A Patient's AML Journey and How Genetic Testing Made a Difference

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Andrew Schorr:
So, Kuldip, you've had quite a rough go and you worked for many years in the healthcare technology field, so you're a pretty astute patient, but what happened in 2015? What began for you? How were you feeling where it maybe it led to illness?

Kuldip Ahluwalia:
It actually started in 2014. So the only symptom I had was—I used to walk a lot. I was really active, (?) life in my career and all, I used to fly around a lot. I would—typically I would travel about 300 days a year, so I was pretty active, walking a lot. And suddenly I realized at about five miles per day I was really losing my strength, my ability and all.

It got progressively worse to the point where I couldn't even go upstairs to the bathroom, so at that time I realized something had to be done. So I went to the hospital, got tested. I got back the initial report, and the doctor was laughing at me saying that, you know, we looked at—we ran the normal panels and everything was normal, blood sugar levels, triglycerides, everything else, you know. He said your white blood cells, red blood cells all looked pretty good, and he said you probably have something minor. We'll give you a few inhalers or something else, and maybe you'll recover.

About two weeks later, I started taking the inhalers, and things got really worse.

Went back, talked to the doctor and said let's take a serious look at it. Three days later, I was driving and got a phone call. I was driving on 101, got a phone call, and the way the call started was sort of surprising. They sort of said what are you doing? I said, I'm driving. They said, could you pull up to the curb? I was a little surprised. I pulled up to the curb, and they sort of said, you know, if you don't mind, stop driving, and we'll send an ambulance to pick you up. And I said, what's wrong? They wouldn't tell me.

So anyway, I negotiated my way, and I said, I'm perfectly fine. I'm capable of driving. Let me drive home and then come over to the clinic in the morning. So I showed up in the morning, and my GP, my physician, he had assembled a team over there by that time. So before I walked into the room, I knew there was something serious. They didn't quite want to tell me what was going on, but I'm pretty persuasive when I want to be.

I talked to them. They sort of said, you know, you have a rare leukemia, a condition. You know, they weren't quite sure exactly what it was, that my platelets had virtually gone down to zero. We were down to the 6,000 level. So they said

you're really in danger of a lot of different things. We have to do a biopsy right away. It was Thursday morning. On Friday, I ended up going to the hospital, getting a biopsy. And then the fun started.

Andrew Schorr:
So ultimately in 2015 then you had a transplant, a half haplo transplant, there was no donor. So they were trying to use cells from your son to put you in remission.

Kuldip Ahluwalia:
Correct.

Andrew Schorr:
And that lasted for about how long?

Kuldip Ahluwalia:
So that lasted just over a year. So the actual transplant took place in April and till, May, June, 2016 I was perfectly fine.

Andrew Schorr:
Okay. And then you had another transplant, because you sort of crashed, and that was a pretty unusual double cord blood transplant. And I understand one of the donor cells, sample of one of the donors had hepatitis C that they had to treat those cells for that.

Kuldip Ahluwalia:
Correct. So we had to sort of take some precautions, but one of the donors was from this country, the other one was from offshore, and then there were a few unknowns, so we had to sort of navigate through all of that.

Andrew Schorr:
But the point is here you are, you survived that, and I understand you just got out of all your isolation and treatment and all that in March, and here we are in the late fall and you're with us. How are you feeling now?

Kuldip Ahluwalia:
I'm feeling great. I used to be 200 pounds. I was down to 128. I'm up to about 150 pounds, but I'm feeling great. And I'm starting to resume an active life again.

Andrew Schorr:
So genetic testing is the theme of this program, and I imagine you had a whole bunch of testing including genetic testing along the way.

Kuldip Ahluwalia:
Correct.

Andrew Schorr:
And what is your understanding of how the genetic testing can help?

Kuldip Ahluwalia:
I was sort of lucky, because, as I mentioned, when I first got diagnosed the indication and the physicians insisted that we go to chemotherapy right away. I asked them, you know, we started doing the bone marrow biopsy, why don't we wait to get the cytogenetics and the testing results? That was a tug of war with the physicians at that time. They acquiesced.

They—it took about two weeks to get all the results and all in.
Because of that, we changed the treatments a little bit. So initially we started with azacitidine (Vidaza) for MDS. We went through two cycles of that over two months. That didn't respond. Then we went into the standard AML treatment for chemotherapy, standard induction therapy, but that also gave time for my doctor to get approval to get a bone marrow

transplant. So everything sort of worked into place because of the genetic testing. But we were able to determine that I was a poor risk, and I would be better served by having a bone marrow transplant set up, approved by the insurance company and also have Stanford in this case look for donors for me.

Andrew Schorr:
Right. What was the right treatment for you.