of why I wanted to talk to you today, that I just don't understand in my own mind, if you can't be with the myeloma specialists because they don't grow up on trees. There's 15% of the people have a myeloma specialist call them up today. Some of them say I'll see you in three months, I'll see you in whenever for the longest time and you can't wait that long. The oncologist wants you to start with revlimid and dexamethasone the first day and when I backed away, I found that it's kind of like you are in a car next to a train, right? And the train is the cures in the all the new stuff going on and if you're in your car and you're zooming along and you're looking over there, you're keeping up with what's going on every day. All of the neat things, the CAR-T, the by-specifics, the antibody drug conjugates are all those things but I tell you when you stop your car and that stuff just goes flying by, you have no clue what's going on in the real world and with multiple myeloma at the speed of which it's going right now and all the things associated with it, if you don't keep up to date and nobody can, the local oncologist he's going to see breast cancer, DCIS and doing a procedure for that or you got kidney cancer they'll go and slice it out and then take some radiotherapy and assuming that's it but with myeloma, that train is just going so fast. And not only that if you look like you said, other types of diseases, what you get 90% of them are metastatic, 90% of them are easier to treat and you don't necessarily have to have a specialist. Myeloma is not that way when you get it you're already metastatic and I see that in my sister, she just found out that she has got the metastatic breast cancer, it's in her liver and they are not giving her much of an opportunity. But then I look at the most of her current treatment happens to be with 1-2 new drugs that have been developed and approved in the last year and a half.

Jennifer Ahlstrom: Yeah, take advantage of the new stuff. I know it takes several years for the community practices to catch up with how myeloma experts are treating. So, the community experts are not treating, I

don't know how it's humanly possible to treat that many cancers and they're doing an amazing job for what they have to work with. But just the sheer volume of information, like you're saying is changing so fast and so quickly, so we are, outside of the foundation, we are working on kind of flipping this around and providing clinical decision support tools for the clinicians using the data that patients are contributing. Because when we first started this, that was our thought let's provide tools to the general oncologists and when we did those interviews, they said, we know how to treat myeloma and I don't want to be insulting to anybody who's trying to help patient care, but it's really humanly impossible. And the data shows that they are not treating in the same way, they are not having the same outcomes and it's very, myeloma is very nuanced, there are different types of myelomas. I mean, how can a clinician treat my myeloma from without doing a bone marrow biopsy to even see what kind of myeloma that I had and had I done that I would not have any disease left and I would have no clue what I was kind of working with. My doctor would always say you're fighting a war, so you need to understand your enemy. Even things like the basics like that where the right test run, are the right genetics testing understood, are we treating for that disease, are we treating for a standard risk disease, are we treating for a more aggressive disease, how do we do that? So, we started by providing these tools to the patients like the thing, the patients love the most about it in HealthTree Cure Hub, is they love contributing to the research. But they also love seeing a whole dashboard about their disease, because it's easier to use than like my chart or whatever portal they're logging into. And they can watch their Labs track over time. They can be automatically imported and things like that. So, but that all contributes to the data that we all need to be able to make these key treatment decisions, which patients are doing better on revlimid, which patients are doing better on Selinexor, which patients are doing better after stem cell transplant, for which patients did stem cell transplant does not work. I mean, there's so many questions that need to be answered. And when you look at clinical trial development, pharma companies are focused on moving new therapies into the clinic and that is their primary focus. That is their job. That's what they're going to pay for a clinical trial to have happen. A lot of these ancillary questions that could help patients today are not being asked because their focus is on getting drugs through. So, who's there to pay for the study of the investigator and their time and their research team and their stats people. Well, that's the NCI and people like that without funding is very limited and you have to apply for it. And you have to prioritize as an investigator of what you're actually going to study. But if we can increase the pace of this kind of research, this very practical real-world research, we could come to a lot of conclusions very, very quickly. So, what we're working on right now is two things, flipping those tools around for the clinician so they would have access to data sources that would be informing the decisions. So, instead of having a group of myeloma experts get together and say well this is the treatment path I would follow, you could either pull clinical trial data and that could be one of your data sets that you use. You could pull actual data in an Aggregate and use one of those, you could pull twin match data and just see okay, for this type of patient who has this type of genetics, who's have this prior therapy, this treatment path might be the best. And automating that is kind of the next step. And that's where I think the general oncologist would say, okay, you're showing me the data, you're showing me the resources where you're pulling the data from the data is accurate and it makes sense. So, let's all use these new tools and even the experts in the myeloma space are developing these new models. You have the University of Miami developing genetic-based treatment models. You have other groups in Germany that we are working with and that are working on the same types of things. So, this is kind of the next level of care for patients, even from experts but bringing that to everyone in the general oncology clinic, so they can treat as if they were myeloma expert without spending their life studying myeloma is like the golden ticket, right? That would be amazing.

