Camille Edwards, MD (00:01)
Hello and welcome to Advancing Relapse Refractory Multiple Myeloma Care through Communities of Practice where we're educating community-based hematologic teams on the use of BCMA directed bispecific antibodies. I am Dr. Camille Edwards, Assistant Professor of Medicine at Boston University Chobanian and Avedisian School of Medicine.

Camille Edwards, MD (00:24)
And today we have a very special guest joining us to talk about their personal experience receiving a bispecific antibody for multiple myeloma, Theresa, could you tell us a little bit about yourself?

Theresa (00:37)
Thank you, Dr. Edwards. I have been diagnosed with multiple myeloma since July of 2017. I went through the standard induction. Six months later, had the stem cell transplant. I was fortunate in that it lasted about four years. Then I relapsed, and though my treatment was working, it wasn't working the best way I wanted to. And I was speaking to my doctor and my specialist about some of the clinical trial studies. And he forwarded me to a clinical trial through the Henry Ford Health System here in the Detroit suburbs. And that's how I got on a bispecific antibody. So I've been on it since May of 2023. And I'm doing well. I'm minimal residual disease negative. And I'm much happier on this than any other therapy I've been on.

Camille Edwards, MD (01:26)

Thank you, Theresa, for sharing that with us and a brief introduction of yourself. Now to introduce the episode, in this episode, we will focus on bispecific antibody therapy for relapsed refractory multiple myeloma and we'll walk through that decision-making process, side effects, step-up dosing, and really what it's like to make that transition of care from a specialty center to the community.

Just to give a bit of a brief background about bispecifics in multiple myeloma despite the significant advances in multiple myeloma treatment that we're all aware of, it remains incurable and many patients eventually relapse and require new effective treatment options. Bispecifics represent a novel therapeutic approach to the treatment of relapsed refractive multiple myeloma designed to engage a patient's endogenous T cells and really redirect them back to attack multiple myeloma cells. And they've shown promising responses in patients, particularly those who have exhausted other lines of therapy. But the decision to choose a bispecific antibody for the treatment of relapsed refractory multiple myeloma is a complex decision. It requires careful patient and disease specific considerations. And importantly, the patient perspective is a key factor in making these complex decisions. And so we're so glad to have Theresa here today to speak on her experience. And so I'd love to know, can you tell us a bit about where you were in your treatment journey when your care team introduced the option of a bispecific antibody?

Theresa (03:05)

I was in the relapse phase of coming out of the stem cell transplant. And although it was working, one of the problems during the relapse phase is that I was going to the clinic every two weeks, every three weeks, every one week. It was just really hard to maintain my job and still continue what I call the treatment treadmill. I'd go to my treatment and it'd be on Thursday. I Friday, Saturday, Sunday to recover, go back to work Monday, Tuesday, Wednesday, and then repeat on Thursday. And it was just the life of treatment, recovery work, treatment life. And I didn't feel like I had any other life, but working on my multiple myeloma. And I knew that there was other, lines out there that, that would work and would hopefully give me back more of my quality of life.

Camille Edwards, MD (03:55)
That's interesting. And can you tell us a little bit more about how you first learned about the bispecific antibody treatment?

Theresa (04:01)
I had heard it from my primary oncologist, my multiple myeloma specialist when I was going to the hematology oncology consultants ~ and Dr. Q. he introduced me. He said that, you know, they were doing a study at another healthcare center here in the Detroit area. And he said, I'd lose you as a patient, but I really think you'd be a great candidate for the bispecific antibodies considering, you know, where you're at in your journey and how much healthier you are and that you wouldn't have a big problem with any of the side effects if you should have to endure them.

Camille Edwards, MD (04:36)
And thank you for sharing that I think that is a prime example of how providers and patients can partner to decide on when to try a bispecific antibody. So I'd love to know, you mentioned some of the challenges you had on your other treatments. I'd love to know what, you know, when you felt confident about moving forward, what factors were most important to you when you decided to try the bispecific there?

Theresa (05:01)
It was less downtime. There was no risk to my job in terms of getting sick. I had to keep my job to be able to keep my insurance. It had required little to minimum caregiver needs, because I live alone. It was off the shelf. I didn't have to wait, you know, four to eight to 12 weeks for the CAR T cells to be re-engineered. Those were the big things that said, yeah, let me try this. And it's really worked good for me.

Camille Edwards, MD (05:30)
I'm glad to hear that. I'd love to hear, given that experience that you had and the things that were important to you, what advice would you give to patients to advocate for themselves?

