



Patient Power

Cherie Rineker: Post-CAR T-Cell Trial for Multiple Myeloma

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Myeloma Patient, Author and Blogger

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Cynthia Chmielewski:

Hello, everyone, and welcome to Patient Power. I'm Cynthia Chmielewski, and today we're gonna be talking to my virtual friend and fellow myeloma patient Cherie about her—hi, Cherie—about her recent experiences with the CAR T-cell trial. And, Cherie, I just wanna thank you for sharing your journey with us. I guess it's your pilgrimage towards health, the title of your second book that's coming out. You've been home from the hospital probably less than a week, and can we just start just a little bit about yourself, when you were diagnosed, if you had genetic testing, what the results to that were, and what treatments you had prior to your CAR T-cell therapy?

Cherie Rineker:

Sure. Sure, sure. Yes, well, my name is Cherie, and I was originally born and raised in Holland, came to America in 1989, never want to go back, love the country, and lived a very, very healthy life. I was very health conscious. I was actually a massage therapist and colon hydrotherapist, reflexologist, had gone to Clayton College for Natural Health to become a naturopathic educator and was working at a very world-renowned health spa in Arizona when I started having very bad back issue back in the end of 2011 going into 2012. And I was a massage therapist, so I just thought I'm working very hard, and that was it.

But the pain and the fatigue that I was feeling wasn't going away but was getting worse. I also had my first flu in my life ever that was diagnosed, and 104 fever, and really knocked me out for a good couple of weeks. And then I ended up getting a lung infection and low-grade fevers, and was going to specialists and doctors and stuff, and I also had very, very severe back issues and just couldn't do much. I had a hard time walking, walked into an urgent care where I saw a doctor, and I suggested that maybe we could do a CAT scan.

And he said, "No, we can't. Insurance companies frown upon the cost of CAT scans," so he did an X-ray and couldn't find anything, and gave me a shot in my bottom, but the pain still didn't go away. And it took a good six to 10 months from when all these issues started to happen until I decided to go to the emergency room on November 3, 2012. I remember it like it was yesterday. I had to find a babysitter for my daughter, who had just turned seven a couple weeks earlier. And I went with one of my best friends to the emergency room, and I said, "We're not leaving until I find out what it is."

So, went to the emergency room, and I had lesions and a plasmacytoma on T3 and T4, which is right around this heart area up front. So, I had told one doctor that I was hurting in this area, and he actually got very upset with me because he said, "You should never tell a doctor you're hurting there unless you're having a heart attack, because now I need to do all these

tests and stuff.” I said, “Well, but that’s where I’m hurting. Somewhere in there.” And he said, “Well, let’s just pretend that you’re in a court of law, I’m your lawyer, and I just wanna hear yes or no answers,” and there were no yes or no answers, so he sent me home.

He said before he came in, based on what I wrote down, what was wrong with me, he figured that I had asthma. So instead of finding out that I have multiple myeloma and do blood tests and stuff, he just sent me on my way with an inhaler, telling me that I had asthma. And so, yeah, I was very frustrated with the doctors. And that day, they helped me right away, because I was pointing at here again, and they did blood tests, and they did a CAT scan, and they gave me morphine, and for the first time in months and months, I was feeling somewhat better.

And we were just kinda joking around, my friend and I. And after a few hours, the doctor walks in, doesn’t look at me, doesn’t sit down, and just says, “Well, you’re severely anemic, and you have cancer, and you can’t go.” And my friend and I were talking to each other, and we just started laughing. And I said, “Ha-ha, you’re kidding.” And he looks at me and says, “I don’t joke about things like that.” And I just completely lost it. I was 44 years old, I had my 7-year-old, and did a bunch of crying.

Called my husband who was on a biking trip, and they didn’t wanna let me go, and I said, “Well, you have to let me go, because I have to pick up my daughter from the babysitter, and I have to take her home, and I have to feed her, and I have to tuck her in, and I have to pretend nothing’s wrong.” And I was completely devastated. So, then over a week’s time, they found out that I had multiple myeloma in the hospital, every possible test, and then I moved back to Houston where my husband and I were living, and left my job obviously, and came under care of Dr. Orlowski. Had a bone marrow test done that they couldn’t see, they couldn’t do the FISH test, they didn’t know how much percentage I had.

They put me on Revlimid first, the usual lenalidomide (Revlimid), dex (Decadron), and bortezomib (Velcade), and I couldn’t handle the Revlimid. And changed up my medication three or four times prior to going into the first stem cell. And after nine treatments, my neuropathy was getting really bad. I was just worse and worse from the cancer. And so, we decided to go ahead and start with the stem cell transplant even though the blood tests weren’t coming back good and the Bence Jones.

