



Patient Power

Man Living With Myeloma Runs 1,200 Miles Across North Carolina

Kenny Capps

Myeloma Patient Advocate and Founder, Throwing Bones for a Cure

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Andrew Schorr:

Hello. It's Andrew Schorr, and I am recording this in Dallas, Texas, with a wonderful advocate, Kenny Capps, from Asheville, North Carolina.

Kenny Capps:

Yes, sir.

Andrew Schorr:

And Kenny has been living with multiple myeloma for how long, Kenny?

Kenny Capps:

A little over four years now.

Andrew Schorr:

Okay. And I've met 140 patient advocates here, and Kenny is just incredible for what he's done not just emotionally but physically, and I wanted to bring that story to you because no matter what you can do it's to the good, but what he's done is far, far from what most of us can imagine. I wanted him to tell that story. You rode your bike...

Kenny Capps:

...no, I ran.

Andrew Schorr:

Oh, you ran, sorry. You do a lot of bike riding, too.

Kenny Capps:

I do. I do.

Andrew Schorr:

You ran more than 20 miles a day.

Kenny Capps:

Yep, about 22, 23.

Andrew Schorr:

1,200 miles, zigzag east to west, North Carolina, your state.

Kenny Capps:

Correct, yeah.

Andrew Schorr:

And as a myeloma patient.

Kenny Capps:

As a multiple myeloma patient.

Andrew Schorr:

Okay. So first, why did you do it? And how did you do it?

Kenny Capps:

Sure. I actually—well, I was diagnosed in 2015 with multiple myeloma, which is a blood cancer that typically, very often affects the bones, and I do have lesions all through my bones. And I've been a runner, an endurance athlete for many years, started out with cycling, then running and swimming also.

And so when I was diagnosed I was shut down from running. I couldn't do it for a while, and as we came out of that, as I went through—after I went through a bone marrow transplant and I started running again slowly. I put in 16 races during 2016, and I thought I needed to do something to actually address some of the gaps that I thought were happening not only in the multiple myeloma world but also just in general cancer and that people needed to keep moving forward.

They needed motivation. They needed to understand that keeping moving forward was the way that they stayed alive in some way. So I talked to my wife about this, and there's a trail that runs from the outer banks of North Carolina all the way to the border of North Carolina and Tennessee, which is about 1,200 miles away as it zigzags across the state, and I said I think I can do it. I think I can run the whole thing. And surprisingly, she didn't say no or lock me out of the house. She said all right. How long will it take you to do it? I said I think I can do it less than two months.

So on April 1st, 2018, I started on the outer banks, Jockey's Ridge State Park, which is near Kill Devil Hills, and I started running. For the whole trip I averaged about 23 miles a day for 54 days. During the month of May, I averaged almost 30 miles a day for the whole thing, and that was going into the mountains. I finished up.

And the reason, you ask asked me the reason why I did it. So multiple reasons. One, I wanted to raise awareness for the organization that we started called Throwing Bones for a Cure. And the mission of Throwing Bones is to encourage myeloma patients to stay healthy and active through and after treatment.

And the other reason is to show that I can. Somebody with multiple myeloma can do this, and not to say that everybody should, but to say that they can. They can do, they can move, and they can keep moving, and that's what we want to encourage.

Andrew Schorr:

All right, Kenny. So this is amazing. I mean, I've run some marathons, and then I need to recuperate for like months, 26 miles. And you were running like virtually a marathon a day. Just incredible. So thinking about that, it's not how far somebody goes. What I hear you saying is do something.

Kenny Capps:

That's right.

Andrew Schorr:

Do something. Get moving, and all the research folks says if you as a cancer patient are physically active, to whatever extent you can you're better off.

Kenny Capps:

Absolutely.

Andrew Schorr:

You're better off. You can have more energy even when you're tired, and your overall health...

Kenny Capps:

...better results for the physicians who are trying to get you better. They can have a maximum results on what it is that they're dealing with. It's also a great way for pain management.

Andrew Schorr:

So you're a relatively young guy with myeloma.

Kenny Capps:

Yes, I am, because the average age of multiple myeloma is 65 years old. I was diagnosed at the age of 43

Andrew Schorr:

So how do you feel about the future, Kenny?

Kenny Capps:

I feel great. There are so many more drugs that have come out, for one thing, since I was diagnosed. I'm actually on sort of some of the relatively early stuff just because I haven't failed on my current maintenance treatment. And...

Andrew Schorr:

...I always like to say it's not that you would fail, they fail you at some point.

Kenny Capps:

Okay. All right. Nice—yeah. Thank you for the correction.

Andrew Schorr:

So you feel you have a line of treatments that await you should you need it.

Kenny Capps:

I do, and I have things that they can try, absolutely. But the better part is that regardless of that I'm living my best life right now because of that, and I think that other people can, too. It's just that they haven't realized that yet. They haven't figured it out, and that's what we're trying to encourage.

Andrew Schorr:

That's the—we talk about it as I'm a leukemia survivor or a thriver, and you're a thriver...

Kenny Capps:

Sure.

Andrew Schorr:

...is that it gives us a new perspective on life and helps us appreciate things.

Kenny Capps:

Sure, absolutely. There's nothing more confidence-building than saying that you went farther than you went the day before or you moved faster or you did it better. You felt better when you did the same.

Andrew Schorr:

So what were you thinking about with every footstep, 1,200 miles? What had you—because you had to be tired.

Kenny Capps:

Sure.

Andrew Schorr:

There had to be obstacles, days you just didn't feeling like doing it. What had you keep going?

Kenny Capps:

Well, although I'm a very results-driven kind of person I see that there's was an end goal, and so regardless of the fact that it was several days away as opposed to minutes or hours away, I knew I had a goal. And I could break that down. I could compartmentalize that to little things. So honestly, it was just more of my way of living in the moment. It's being present every single day for that. And so it changed depending on what it was. I got to see an amazing part of the state that I grew up in in a way that very people ever get to do.

Andrew Schorr:

Well, I don't run as far as you do, sometimes three miles with my wife, Esther, but every footstep when I do it, I almost feel it's an affirmation of life.

Andrew Schorr:

Absolutely.

Andrew Schorr:

It's an affirmation

Kenny Capps:

Yeah, it's beautiful.

Andrew Schorr:

So, Kenny Capps, having affirmed himself across 1,200 miles and living with myeloma but living well, Kenny, congratulations on that as an achievement but also your organization. The name of it again?

Kenny Capps:

Throwing Bones for a Cure.

Andrew Schorr:

Okay.

Kenny Capps:

And it's throwingbones.org if you want to check us out.

Andrew Schorr:

Okay. Thank you so much for being with us.

Kenny Capps:

Yeah.

Andrew Schorr:

And, as I like to say, knowledge can be the best medicine of all.

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