Theresa (05:42)
Ask about studies, ask about local studies, they're there, you just gotta ask about them. Somebody knows something and believe me, all these wonderful physicians in a big metropolitan area, they talk with each other all the time. They know what they're doing. So yeah,

it's really a lot about asking. And people that I speak to, they're willing to try a study for better quality of life. And so was I, I needed a better quality of life. I was just recovering all the time and that doesn't work.

Camille Edwards, MD (06:14)
Absolutely. So it sounds like you've found something that works for your life, your life and your lifestyle. Were there any resources that you found that were particularly helpful?

Theresa (06:20)
Yeah, the International Myeloma Foundation, the myeloma.org, the lymphoma leukemia, multiple myeloma organization, they were great. A lot of online spots. It's highly talked about in the support groups that are online on the social media. I'm a member of three or four groups on there and we just get on there and we all talk. I've met many people who are in the same study I was in or something similar and it was great that we would share side effects and tricks and things. So those were a lot of my resources. The doctor's offices were great, the doctors were great. They would direct me here and there and fortunately the big academic health system I'm in now, Henry Ford Health, they had a wonderful cancer information. Beaumont had an entire like a library for cancer patients to go to. So anytime you had questions, you just had to call them up and they'd help you find it online. It was great.

Camille Edwards, MD (07:26)
Wow, thank you for sharing those resources. I think you mentioned earlier as well that you were on a clinical trial.

Theresa (07:35)
Yes, the clinical trial is what I was referred to initially and that started in May of 2023. It was called Magnetism Number Nine. We had the one week in the hospital for the step-up dosing, then once a week for the dosing at the clinic for six weeks, and then once every two weeks to the six months, and then once a month to the year, and then every eight weeks to the two year mark and that just finished in May, which has been great because now I'm on it every eight week schedule and it feels like you could have a life the other seven weeks. And I was really grateful for that.

Camille Edwards, MD (08:11)
Yes, and you highlighted earlier what factors were important and it sounds like this was definitely one of the things that helped with that. In thinking about being on the clinical trial and talking about the resources that you found helpful, were there any that were specifically helpful to improve any barriers to being on the clinical trial?

Theresa (08:32)
At the clinical trial has a clinical trial office they call them and there's specific nurses and or coordinators in the clinical trial office at Henry Ford Health System and they were really great. They would coordinate every visit. They would coordinate every injection. They would coordinate having the drug there. Any side effects I experienced, they got me any help I needed

with that. So, I didn't have to do anything. I didn't have to make appointments for myself. It was good. The clinical office was just wonderful.

Camille Edwards, MD (09:02)
That is great to hear and it sounds like it made your life a lot easier as well being on the trial, which many patients may not know. So thank you for sharing that as well.

Theresa (09:12)
Being on the trial has been easy. I can text them if I had questions. They were always responsive. The clinical trial organizers were great.

Camille Edwards, MD (09:20)
That's wonderful. So I want to change gears just a little bit to hear a little bit more about your experience. And this part of the experience is important for patients and providers, specifically side effects. Bispecifics offer new hope for patients with relapsed refractory multiple myeloma, but we have to also talk about the immune related side effects, including cytokine release syndrome and ICANS, things that happen early on and also some later side effects to think about, cytopenias or low blood counts and infections. And managing these side effects often requires very close monitoring, especially early on in the treatment. So sometimes also there's not a lot of focus on the later side effects. So I'd love to touch a little bit on that as well.

Can you share with us what side effects you may have experienced during your bispecific antibody treatment?

Theresa (10:22)
I was very fortunate. I did not have any of the cytokine release syndrome or the ICANS during the first week in the step-up dosing or in the first six weeks or one month, three month time frame. I had none of that. I just filled in my sentence every hour like they wanted me to do during the six days in the hospital and my handwriting stayed great. And they always talked about the ICANS and the CRS and as they should, it's the wickedest one you might have to go through. But if when you get through that and all of sudden you're into the two month, four month, six month time frame, I found myself experiencing some of the things that they didn't talk about. And one of the things I wasn't quite warned about was the low immune globulins that I would get and therefore have to be put on supplemental intravenous immune globulin medications. And we'd get my IgG level, get to a certain point, and then they would want to give me a dose. And coordinating that dose was all handled by the clinical trial office nurses and that was wonderful. They took care of it all. I just had to go in, give blood and walk out. It was great. The other side effect that I don't feel that they talked about was then maybe they didn't know it was the skin reaction on my hands and on my feet. I found my skin peeling for the first time in my life. It doesn't hurt, it doesn't itch, it just peels. And there's pictures out on the internet of other people like that. I put my pictures up on the internet on the Facebook support groups. But there's not a lot you can do with it. you know, lots of lotion and keep going. But the one thing that we did learn was, and that again, I learned through the resources of the social media support groups, was about the joint pain. I suddenly start experiencing knee pain. I mean, I had