And I asked Dr. Orlowski, I said, “What is it you’re looking for with the bone marrow? Like, what’s positive?” And he said, “Well, we’re usually looking around 0 to 5 percent, which would be good.” So, my test results came back, and I had 80 percent of multiple myelomas still in my bone marrow going into my first stem cell transplant. So, I was pretty bummed out about that. Did my first, was very, very scared of the stem cell, which turned out not to be as bad as I feared. And after that, they took a test again, and I remember Doctor walking in and telling me that the bone marrow biopsy had gone down to 30 percent.

And I was crying with joy, because I was so happy that it had gone down, not realizing later how bad that still was. So, he said, “We still have a long way to go,” and I told my stem cell doctor, I said, “Well, let’s just do a second one then.” So, four months later, we did the second stem cell transplant, which brought my numbers down to 20 percent in the bone marrow. And at that point, Dr. Orlowski said, “Well, we’re gonna put you on aggressive maintenance,” which was carfilzomib (Kyprolis) and Revlimid, low dose. And that kept me stable for about 15 months, at which point I started developing a very large tumor on one of my ribs. And so, the cancer was acting up again.

And at that point, I had done a lot of research, was looking into cannabis, and told Dr. Orlowski, “I wanna do a trial. I wanna go to Colorado, and I wanna see if cannabis can help with all the side effects that I was having,” you know, severe pain, tingling of hands and feet—can’t remember the name—neuropathy, and nausea. I had a tremendous amount of nausea throughout my journey, lack of appetite, lack of sleep, depression, anxiety and everything. And so, I went there for two months and was started on pomalidomide (Pomalyst) and found out that my cancer numbers weren’t better.

So the trial failed as in cannabis can cure cancer—no, it can’t cure multiple myeloma, but it did really help with my neuropathy, with the pain, and with my appetite, and with my sleep.

Cynthia Chmielewski:

Wow, what a journey. So, what made you decide to start looking into the CAR T-cell trials? At what point did you think this was the next step of your treatment path?

Cherie Rineker:

So based on Dr. Orlowski's map of what I've done, I've done 13 different treatments for multiple myeloma. And it was after the daratumumab (Darzalex) and elotumumab (Empliciti) failed in 2016, and I was put on bendamustine (Treanda) with carfilzomib (Kyprolis) and dex, and it failed after about four months, six months in 2017 that I realized I was not an incurable cancer patient. I was actually terminal cancer patient. We were really running out of options, and my daughter was now 11 years old. I was going into my 50th birthday, and this wasn't good.

So he put me on one more treatment which was panobinostat (Farydak) with Kyprolis and dexamethasone, and it worked for three months, I think. Really went down, and then right went back up again. And that was actually—I was working towards a fundraiser for my 50th birthday because all I wanted was a cure, and I figured the only way we could get a cure is by raising money, so I did a fundraiser, was able to raise a bit of money for Dr. Orlowski and his research. And so, right after my birthday, I found out that I'd relapsed once again.

And at that point, Dr. Orlowski started talking about maybe putting four chemotherapies together, and we started talking about trials, and I said, "You know what, Dr. Orlowski? I am done with chemo. I mean, my immune system had been so low that I was needing once or twice a month, I was needing platelets. My white blood cells did not come out of the 1.3-.6, needed filgrastim (Neupogen) shots constantly, and I just didn't see myself going—and you have to remember, when you're a young person, and you're raising a child, and you're looking at this long term, it doesn't look good.

So, I had been reading a lot about the CAR T, and that seemed to be a very, very positive and hopeful thing. I've actually seen a couple things on TV. And so, I said, "I wanna do the CAR T." So, he said, "Okay." But the problem with getting into a CAR T is that, A) You have to be relapsed, which I was, B) you have to find a trial that has availability, which is extremely difficult, and C) you have to hope that you don't progress so bad that you don't make it in, or you have to go back on chemo. So that was a really scary time, and I just started looking into all kinds of trials.

And then the one at Sarah Cannon with Dr. Jesus Berdeja, had a Phase II coming out. And it was a 14-hour drive. I really wasn't feeling good anymore, and I was very afraid to get on the plane, so my girlfriend and I jumped in the car—or crawled in the car—and it took us two days to get there just to have an interview with Dr. Berdeja who said, "Well, you seem like a good candidate," but at that point, my myeloma markers actually didn't look—you were supposed to have 100 kappa light chains, and I was, like, 87, but it was substantially going up, so I knew that wasn't gonna be a problem.

But my platelets weren't coming out of the 20s and 30s, and it had to be 50, and you weren't allowed to get infusions either. And then another thing that you needed was your ANC had to be at least 1, and mine wasn't doing that with that Neupogen, which you weren't allowed to get either. So we were hoping with the break in the chemo that I was gonna be able to have that go up. And when we left, I thought that I was accepted and that I was gonna go ahead, and then the next day I got a call, "Well, you're number 30-something on the list." And I had a very good friend of mine who was trying to get into the same trial who's since passed. And so, at that point, I wrote an article, "Dying to Get Into the Trial."

