



Making a Difference: How Does Patient Advocacy Impact Myeloma Care

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Cindy Chmielewski:

How do you think advocates like yourself have shifted that patient-doctor relationship and have maybe helped improve research? Do you think what—advocates become part of the fabric of the scientific and medical community, do you think will be of benefit for everyone involved? Thoughts. Anyone have thoughts on this?

Reina Weiner:

There is always a benefit if you get involved with the trial itself, either you are participating in it as a patient or you are contributing to the schema. You know how they set it up. So everything has, do you know what I mean, it spreads out. All the benefits seem to be available at the time and it grows. It just keeps taking off from there. So that's what, you know. My experience has been volunteering in trials. I certainly haven't been involved in setting up any, but if anybody would like my two cents I am happy to supply it if they would like to hear about it.

Cindy Chmielewski:

I think the patient perspective is valuable.

Jack, do you have anything to add to the discussion?

Jack Aiello:

I think a couple parts to your question. In terms of how advocates can help patients relate to their doctors I think we can give them good questions to ask their doctors. I can remember, and I'm sure all of you could when you were first introduced to this disease and there was so much terminology, and then if you went to a meeting somebody would say, well, what's your IgG or what's your M spike, and you had no idea what those things are.

But after a while you learn and after a while you learn to ask your doctor what's my IgG? What's my M spike? And what's the trend? And what are the new treatments that are out there? And then you take a more active role in learning maybe perhaps what trials are out there and what drugs are being designed and what phases of those trials are in. And then if you go further you can be involved in trial development, whether it's working with a pharma company and perhaps in their trial design or whether it's working with one of the cooperative groups or NCI in terms of offering a patient perspective in terms of what makes a trial valuable to a patient.

What makes a trial more easily able to accrue patients to it? What makes a trial more tolerable to patients in terms of the burden that trials can place on patients? What kind of patient responses—patient response outcomes can we get from trials, not only in terms of what the physical side effects will be but what about the mental side effects?

What if somebody says you're MRD negative now and you can stop treatment? Well, how does the patient feel about stopping treatment when it's already been working so well? Some might feel great, and some might be pretty hesitant. So you can really take things along a timeline and become more and more involved in the whole realm of development for myeloma.

Cindy Chmielewski:

I'm glad you showed us a whole gamut of advocacy opportunities from just encouraging others to be actively involved in their care to maybe working with specialists in helping design those trials. There's so many different opportunities. And I know Matt was talking about the LLS First Connection program, and I'm sure during your conversations with others that you encourage them to be empowered patients and actively involved in their care and talking with their doctor and asking questions.

Any other ideas on how advocates are playing an important part in that relationship? Eric, what do you think?

Eric Hansen:

Yeah, I really second everything Jack said, and I think one of the first things that I learned, the first oncologist I saw after diagnosis ran me through the information and said, well, you've had a pretty good life so that's the way it is. And I rebelled at that attitude fortunately, and went to another specialist.

He started talking about trials and different drug options and so on, and so I got interested that way. But all these drugs, some of the doctors just get really giddy about drugs, and when you read the fine print you will find that almost all of them only work on a fraction of patients and many of them only work for a few months to a year or two. And all of them have some sort of—almost all of them now but a few don't, but most drugs have some side effects.

And so the more a patient can learn and discuss with their doctor those kind of things, about the drug options, side effects, do you have to travel to a chemo center, all those considerations need to be not only discussed and understood by the patient, first of all. And often unless you're assertive at some point about that you may not get the information you really need. The doctors are going to go where they're going, and that may very possibly be the best possible route but it may not for you.

And so being informed and being part of the decision-making process on the treatment and the trials available and so on I think is just critical.

Reina Weiner:

Cindy, if I could say something.

Cindy Chmielewski:

Go on.

Reina Weiner:

When I was in the second trial, which was really the more progressive one with CRD that was offered to smoldering and active disease patients, so many people said to my husband at work, how can you let your wife do that? She's going to be a guinea pig. And so dispelling the myth of trials, that they will just experiment on you and that it is not well regulated, well controlled and so forth is something that I really try to mention to anybody who is at all considering a trial.

And I do a little presentation about clinical trials. The first thing I do is I put up my picture and a guinea pig, and I just say I'm the one on the right. That's not me, and just letting people know that in the preclinical trials those are where animals are used, but in the human trials they are not.

And the sense of intimidation of patients with doctors in the examining room, people are really afraid, really, really afraid. And, I don't know, I have always a hashtag that says ask for what you need, but my concern is that a lot of people really don't. And that's, I don't know, really how hard you can work on that, but I think that's really necessary. As Eric said, you get prepared. As Jack said, you get ready to ask all your questions so that you become more knowledgeable and then able to ask better questions.

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