



## Jim Bond: AML's Man in Positive Motion

### James (Jim) Bond

25-Year Stage III Myeloma Survivor (Jim.bond48@gmail.com)

11-year ACS Pan Ohio Hope Ride cyclist POHR.org

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### Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr down in Carlsbad, California, near San Diego, and with us is someone who knows AML as it came out, MDS first and then AML from years of treatment and transplant for multiple myeloma, and that's Jim bond who joins us from Shaker Heights, Ohio, outside Cleveland. Jim, thank you so much for being with us.

### Jim Bond:

You're welcome.

### Andrew Schorr:

So, Jim, there are people who develop primary AML, and there are people who have had myeloma where it develops, and there are people with a condition. I have myeloma fibrosis, one of the myeloproliferative neoplasms, or MPNs, where it can transform to that. And then we're told our best hope, there are some new medicines approved, and they may come into play, but our hope as part of that be may be a transplant.

You had a transplant for that, and nobody knew whether it was going to work out. Tell us about the process of going forward with a transplant. And we should tell people right up front that transplant for AML was five years ago. So, yay. But tell us about looking at transplant for AML.

### Jim Bond:

Yeah, well, my AML is probably different from many of your AML listeners. My AML is caused by treatments for myeloma, as you said, and my transplant doctor explained that having treatment-related AML is different than having other AML. So he explained to me that my only chance for survival, this was in 2012, but in 2012 my only chance for surviving my treatment-related AML is to get in the hospital, hope they can get the high level of the blasts that were in my bone marrow, try to get those down to a low enough level that I would qualify for a transplant.

And then, if all that went well, he was hopeful he could find a matching donor. My previous allo donor-sister would not work anymore, so it had to be a new one. And lo and behold they were able to find one. The way I was diagnosed to begin with is, as you said, I had MDS because my nurse picked up in my monthly blood test I do for myeloma that my counts weren't correct, quite right. They did yet another bone marrow biopsy. I've had 38 bone marrow biopsies since my myeloma began 20 years ago, so I'm not a fan of getting a lot of these. I had to get one.

They said, hey, you've got MDS, and maybe we ought to start the process now and treat it like it's leukemia, and I said not so fast. I said I'm a believer in second opinions. Let me listen to somebody else at another hospital. I did. My wife and I

judged what we heard, and we made a decision to follow the advice that said let's watch this MDS and see what happens, see how it develops.

Well, nine months later, it developed into full-blown leukemia, so now I'm in the hospital, now they're trying to find a match for me, and lo and behold they find one. I'm lucky enough that they found one. I'm happy. I'm thinking I'm going to keep living, when the team at the hospital said, we're not so sure you can live through this. In fact, our committee is voting no against you, and yet they knew that was the only way to keep my alive, but they couldn't be the ones responsible for taking my life.

So they went back, they reconvened, they came back the next day and they said, good news. We're going to take a chance on you with a fourth transplant, because you had cycled your bike 328 miles, four days, two months earlier to raise money and awareness for the American Cancer Society Hope Lodges in this event my wife found called the Pan Ohio Hope Ride. So that Hope Ride and the American Cancer Society saved my life, because then they said okay, we'll do it. You seem to have the strength, both physically and emotionally that we're going to take a chance on you.

So, as luck would have it, I got this German woman's donor cells on Halloween of 2012, and by Christmas of 2012 I was discharged, 75 days after entering the transplant unit, sent home. And I was pronounced in remission with yet another bone marrow biopsy, and that's where I remain today. And I take no maintenance drugs for either the leukemia or the myeloma. Instead, the medical team that I believe in that treats me says we're going to follow you every month, and the idea in my mind is if and when these diseases flare back up, we're going to act on it quick enough to do some good. So that's where I'm at.

**Andrew Schorr:**

Wow, what a great story. But I think you said it at the outset everybody's story is different.

**Jim Bond:**

Yes.

**Andrew Schorr:**

Certainly there are people who need a transplant, it's their last hope, and it doesn't work out. And thank God it's worked. Or there can be complications. There can be graft-versus-host problems. You maybe have some issues that you live with now.

**Jim Bond:**

Oh, yeah, big time. I couldn't drive my car after the fourth—the AML transplant. The graft-versus-host decided to settle primarily in my—on the cornea of my eyeballs. And they were scratchy, they hurt, I couldn't see. My eyesight was 20/300. And I was grumpy, I was irritable. And I asked my transplant doctor, what can I do? Who can I go to? Because I had run out of all the eye doctors in my home town knowing anything that could help me. And he said, hey, I know someone who's got extra expertise in that. We tried that person, that led to another person, and I got treatment.

And now I got trained. It took me three weeks of training, intense training every day to learn how to put these devices in in the morning and take them out each night. They call them prosthetic eye devices. They look like an overblown contact lens, but they're much more involved in getting them in and taking them out. But if anybody has that problem of graft-versus-host settling in their eye, which they've named ocular GVHD, you know, I would just say contact me. Andrew's got my email on his website. Because it's rare, but that's the biggest GVHD I got.

I've got other GVHD that's chronic, you know, skin irritations. I've got to stay out of the sun as much as I can. I've got a little bit of GVHD in the gut, but it doesn't really impair me the way that the cornea GVHD did, but it's real. It's as real as cancer.

**Andrew Schorr:**

It is real, but having this, and I'm not saying it's pleasant, beats the alternative that you were facing.

**Jim Bond:**

Oh, yeah. And again I had no choice. Other AML patients may be able to weigh the transplant versus some new drugs that I've heard are out and available, but I was not one of those. I did not have those options. It was me—it was death or try this transplant, and I'm very happy to try the transplant and see where my chances fell on it.

It worked out well, but here's the thing about it: If you're looking seriously at getting a bone marrow stem cell transplant, and I assume other AMLs are like mine and that is allotransplants, it really is worth our while to get a second opinion on where to get this done. Because your case is unique, and your hospital is unique. And as good as any hospital—any one hospital is, we have found with 25 years of dealing with this incurable, deadly multiple myeloma that every time we've been out of town for a second opinion, and that makes six so far, we have gotten more knowledgeable and more comfortable with what's going to happen next. And that may very well mean staying at home and getting your transplant where you started. But we really believe it's worth getting a second opinion, and we live by that.

**Andrew Schorr:**

Wow. Great advice. Everybody's situation is different, but knowledge is power, we all say it. Second opinions, seeing a specialist in what you have. Is it myeloma, like Jim started with? Is it MDS? Is it AML?

**Jim Bond:**

Right.

**Andrew Schorr:**

Somebody who's knowledgeable, and now you alluded to it, new medicines that have come out, where the medicines fit in with transplant or apart from transplant and what applies to your situation. Jim Bond from Shaker Heights, Ohio, outside Cleveland, we wish you all the best. You started your cancer journey 25 years ago. You've had these four transplants, the last for AML five years ago. We're delighted you could be with us and thank you so much for what you and your wife do in fundraising to help all of us.

**Jim Bond:**

Thank you very much. And go tribe. Let's win the World Series this year.

**Andrew Schorr:**

Okay. Andrew Schorr here in California with Jim back in Ohio, and we wish all of our listeners all the best. And if it is an AML diagnosis, whether primary or one that's transformed from something else, get to an expert, and maybe a second one, maybe even a third one so you get what's right for you. Remember, knowledge can be the best medicine of all.

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