



Advancing Myeloma Research: How Can Patients Help?

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Jack Aiello:

We as patients appreciate all the new drugs out there, MRD testing out there, perhaps treating earlier. What can we do, though, to enhance our ability to survive this disease for longer periods of time? Dr. Raje?

Dr. Raje:

The good news is myeloma patients are already doing a lot. There's a lot of advocacy, there's a lot of education. Jack, you've been involved in a lot of this, a lot of patient education. What I always say to my patients is know a lot about your disease, make sure you're in touch with somebody who is a myeloma expert. The reason being there's so much happening in myeloma so that you have your finger on the pulse. Make sure you have access to the best possible medications.

And the biggest thing you can do for yourself is make sure you have all your options; don't burn any bridges. Get to whatever option you need to when you need it and keep living your life. You can keep thinking of myeloma 24/7. The less you worry about myeloma and let some of your doctors, your team take care of that, that's going to be good for your myeloma, as well.

Jack Aiello:

Dr. Burke, anything to add to that?

Dr. Burke:

I'll say two things. Number one, I agree with really staying educated about your disease. As a patient, it's critically important to do that. I think we're probably preaching to the choir, because the people who are watching this video are probably staying educated about their disease more than those who are not. But I think that's critically important to make sure they're aware of the options and that they discuss those options with their doctor. Number two, I would add just to

your question about are we treating patients with myeloma earlier. And I think what you're getting at is that historically there's been a group of myeloma patients where we diagnose them and then do not treat them.

And those are the so-called smoldering myeloma patients who really don't have any symptoms. They are found to have the disease in their bodies, but it does not appear to be damaging their organs. I think there's one really critical aspect of the management of those patients now that wasn't present in the past, which is guidelines that are not probably widely known by community doctors like myself, that state that such patients should undergo a very good sensitive imaging study looking for bone involvement of their myeloma.

That historically, we've just done X-rays on those patients, and we now know that X-rays may miss patients with real bone disease and that such patients probably should be treated, because they are likely, within a couple of years if untreated, to suffer some of the complications of those bone lesions such as fractures and pain. That has changed my practice this year. Because I can tell you about a couple of smoldering myeloma patients I've seen where I wasn't going to treat them, but I did a more sensitive scan, and that found bone lesions that then led me to treat those patients.

So I think it's important for patients to be aware of that and doctors to be aware of that—and probably not all doctors are. And so I think for patients to be aware of that and asking their doctors about that, because it could help prevent some problems for a few patients.

Jack Aiello:

That's really good advice. Dr. Davies?

Dr. Davies:

I can only agree with my colleague—patients taking an active involvement in their disease course is important. But I think one of the things that we have learned at this ASH and one of the exciting things about having so many new drugs means that we're now beginning to learn about managing side effects better. We know that often when we use a combination chemotherapy with many of the newer agents, the side effects are less. But we also know that if we can help patients to continue on therapy, that patients tend to do better.

And therefore I guess I would encourage patients to tell their doctor about side effects. I think previously with myeloma, we've actually, maybe as doctors—well, not only maybe—definitely as doctors we've tended to listen about side effects but pat patients on the back and say: there, there, never mind; please just put up with it. We're now in an era where actually we can do something about side effects. Many of these new agents have got less side effects and we can maybe change agents or reduce the dose, or reduce the frequency to ensure that patients—that those side effects aren't so troublesome. So I think I'd encourage discussion with doctors about that.

Jack Aiello:

Dr. Davies, Dr. Burke, Dr. Raje., thanks so much all of you for sharing this very valuable information to patients. We are always looking to stay educated, and you have helped. Thank you.

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