never had knee pain in my life. And they're like, well, let's check out if you've got arthritis developing at your age. And I'm like, I'm not that old. And so we went through the orthopedic. I scheduled an appointment with the orthopedic. And she says, no, your x-rays look good. You've got lots of space, a problem. I finally put it out there on the Facebook support groups. And I said, anybody else having this? And I got a response from a wonderful physician at Sloan Kettering in the East Coast and he says, yeah, we're seeing this dose of, methylprednisolone dose pack will help get rid of it for you. And I'm like, yeah, something to control the pain. It has faded over the two year timeframe. But when I first got it and it was so surprising because I wasn't ready for it. yeah, it stopped me from doing anything. I just was hurting. And I stand as a job, you know, so I had to have something to help with the pain.

One of the things that they don't talk about that unfortunately was reactivation of old viruses that you've been exposed to. For me, it was the HPV virus that resulted in me having, as a post-menopausal woman, having to have a hysterectomy. The other one that they keep monitoring for is the cytomegalovirus returning. And this is just because your immune system and your plasma cells, which make your immune globulins, your immune globulins fights viruses, has been damaged and reduced and not active as it once was. And you're losing your memory cells. So all those wonderful exposures you had to, and memory cells that you had when you were in your 20s and 30s and 40s, they kind of go away. So other viruses want to pop back up and say, hey, I'm here.

So that was some things I had to deal with. But the one that's constant is the fatigue. And I just handle that by going to bed early and getting up early. It sounds counterintuitive, but I do walk even with the pains in the joints because walking is good. And I found that the more I walk, the longer I walk, the better I felt. And I know it sounds like, I shouldn't walk if I'm in pain. Well, maybe not.Depends on you, give it a try.

Camille Edwards, MD (14:11)
I love how you highlighted your journey through the earlier side effects and how you were anticipating those. And it sounds like in your experience, you experienced mostly the longer term side effects and we're surprised by that. And that affected your daily life as well. Thank you for sharing that. And so I wonder how did your care team support you in managing these long-term side effects?

Theresa (14:35)
Getting me the intravenous immune globulin. They handled all of that, getting its prior authorization through my insurance and stuff and getting those infusions. And they can take, you know, some time. We looked into the subcutaneous infusions at home, but my insurance wouldn't pay for it. So I want to put that out there. If your insurance will pay for this, ones you can do at home, that's great. Other than that, I've even just started getting the intravenous immune globulins through home infusion. I did that for the first time last week a couple of weeks ago and that's been, that was great. The nurse met me at the house and she put in a peripheral IV and away we went and we chatted for four hours and off she went again. It was great. I didn't

even have to go into the 40 mile hospital drive, you know, so that was cool. So, and that was coordinated by the clinical trial office.

This skin rash, I got tons of samples of skin cream to help me out with that. He sent me to the dermatologist. We tried to look into that, see if it was a steroid, something would respond to steroids. Nope, but that's okay. Time kind of took care of it.

The joint pain, I got instantaneous referrals to the orthopedic department. And I mean, most orthopedic visits take anywhere from six to eight to 12 weeks to get in. I get a call from the clinical trial office and I was seen in two weeks. So yeah, that's how they helped me at the clinical trial office get the care I needed during the clinical trial.

Camille Edwards, MD (15:53)
That's wonderful support. I wonder, as you were experiencing the side effects and you look back, is there any point you could have envisioned where you would have wanted to hear more about these side effects or how, what advice would you give to oncologists about how to introduce these side effects to their patients so that they're looking out for them and potentially expecting those longer-term side effects.

Theresa (16:18)
I know that everybody's worried about the ICANS and the CRS at the beginning, but when that has faded into the background, I would recommend having a conversation, okay, now we're getting into the fourth week, sixth week, eighth week, we need to start watching for any of these. And if you experience them, let me know. We've got some things we can do for you. That's what I would recommend to oncologists. I can completely understand you can't bring up everything at once. It'll scare folks, but definitely as we're going into that phase, bring it up.