It was one of the lowest points in my life that I felt that there was something out there to possibly extend or save my life, and it was really close, but I wasn't sure if I was gonna make it—getting in. So that was a rough time. Everything just started getting worse. My pain got uncontrollable. I ended up at MD Anderson for 12 days in the hospital due to uncontrolled pain, because I had a plasmacytoma on my sternum, and I had one on T11, and I couldn't move. And I spent a weekend contemplating, praying, not knowing. I wanted to be close to home, of course. Nashville was a 14-hour drive away, and finally decided I felt safest doing the one at Nashville, so we decided on doing that, and then all the testing started.

Cynthia Chmielewski:

So was there testing to get into the trial?

Cherie Rineker:

So first, in order to get into trial, like I said, you need to have 100 kappa light chains. So I was tested for that, and by the time they tested me, it was already well over the 100, so that was good. And then the platelets slowly started coming up, so they were like a 52. I had made it by two. But what I didn't realize for the next following weeks, they kept testing it, and things would go up and down. And one of the things that kept crashing was my ANCs. And by like .2 I made it. I thought I was already in the trial. But she said had not come up, you would not have made it. So that bone marrow biopsy, which had gone from like 2 percent to 10 to 15 percent in just a month's time. I was really lucky. When they said there's 30-something in front of you, the next week, they called me, and they said there's space. So, for any of the people out there that think the lists are too long, go for it. Try it. Show up because you don't know.

Cynthia Chmielewski:

That's really good advice. points that you just keep on plugging, and if you're 30 on the list, you may make it up to the top.

Cherie Rineker:

I became number two on the trial.

Cynthia Chmielewski:

Wow, that's great. So, then I guess the next step was to harvest your T cells. Is that what happened?

Cherie Rineker:

Yes. Yes. So, then...

Cynthia Chmielewski:

How long?

Cherie Rineker:

Yeah, they had to put in one of those quadruple—my terminology's not very good, but they had to put that in in order to get that, which had its complications, but we got through that in four hours, and then they did PET scans and another bone marrow biopsy. One of the things is if you do bridge therapy, which I really need it because of the plasmacytomas and stuff, they then have to redo all your PET scans and bone marrow biopsy to see again where you're at. So, it was a lot of testing in a month's time. And I went back and forth—we drove back and forth four times.

And then two days before you get your CAR Ts, you have to do chemo. That'll wipe out your immune system so that the new CAR-T cells will be able to have the space to grow and do what they have to. So we did three days of that. And at that point I was so sick. I was so cold. And I was anemic, and I went everywhere with my blanket on.

Cynthia Chmielewski:

I remember seeing those pictures.

Cherie Rineker:

...dying from the myeloma. Yeah, yeah, I was just miserable. All I could do was lay in bed, and I was just waiting for this CAR T, and it really felt like it was my only hope. On Sunday night, I was taken to the hospital, and sadly, my husband had to go home because he had a job to go to and a child to take care of, so I was by myself for the next two weeks in the hospital. And then on Monday, they came to access my port—they have to put in the CAR T. They need two points to go in in case something goes wrong.

And because of the years of being poked, they had to stick me seven times because every vein blew, and there was so much scar tissue, so they needed three nurses and seven tries before they finally got me in. So that's one for the book. And then they came in these blue suits and this gear on, and it felt like I was very contagious, like this dangerous person, but in the end, I heard they actually did that for my protection. And then these four little bags of white liquid were put in over a point of, I would say, an hour. That went in real quick. And then that was it.

They check your temperature constantly and everything and stuff, and I was feeling great. Had my dinner that night, and felt good and everything, and I think I was also on a lot of morphine because of my pain still, so that made life a little easier.

But that night, I got really sick. I don't know if it was the CAR T, or if it was the hospital food, or if it was the chemo that I had done, but I started vomiting really, really bad, and that ended up getting into my lungs.

So when the storm hit the next day, not only did I have 102 to 103 point something fever to put up with, but also 80 percent oxygen and pneumonia that had set in overnight, so they started treating that immediately. The next few days are kind of a blur. I remember that I had a big storm. The pneumonia wasn't fun, and then on the second or third day, my tailbone started pulsating and throbbing, and then that went up my entire spine, like there was just somebody constantly going like this, and needed a lot of pain medication for that, which Dr. Berdeja said it's happened to a few people.

