



Mother, Wife, Fitness Guru: Diagnosed With Myeloma in the Prime of Life

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Andrew Schorr:

So, first, Cherie, to start with, you were diagnosed back in 2012. And I think you were traveling at the time, is that right?

Cherie Rineker:

No. I was actually going to school to become a natural esthetician before getting very sick.

Andrew Schorr:

In your professional background, I know you've been a triathlete. You've been a very active woman.

Cherie Rineker:

Yes.

Andrew Schorr:

And you've done a lot of different things. You've been a massage therapist but particularly active. So, it started with pain in your arm and your side, right?

Cherie Rineker:

Pain in my side, pain in my ribs and my sternum, in my back. I was a massage therapist, so I kept self-massaging myself with tennis balls that I would lay on trying to find the right spot. And it just would go to different places. It would never ease up. It was just slowly getting worse and worse.

Andrew Schorr:

And this went on for like six months, you were going through all sorts of problems and fatigue.

Cherie Rineker:

Right, right. Yeah. Slowly, the fatigue was getting worse and worse, to the point that my daughter was 6, at the time, and I would still pick her up, and I couldn't do that anymore.

And I had a hard time climbing up the stairs to my apartment. I ended up having low-grade fevers and a lung infection that just didn't want to go away. And I was being tested for all kinds of things. Everything came up negative. This little word, cancer, started creeping in my mind. And that's what it ended up being.

Andrew Schorr:

And you have lesions on your bones, right?

Cherie Rineker:

They were all over my rib cage, all over my spine and my scalp, on my pelvis, yes.

Andrew Schorr:

How old were you, at the time of diagnosis, Cherie?

Cherie Rineker:

I was 44 years old. But I really believe that I had some form of myeloma for years, because I remember at 40 feeling very fragile, in my bones. And I asked my gynecologist, if I could get a bone density test. And he asked me if I was still having regular periods. I said yes, and he said you're fine, don't worry about it.

And I think that maybe they could have found something, at that time, already.

Andrew Schorr:

I have a question for Tiffany just while we're talking about diagnosis. So, Tiffany, she was a pretty young woman. Often, we think of people older with myeloma. But really, there is an age range, isn't there?

Tiffany Richards:

There is. Certainly, the median age is about 69 years of age. But we do see patients who are younger being diagnosed with myeloma.

Andrew Schorr:

Okay. So, Cherie, you had your diagnosis. It's a shocker. So, since 2012, you've been through a whole range of treatments.

Cherie Rineker:

Yeah. They started out they were going to do surgery on my spine. I had plasmacytomas on T3 and T4, one at one end to the spinal canal, so they were worried I was going to be paralyzed. The surgery was too tricky, so they chose for radiation. And after that, I moved from Tempe, Arizona to Houston, Texas to be closer to MD Anderson and went through nine months of induction chemo, which we changed up I think three or four times.

And the side effects got worse and worse. So, we went ahead with bone marrow stem cell, my first one, in August 2013, even though I still had 80 percent of my lung and my bone marrow. And four months later, I chose for a second stem cell transplant, which only brought my numbers down to 20%. And then, I've been on continuous chemo

through December of 2017, when I told Dr. Lasky I am done with chemo. It was destroying my immune system. And I was just very sick. And that's when I started searching for a CAR T trial.

Andrew Schorr:

Oh, man. So, you've been through it. There are some people who have done pretty well with transplant.

Some people even have had oral therapies or infused therapies. But for you, you kept running through them.

Cherie Rineker:

Yes. And I found out later I had translocation (11;14), which is not supposed to be very aggressive myeloma. But Dr. Lasky said mine was just very stubborn. And it just didn't do good with medicine. I would have short responses, and then, I would relapse again. And that's how I went through the 13 different regimens.

Andrew Schorr:

And so, you had testing many different times. But the news often came back not so good.

Cherie Rineker:

Yeah. Some months, it would go better than others. And I would have a graph, in my bathroom sink, just for positive affirmation. And seeing that go down to zero, my first one, I think based on that analogy, I was supposed to be in complete remission August of 2013, which, obviously, didn't happen.

And it was just so devastating every time to see the numbers go down for a bit and then, creep back up again. And going up, Dr. Lasky often said that sometimes happens. But after so many relapses, I knew, as soon as those numbers went in the wrong direction that meant I had become refractory, and I had relapsed.

Andrew Schorr:

All right. So, just for our audience, CAR T-cell therapy that some people have heard about for this blood-related cancer and for some others now, too, remains experimental, in some areas. And some lymphoma is approved, but not yet in myeloma. But you entered a trial. And, so far, over nine months now, it's worked out, right?

Cherie Rineker:

Yes. I got my CAR T cells back on March 12. It's my fourth birthday now, after my birth and two stem cell transplants.

And I went through a serious cytokine release storm for about a week and then, came out and started feeling better than I had in years real quick. And about three weeks later, I had my first complete remission, negative, no Bence Jones in my urine, no kappa light chains, ratio good. And then, the first bone marrow biopsy showed complete negative. They couldn't find any myeloma.

Andrew Schorr:

And you're going to go back for another checkup soon where we hope that that still goes that way. And I should just mention, some people have seen some things we've posted along the way, and Cherie has, too, where I was thrilled when Cherie sent me a picture. And having been really almost at death's door, she was out gardening, right, Cherie?

Cherie Rineker:

Yes. I do everything now. I'm back to teaching yoga and meditation. I'm doing reflexology again.

I'm going to the gym, for the last month, trying to get strength in my body and my bones and my muscles. I have weened myself off all opioids. So, my medicine cabinet that was just bursting at the seams before, now, just has three

little things that Valtrex, we, I guess, have to be on indefinitely and a couple of other little things. But, yeah, I feel healthier than I did probably one or two years prior to my diagnosis. So, it's really incredible.

Andrew Schorr:

This is maybe the new age of myeloma care, with a much broader range of treatments than we've ever had before. And for someone like Cherie where so many other treatments that have worked for some of you who are watching were not working for her. And Doctor, I'm sure, when you hear this story, that makes you feel great that medical science has advanced, in this way.

Dr. Manasanch:

Yes. It's great that we can use our own cells to treat diseases, including cancer. I do think that, of course, these therapies are some of the major advances that we've had over the last five years. In fact, when the CAR T-cells were starting, I was a fellow at the National Institutes of Health. And the first patient that got one of those infusions was a patient with, actually, leukemia. And I was on-call that night, and I was called because the patient was getting a cytogram release, so I had to send this patient to the ICU. And the patient, subsequently, did all right, but this was many years before this was going to be done in myeloma.

And then, I remember very well, when I left NIH to come here, that was in 2014, one of the days I was leaving, I kind of ran into Dr. Kirkendorfer who is really the person, the scientist, that has developed this in myeloma with targeting the PCMA antigen.

So, he really should have a lot of credit for this. He's the one that really started the identification of this target that now is used in many other therapies, as well in clinical trials, not just for CAR T-cells. And he kind of was waving to me and saying, "You know, I'm going to be starting this PCMA CAR T-cell study here. So, send me some patients." So, this was back in 2014, of course. This therapy seemed to work very well. Unfortunately, most patients still do relapse from these therapies. And so, this just means to us that we have to keep fighting to improve these therapies. So, these are still first generation of these therapies.

I think that we can improve on them. And I think there's a lot of research going on on that.

Still there are some patients, like Cherie was saying, that are years out and doing well. So, I know that is not like this for everybody. But the hope is still there that we can improve on these therapies.

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