

Jayshree Shah, APN-C, RN, MSN, BSN, BS

Jayshree Shah: So, let me introduce myself. You guys know me as Jayshree. Recently, one of my patients actually gave me a different name. So, my patients call me usually Jay because Jayshree is a little bit difficult sometimes for my patients and caregivers to pronounce unless I break it up for them and say 'Jay' and 'shree' and they're like oh, yeah. That's easy. So, my patients usually end up calling me Jay regardless which is fine. So, my new patient that I recently encountered in taking care of called me, "Okay, Jay. I've gotten to know you. You've been taking care of me, talking to me about my disease and stuff, so I'm going to have to rename you because you're now Super Jay." Okay. That's a really big upgrade here. So, I better live up to this. Better live up to this. So, I'm a nurse practitioner similar to Joan that you guys have met and Dr. Rossetti talked about. I currently work at Hackensack University Medical Center and you'll probably think, Jay, I don't know where that it is. It's in New Jersey. It's about 10 minutes, literally 10 minutes south of George Washington Bridge in New York. That gives you kind of a landmark of where I'm from. Very densely populated similar to your 376 West highway construction happening with the backup. Very congested. Where I work at we're very fortunate. We have divisions now separated for the different types of cancers patients have and right now we have a leukemia division dedicated to patients who have MDS, myelofibrosis, any kind of bone marrow disorder. They're kind of put into that group of caretaking if you want to call in that division specifically. I was very fortunate to work with Dr. Goldberg. Dr. Goldberg is a hematologist oncologist and I've worked with him for seven plus years. Recently, I shifted gears and switched over to GI cancers and lung cancer and clinical trials. So, my focus is different, a little bit different, now than what it was before. The reason I joined MDS Foundation and to do these patient forum it's a volunteer for me to continue 1) educating patients and caregivers about MDS because it's forever evolving. Before 2000 give or take, year 2000, MDS was not known. It's just come about. It's so new and it's still evolving. I joined the Nurse Leadership Board for MDS Foundation to, again, educate and have patients and caregivers understand about the disease process so they can go back and be their own advocate in taking charge of their cancer and understanding how and what they could do better, different and improve their quality of life and to ask more questions at the end often day.

So, my talk is, yes, it's a slide deck and all *Building Blocks of Hope, A Patient and Caregiver Guide for Living With MDS* and this was created by Sandra Curtain. She's also a nurse practitioner and she works at, I believe, University of Arizona and she developed this *Building Blocks of Hope* which is the book that you guys all have. It gives you the A to Z information about MDS. In addition to Dr. Rossetti speaking about it, having you guys understand what MDS is about, it gives you a book version, a reading version and you guys have MDS Foundation as reference, as a resource. If you guys ever have any questions, you can always reach out, leave your name and phone number. They'll call you back. There's also information in your book with clinical trial information such as the new ones that are coming about for your reference or a family member or whoever, friend, may have developed MDS. So, after your done feel free to browse through and keep note that there's trials happening for MDS itself.

So, this is a group of all the nurse practitioners and PAs and RNs as well as physicians that are part of the Nurse Leadership Board and this includes not just Jersey or Pennsylvania, it actually includes

worldwide. So, we collaborate with nurses in say, Switzerland, Italy, England, South America, all different continents. Why? Because MDS is not just in the United States, it's everywhere. So, we get to learn from other nurses how they take care of MDS patients. How do they give transfusions? In England or, I believe in Europe area, they give transfusions at home and you're like, "Wow. How do they do that?" Exactly. Everyplace is different. We get to learn. This is about sharing. That's why you guys are here today to share and learn and take home some information that you didn't know before.

So, it's individualized treatment, MDS. You guys are all here for a purpose to 1) learn about MDS, but how does it apply to you as a patient, as a caregiver? What could you do to make a difference? Does it mean by offering... I don't know, making breakfast every now and then for your caregiver or the patient. Being there, just being an extra pair of ears. I know my husband, I have to tell you. I'm not a good listener at times. He is. He'll just zip it and he'll listen. He'll absorb differently versus me absorbing it in a different way or understanding in a different way. It's having an extra pair of ears to listen to and understanding in a different way and collaborating at the end of the day and understanding did we come to the same terms? (Attendee) and her son, they shared with me (Attendee) was explaining to her son having the disease of MDS for 15 plus years for a long time to her son what MDS is. Her son just told me today, "Jay, for the last hour and a half that Dr. Rossetti spoke about, I learned more about MDS through him than through my mom." That's not to say he didn't learn. This is different. It's understanding different and how it's explained. We had to speak sometimes layman's terms, people terms, not so high with medical terms, but each and every person here that has MDS, it's different. Not one of you guys have the same kind and that's what makes it so special because... and that's what makes it so difficult with MDS because it's individualized treatment.