Gary Petersen: Does HIPAA get in the way of that in any way.

Jennifer Ahlstrom: No, it doesn't.

Gary Petersen: Okay, well that's fantastic because that's really huge sticking point. I mean drug companies can't even tell you that they have Co-pay programs, I believe. They can't tell, at least they can't tell people who are on Medicare, they just…

Jennifer Ahlstrom: Yeah, they have limitations. Well, it's a highly regulated industry on their side and the doctors are concerned about HIPAA violations because once data comes out of their facility, if they process

claims or they are prescribing, that's when HIPAA kicks in. Patients can choose to do with their data, what they want to do with their data, and we tell patients that participating in HealthTree Cure Hub you own this data. If you want to pull your data out any time, tell us, we do it. We've only had maybe five people out of 11,000 ever do that but it's possible because the patient owns their data. We don't own their data, they are in charge of it, they own it, it's theirs. And that's how we look at it. But the group, joint venture I guess I would call it is just joining together to make research, new kinds of research possible. And in the past their patients have never been given the tools, the data tools, or the software tools, or what not to be able to actually participate in a credible accurate way.

Jennifer Ahlstom: I just have one more thing, like step number five is, I think step number 5 is share. Because what you said earlier Gary is, we're making progress in myeloma, we don't see the length of life is increasing, so that's all good. But we know, plenty of patients who are not involved at all in using these tools, right? And they don't know about them and they're not aware of them. So, number five is get involved and share. If you know family members, tell them that you're involved, tell them, you have myeloma, tell them about resources. I just consulted with a patient whose dad was just diagnosed with myeloma and it was so wonderful to be able to tell them about the different resources and how to find a specialist. And so, share, share and share is number 5. So, talk to people when you go to the clinic, have your family members share what's available. And that is really how we're going to make a difference in multiple myeloma outcomes.

Gary Petersen: When I look at what you're doing, it seems to me that getting back to the harder to treat diseases. And what I mean by that is anything that is turned metastatic because when we get myeloma it's kind of all over our body, it's in our bones, it's in our blood, it's in our brain, it's every place. And when other cancers finally break out, they are looking a lot like what myeloma is today and that's why some of the things that we've done in myeloma are now being used in some of the other diseases like, the solid Tumors and… the fact that because other diseases are starting to mirror myeloma being metastatic and all, you see this platform, this type of format being used much like a template for other diseases.

Jennifer Ahlstrom: Yeah, so because of that, we thought so too. And we knew this could be used and when we've done, when we show this to multiple groups, they all say, oh my gosh, I can't believe that exists. We would love for that exist in our disease. We did a video about it and we got requests for like 50 diseases to do this then. So, we actually took the whole platform, we picked it up and moved it over and started in an AML and in MDS and in CLL. And really It could be replicated in a hundred different diseases, if we had the bandwidth on the program side to be able to lead that but technically, we can do that easily quickly. And we started a whole AML division in less than six months, we started a new website, we can have a website up in a week and it's not that hard technically now because we have the program and it's all completely integrated.

Gary Petersen: Well with that, I see that the gap exists for anybody who is metastatic no matter what their disease is and as a result, this could save so many lives just like it could close the gap with multiple myeloma. And so, that's certainly one of the reasons I wanted to get you on again. To me what you're doing is the answer and everybody needs to be able to access that answer. So, thank you, Jenny. I really do appreciate everything that you do. And like I said, in the past you are the energiser Jenny. I can't believe what you are doing and getting treatment. You ware me out watching you.

Jennifer Ahlstrom: Well, it's been so fun because I had a background in Tech. And so, I wasn't afraid of the tech, my husband has a background in entrepreneurship, so we really treated my myeloma like a start-up, and we are able to apply the skills and to create new tools like if you wanted a different outcome, you need to approach it in a different way. So, now we've deployed these new tools to solve this really, really important life-threatening problem and it's so fun to be able to do it. So, thanks for having me on.

Gary Petersen: Yeah, well great to have you, Jenny. Thank you.