To end it all, you know, the side effects are there, but there wasn't a single one that would have made me quit the clinical trial. They're all manageable, they're all doable, you can live your life through them, never stopped an activity of daily living, and that to me is the wonderment that I feel on this bispecific antibody is the fact that, you know, I can keep going, that nothing's gonna stop me if I wanna go anywhere. I have precautions to take, sure, but you know, life is uncertain. Cancer is uncertain, but so is life.

Camille Edwards, MD (17:25)
Yes, I appreciate that perspective so much and so many things that you've said, even in your advice to oncologists about how to introduce it, but also that many of us are worried about the early sort of side effects that can be more serious. So I really appreciate that and also your perspective on living through these side effects, which one would have to do as a patient with multiple myeloma. So thank you for that.

And I want to step back just a little bit to talk a bit more about how patients are monitored in the early phase of bispecific antibody treatment. In step-up dosing is really a hallmark of bispecific

antibody therapy and it involves gradually increasing the dose to really reduce the risk of cytokine release syndrome, ICANs and other early toxicities.

And this often requires patients to stay near the hospital. Some patients are admitted for observation. I'd love for you to walk us through your experience with the step-up dosing process. What was that experience like for you?

Theresa (18:30)
It was okay, you know, I was admitted for six days and I get a dose and you wait 24, 48 hours and they give you all kinds of, you know, vital signs times four and you have to get your respiration, your blood pressure, temperature, et cetera, taken every hour, every two hours, it gets a further apart. And then they get another dose and they do it, you know, close together and you still have to do the ICANS thing where you're writing. So it really amazed me that one of the fastest ways they could figure out that you're beginning to have nervous system side effects is they look at your handwriting. And I was like, my simple handwriting is going to tell you when this is beginning. Oh yeah, we see that four, six hours ahead of time before it gets really bad. That's an easy thing to do. I'll just write the sentence you give me.

So I finished the step-up dosing at the hospital. Everything went well and I transitioned to the outpatient setting and it went well because again, because the clinical trial office, you know, handle all the appointments and everything. They had all six of my appointments lined up already. I will say that I've got a girlfriend with multiple myeloma whom I met through a social network and she went through getting on a different bispecific antibody, but she did the outpatient.

They had it set up as outpatient and I would much rather do mine inpatient. I felt completely taken care of. I felt comfortable. Was I bored? Yes. Did I bring a lot of movies with me? Yes. But it was worth it because, you know, she's in her seventies and I'm in my sixties and I would much rather have been in the hospital knowing I was going to be monitored for those really serious side effects of cytokine release and ICANS. To have those noticed by professionals a lot faster than I would have been able to in the home setting would have been great. Plus, I didn't have a caregiver. She did. She was able to have somebody at home watching her during that step-up dosing, and I live alone. So those are two. We wondered if that might have been the reason she was selected for outpatient.

Camille Edwards, MD (20:19)
Yes, I'd love to highlight something that you mentioned and this really takes us back to how important it is to integrate our patients into these decisions and our patient perspective. You sort of contrasted your friend's experience with yours and how these patient factors are really important in making the decision on how to move forward to use the bispecific antibody but also in terms of the early monitoring.

And so now when once patients are stabilized and there's ongoing treatment and monitoring as well, not as intense as in the early phase, now we start to think about patients being transitioned

from their academic center or larger center to the local community oncology provider. And this requires, as you know, Theresa, strong communication, coordination, really to ensure that continuity of care and ensure that the management of any side effects as you shared with us that you experienced are done well. So you mentioned earlier that you had your initial care at a larger academic center. What was the process like when your care began transitioning from that larger center to the community oncology team?

Theresa (21:36)
It was seamless it was because, again, we have clinical trial office coordinators. They were all just there, and they would text me, hey, what days are you available for your next injection? And what time are you available? And we worked it out. And fortunately, with today's modern communications, there's not a reason not to be able to communicate. You know, when things have to change and stuff like that. So it's just simple texting. For a person who's not involved in texting, say my girlfriend, who's like I said, in her seventies, approaching eighties, her caregiver is the one that they text with because she's just not as intimately involved in that part of it. Cause she, she's recovering, you know?

And that's one of the things that you mentioned earlier, how can we help? The communication has to be there. That's what I would recommend to the oncologist, massive amounts of open communication. And it works because anybody going into a study or anybody doing this kind of thing knows how important it is to keep their health and to stay on schedule.

Camille Edwards, MD (22:35)
Yes. So it sounds like, Theresa, you're saying that communication is key. It is one of the key factors that really made your transition seamless.