We talked about treatment triggers, initiation of disease, modifying therapy, transfusion dependence. Everybody gets transfusions in a different way. Somebody gets transfusions every two weeks versus once maybe every third month. Who knows? It can vary. Increasing blasts, high risk disease, what level of disease do you have? I think you guys got a good understanding with Dr. Rossetti's lecture where you stand, low risk, intermediate or high risk which where you fall into that category. Individualized treatment also falls into the category of other things like performance status. Are you able to walk, talk? Are you bedridden? Are you able to do your normal activities on a daily basis? What kind of comorbidities do you have? That means like such as thyroid problems, diabetes, high blood pressure, liver disease. Some people may have hepatitis they may have contracted 20 years ago and then developed MDS. How knows? All of those factors come into play for an individualized treatment plan for that person.

Primary or secondary. That's for people that have been pretreated and now developed MDS. You guys ever heard of ABC newscast member Robin Roberts? Robin Roberts. So, she developed breast cancer back in the day, a good few years before she developed MDS. So, she got treated for breast cancer and then developed MDS. Her oncologist noticed, again, a trend with her CBC being abnormal hence prompting them to do an evaluation, doing a bone marrow and finding out what happened to her. What did she develop, if she developed something? Lucky for her her sister was a

perfect match and she went through allogeneic transplant meaning her sister's stem cells going into her, her body and regenerating and growing to make her what she is now which is in remission.

Cytogenetic status which is so important. I hope you guys learned a lot from Dr. Rossetti explain about MDS. So within that bone marrow, it's important to know that there is cytogenetics and the percentage of blasts to look for as trying to figure out what cytopenias do you have. That means is there a problem with the red blood cells, white blood cells and platelets?

Lifestyle. So true. As Dr. Rossetti said, what is your goal? (Attendee's) goal could be, "You know what, Jay? I want to go to church every day, go do gardening every day or travel." Those are her goals. (Attendee's) may be different. (Attendee) may say I want to go to the gym every day. Now, she goes three times a week instead of five days a week. That's doable for her. Her goals changed a little bit, but those are her goals.

For key principles of therapy in MDS. Allogeneic transplant remains the only cure and it may not be applicable for everybody here, but unfortunately that's where science is right now, but doesn't mean it can't change. Things may change. Who knows? That's where science is right now. Age alone should not exclude active therapies and that's just to say Dr. Rossetti also explained that every person is eligible for something. It may not be the right therapy as far as transplant for every person or a treatment plan of heavy dose chemotherapy. Maybe something light, but just so that the patient is stable or remains stable or maintain a quality of life.

Blood counts. All active therapy for MDS require time to work, four to six months of continued treatment. Again as Dr. Rossetti said, you got to be patient when you have MDS. I think there's a lot of expectation at least in America that I've seen. In my patients sometimes, they're like, "Jay, give me a pill." I go, "What pill?" I want a magic pill. I want a magic pill to cure something that I know is detrimental, but I want to take care of it. Do you have that? I say I wish I did because I would share it with everybody, but we got to work with what we have. That's where science is headed. We're learning more and more about it. Blood counts often get worse before they get better. So with MDS, sometimes therapies like Azacitidine, Decitabine, treatment, it works on the bone marrow to fix it little by little versus a blast amount of chemo that totally will knock it out and God forbid you get sick. With MDS, you got to fix it and kind of keep on tuning it.

Proactive management of side effects in the early phases of treatment are key to obtaining the best respond and that's where you guys come in both as patients and caregivers to share with your physicians and practitioners what is your goal, what's happening to you. "Jay, I'm sleeping all day. Fatigue is huge. I can't do anything. I want to do some more stuff, more activities. Can you help me out?" Communication with your healthcare provider is huge letting them know. We may not be able to fix everything, but we may be able to fine tune and do something different. Somebody may have a vitamin D deficiency that may be causing their fatigue or a thyroid problem that may be causing their fatigue. Vitamin B12 that may be causing their fatigue. So, many different things that cause fatigue besides MDS. So, you got to look at the whole picture of the patient.