Oh, another thing that happened where my plasmacytoma had been years earlier on my rib, that area started to really swell up, and was very painful, and I couldn't lay on it and stuff, and this apparently happens to some CAR-T patients, and it's another storm where the T cells really go in there aggressively and clean house, so it was a good thing, but it was no fun. It was a blessing that I didn't remember a lot of that week, because it was really miserable. And then after that, I remember the first time I was able to take a shower, get out of bed, walking into the bathroom, being exhausted, asking for a chair in the shower, and that took all I had. And I was supposed to walk, and I was supposed to do the exercises and stuff, but then within a couple of days, I went from this sick, dying person to walking the hallways.

And just they're saving your life, and you should be grateful, and I'm an optimist and always showing gratitude and stuff, but you're doing the circles and seeing the people living life out there, and you're in a little prison, it was a bit rough. And then I remember Monday morning, my husband and my daughter, she had to get up at 3:00 in the morning to get on a plane and visit momma, and she walked through the door, and it's like [gasps]. The happiness, the things we take for granted, just seeing her walk through the door, and then my husband right after, I just let out a cry.

I was just so happy to have my family, and five hours later, they released me, and I got to feel the outside air for the first time, and we were put up at the hotel for another almost three weeks to come back and forth for the checkups, the blood and stuff. I was still incredibly neutropenic. I'd had a blood transfusion, platelets transfusion.

I mean, they would give me a Neupogen shot, numbers would go up two days later, crash, 1.2 or lower, so that's been my only issue up to this day. But I remember the day that my appetite came back ravenous. And I'm talking years. I haven't had a good appetite in years, and it was probably the day that Dr. Berdeja walked in the room, and we saw on Facebook that piece of paper where my myeloma was up, and it had plummeted to below normal, which had never happened. And I was so incredibly thrilled.

I don't like to use the word remission, because that means cancer can come back, and we can't say the word cure because well, first of all, they say there is none, and second of all, once we say that, maybe researchers will become lazy and donors will become lazy, so I'm not cured. But I do call myself cancer-free in the blood. I don't know what my bone marrow is yet, and I don't know what the PET scan shows still some activity, which they expect to be normal. But yeah, I feel like I'm as cancer-free as my daughter and my husband in my blood. So I decided I'm not gonna wait for the other shoe to drop, which is the toughest emotional exercise for us myeloma patients, I think and most cancer patient.

That is definitely something that I'll get into in my book to keep that positive attitude. Every time your muscle aches, or your bone aches, or you have a little bump here or there to not always go to "Oh, my God, my myeloma's come back," but like I said, when you've relapsed as many times as I have, it's hard to think that everything is doing good and the CAR T still is in there, and they're still doing their job, and that's where I am today.

Cynthia Chmielewski:

You look wonderful. You look full of energy. I know you've had an amazing journey there, and we really thank you for sharing it with us, because I know many patients in the myeloma community—but even other cancer communities—are very curious about this new type of treatment and talking to patients who are so willing to share their experiences is wonderful. We share in your knowledge, and I'm just grateful that you took the time. And maybe in a few weeks, we could reconnect again and see how you're doing. When are you going to have some testing done to see about your myeloma markers? What comes next?

Cherie Rineker:

So I'm waiting on my bone marrow and my Bence Jones currently. That was done before I left, so I'm anxiously awaiting hopefully really good results. And then I go back on the 9th, back to Tennessee to see Dr. Berdeja. They're not doing another bone marrow biopsy then, but it's based on how much blood they draw. The first time they drew all my blood on my first visit, there was a container this big full of vials, and I looked at it, and I thought, "Oh, that's what they have for the next 10 patients for today," and I had to fast because I had a bone marrow afterwards, so I wasn't allowed to drink, I wasn't allowed to eat.

That was when I was really sick and in pain, and she starts drawing and taking one after the other, and I said, "Are they all for me?" She's like, "Oh, yeah." Must've been 50 of them. And I became unwell. They had to stop, and they accessed the port later on to finish the job, but it's a lot of that. People ask me, "Would you do it again?" because mine was particularly rough compared to—I mean, I've heard of one guy who had 106-degree fever, which that must be just incredible, but a lot of people barely get the cytokine release syndrome and nothing or very little, and that's it. And mine was rough—throw pneumonia on top of me.

And so, people would say, "If you knew what you know now, would you do this over again?" And I'm like, "Heck, yeah. Absolutely. Without a doubt." I mean, I really feel like I've been given a second lease on life, so I mean, how can you say no to that? And I'm grateful to the people who helped to get me there. I'm grateful for the pharmaceuticals who I did not like at all when I was holistic practitioner. I do not believe that they're keeping the cure away from us, because they wanna make more money. I mean, all that kind of stuff.

It's really very humbling how cancer and the education I've gone through has humbled me, and it made me step away from my old views and made me adapt to this is the reality of cancer.

Cynthia Chmielewski:

Well, thank you once again for participating in this clinical trial that may be bringing a new treatment to the myeloma community, fingers crossed. It's still early, there are still a lot of bugs to work out of it and thank you for sharing your experience.

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