And you mentioned a few members of your care team, the clinical trials office staff, your oncologists. Was there anyone else that was a part of your care team that was really helpful with this communication?

Theresa (22:45)

The communication, maybe not, but I do want to mention the licensed social workers that approached me. Every six months, I get a quick waiting room visit from the licensed social worker and for somebody who needs it, those kind of short little appointments by them can be so valuable.

Camille Edwards, MD (23:13)
Wonderful, wonderful. And I agree, I've seen that in my own practice. Did you experience, any challenges, any surprises as you made that transition?

Theresa (23:24)
What I would say is that appointments have to get rearranged in infusion clinics, as you know. Um, and when I wasn't communicated, but they had to rearrange, that was the challenge

because I had either made other plans or because I have a life and, or I was working and we had to rearrange for that, and they would forget my schedule. And you just have to make gentle reminders as I call that would be my biggest thing is when things were rescheduled and I didn't know.

Or like one of the challenges I had was with getting a COVID test before each dose. That proved to be problematic because of the clinical trial study. And at first,it was in May of 2023 and all the labs were doing COVID nasal swabs. And then as I transitioned to the end of the study here in May of 2025, a lot of the labs stopped doing COVID nasal testing, I'm not sure why, but then I had to go downtown and get my nasal swab test.

Camille Edwards, MD (24:13)

So you described this seamless sort of transition. You described how communication was key and the communication had to be two-way and regular and really taking into consideration your schedule and the schedule of the clinic. So there's definitely a lot of coordination that's happening to make a seamless transition.

I really want to bring everything together now and first give you an opportunity to tell me anything that any sort of last words that you would give as advice to providers working with patients who are receiving bispecifics in a community setting and then really summarize what we've talked about today.

Theresa (25:01)
The bispecific has been a godsend for me. It has put my multiple myeloma into control, I'm minimal residual disease negative, and it's really, really worked for me. I credit a lot of my health through the fact that I did not have a big tumor load, as they call it, because I got into this study with a lower tumor load than a lot of folks did in terms of not having to experience ICANS or CRS.

The fatigue and the other symptoms are manageable. You can live your and that's at 63 years old is what I want to be able to do. And so I was happy going back from, you know, the study was at the big center and then the infusion clinic was the small one.And their communication is good. I haven't left the United States in eight years as a multiple myeloma patient, and I am going to go to Greece and fulfill a lifelong dream. So, yeah, I'm just going to get, we're coordinating getting my intravenous immune globulin dose before I go.

Camille Edwards, MD (25:46)

Wow, that is amazing. I am so glad to hear that. Theresa, just thank you so much for sharing your experience. Today, we were able to walk through the decision making process, side effects and management, step up dosing, what it's like to transition care from a specialty center to the community from the patient perspective. And it is absolutely just valuable that you were able to share that with us.

I want to emphasize a few more things that you said so beautifully today, which just the importance of providers talking to their patients, but also talking to each other and being aware of clinical trials that are taking place in the area that could benefit their individual patients. And, you know, something you mentioned that patients bringing up this thing, this clinical trials and treatment to their providers, and bringing up that they want to be a part of these studies is also helpful. So that partnership with patients and providers working on both ends has really worked out beautifully for you. And I thank you for demonstrating that to us today.

You did mention some resources as well that were very helpful on the IMF, the Multiple Myeloma Foundation as well. so that was very helpful. And then lastly, something that I really want to emphasize is just that patients are really willing to be a part of these studies and will drive far away to be a part of these studies in order to treat their relapsed refractory multiple myeloma. There are resources available for those who may have transportation or other barriers to clinical trials.

You shared some of those with us, I believe earlier. And also there's the road to recovery from American Cancer Society provides rides.

Theresa (27:49)
Yeah, I signed up for that too. Yep, just in case, because there might be a time when I need it and it's a lot easier to sign up now. But that road for recovery as a single person who lives alone made it so much more, well, if I can't get so and so to take me, when am going to do? And so it just relieves burden. It relieves worry. You you can set up your life to really handle this well. You just have to do it.

Camille Edwards, MD (28:12)
Well, thank you. Thank you, Theresa. And thank you to our listeners for tuning in. Definitely check out this podcast episode, Rewind, whatever it is, get these wonderful nuggets that we've shared today through Theresa's experience about bispecific antibodies in relapse factory multiple myeloma and really transitioning care from specialty centers to community-based settings. Thank you.