Why is time required? Considered what's happening, let me go backwards here. So, blood counts drop as MDS progresses and normal blood counts are crowded out. So, that's what happens in the bone marrow. The bone marrow is right here. That's your main bone marrow. We have a little bone marrow in the sternum also, but main bone marrow is right here. That's where the bone marrow biopsies that doctors and practitioners take. So when abnormal cells crowd out the normal cells, we need medication to change it such as Vidaza, Revlimid, Lenalidomide or Dacogen, Decitabine, any of those drugs to kind of change the morphology of the bone marrow and it takes time, as I mentioned, to fix the problem.

Patients can be weaned from supportive care to a robust response sets in. It depends on what therapy is offered to the patient. Early toxicities may be difficult and discouraging for the patient depending on what treatments that are offered. That's why it's a contract that you have to build with your practitioner and let them know each way what's happening to you and vice versa. I have to tell my patients a lot of times who have MDS that this is a contract for life. You have to tell me what's happening to you because I don't know what's happening to you after you leave with me after 20 – 30 minutes that I sit with you and chat with you and what's going on with your disease. You need to let me know what toxicities you're experiencing at home, so I can help you fix it or change it or do something different. Maybe just means modifying the dose of the treatment such as, for example, I ask (Attendee) what her dose for Lenalidomide is, the Revlimid. She told me she was taking five milligrams twice a week, but her neuropathy, the numbness and tingling was so bad that Dr. Rossetti decided, "You know what? Let's change it a little bit. Let's fine tune it to make it a little bit better possibly for her so that she doesn't experience that toxicity such as for her now she takes 2.5 Monday through Friday. So, a little bit of fine tuning. It varies for every patient.

Again, key principles for therapy for MDS. Time is required for the best response. Be patient. I've had patients who have MDS tell me, "Jay, so after six months I'm done?" I would love to say yes. I would love to say yes, but with MDS it's a lifelong commitment between you and me. It's a marriage. Cytopenias as I mentioned get worse before they get better. So, be patient and strategies for getting through the initial therapies, dose medications as I just mentioned, supported care, blood transfusions, platelet transfusions. Those things may come into play. They may be temporary in the beginning and then you may not need them which would be great.

Setting expectations. What are your goals? What are my goals? What am I going to try to achieve for you and what you are going to do at home and everything else. So, it's a vice versa. It's a communication back and forth.

So, this is just a nice slide to show you what happens to a patient that has received... This is Sandy's patient, Sandra Curtain who developed the *Building Blocks of Hope*. Lineage response following four cycles of Azacitidine. Again, patient had low counts with the hemoglobin going down from 12 all the way down to seven and the Azacitidine was given and what happened to the hemoglobin going up and up. The patient did get Vidaza... sorry, transplant. ACT stands for... So, patient... This patient received cycle one of Vidaza, cycle two and three and four. Luckily, they had a transplant already booked and ready to go meaning they found a good donor for the patient, had the transplant and day 100 follow up going through, the patient did well thereafter with the blood counts and white cell, but

again counts may go down and then up and then luckily for this patient of hers ended up having the transplant as a cure to go through and did well.

This is another patient of hers. It's the same (inaudible 18:12) asymptomatic cytopenias and a new normal. So not everybody in this room that goes through therapy, I mean, everybody would like to have a great hemoglobin of 12, 13 or 14, but now with MDS setting in the new norm may be different. Your norm may be now 10 versus, say, 12 or 14 when you are running and 15 before you got sick. So, that's your new norm and your body will have to adjust to that, but what the key component or key principle is that your individualized therapy will be to maintain that and how will we work together to help you maintain that so that you stay stable, you don't develop other issues or compromise other organs. That's going to be our key.

So, what can I do to stay healthy? Balanced diet, daily activity, exercise, avoiding infection. Again, that does not mean stay in a bubble as Dr. Rossetti said earlier. Avoid bleeding, not doing some axe work or machinery work that would cause you to be a higher risk for development of bleeding. Continue to enjoy things you love. It's so important. I think we had a discussion at our lunch table and (Attendee's) husband asked me, "So, Jay, what would you want to teach us for us as a caregiver for my wife that has MDS?" What I can tell you is that just live. Enjoy life. Remember MDS when you go to the doctor's office, be ready, be prepped. Don't go there and just sit there for 10 minutes and be like, "Oh, shoot, I forgot to ask this, this, this." Write down your questions when you have them or when you think of it. Have a book ready to go and say, "Doc, I got five questions. I want to hit, meaning to go over with you, and I need for your answer so I can understand this." Dr. Rossetti has a PA. Work with Valerie to see if she could be of assistance in addition to Dr. Rossetti. Reach out to the resources that are available. Ask them. I'm sure there's a social worker. I'm sure there's a nutritionist at the facility. Reach out for other things. You never know and this is a great avenue for you guys to meet each other and maybe develop a patient support group amongst yourself. That's something for you to think about. Again, it's not to talk more about disease, we can talk about other things. I don't know, knitting, crocheting, gym. I don't know. Golf. Something besides the traffic on 376 as I mentioned on the highway.

Take advantage of available resources. Get enough rest. So important. Insomnia is huge. Restlessness is huge when people develop bone marrow issues. Be active participating in building hope. You coming here today represents that there is hope still present and it's going to continue because we're going to see each other again, as I mentioned next year.

Q1: Is once a year enough?

Jayshree Shah: We're going to hope so. I would like to. I would love to because next year you're going to tell me, "Jay, she doesn't need any more transfusions. We found another way of," I don't know, "a treatment." Who knows? Things may turn around. Oh, we addressed her ferritin level. No more brown spots. Things may change.

I'm leaving the forum now open to you guys because we have about a good 30 minutes or so. Feel free to ask any questions that I may be able to answer and if I don't know the answer, I'll get back to you.

Q2: I just want to make a comment. The lady over there that has the brown spots. What's her name again?

Q1: (Attendee).

Q2: (Attendee). The ferritin level. Mine was real high and they sent me and what do you call it when they take the blood from you to take to get the...

Jayshree Shah: Take the blood out?

Q2: Yeah.

Jayshree Shah: Oh, well, chelation. You're taking...

Q2: I went in and I forget how many times for how long. I can't remember that.

Jayshree Shah: So, they took actual blood out.

Q2: Yeah and then they've sent me in here somewhere near West Penn... in West Penn and I went... What do you call it when you go to the chamber and you check your organs and all? They checked all my organs.

Jayshree Shah: Okay, a CAT scan or an MRI.

Q2: And to see if there's been any damage and so forth whatever you check, but I had the blood taken out so that all that iron would not damage my organs

Jayshree Shah: Other organs. Right. So, what she's referring to the procedure it's called phlebotomy. Phlebotomy is basically taking out extra blood. In her case, that's one way of taking out extra iron because her iron deposits are way too much in her system and her ferritin level as probably in the higher end, above 1,000. The normal can vary between 1,000 to 2,000 depending on the facility, but I think what's important is that for her the doctors were concerned that the extra iron was going to hurt her other organs. That's why she sought... they did the evaluation. Phlebotomizing, taking extra blood out, will leach and take out extra iron from the system hence to balance the ferritin in her system and the iron in her system. That's one way of doing it. There are other ways of treating extra iron within the body, by taking a pill, getting subcutaneous injection. There's other ways of doing it, but that discussion should happen with your

practitioner oncologist after finding out what your ferritin level is and having that discussion on what to do next.

Q3: Is it painless?

Jayshree Shah: Is it painless?

Q3: Yeah.

Jayshree Shah: What, the phlebotomy?

Q3: Taking your blood out.

Jayshree Shah: Oh, it's painless. It's like getting a stitch. You just stay there and it just drains out. You don't need to do anything except the bag doesn't explode, so you got to stand there because it can fill up really quick, really quick. The needle is big, but once it fills up and you take out 250 ccs, you're done.

Q3: I went like at first maybe two, three times a week and then this...

Jayshree Shah: It brought it down.

Q3: It's too long ago to remember.

Jayshree Shah: You been through a lot. Anybody else? Anybody want to share anything that they learned or anything related today, Saturday?

Q4: One thing that I think I learned is as a caregiver is I've been way too passive in listening to my mother and really getting more involved in understanding her care. I think what happened with me was when she got onto the Revlimid and she stopped having to have the transfusions and she seemed to be doing so well, I kind of started treating it like she was cured. Like oh, well, you have some sickness and you take a pill and now it's... and you're better.

Jayshree Shah: It's like diabetes or high blood pressure that you end up taking it, but you forget that you have high blood pressure or diabetes or something like that because it's the norm for you to just keep moving, which is fine. It's fine to keep moving. You just have to remember when you go to the doctors you have a set of questions ready to go.

Q4: And as a caregiver, I think, too, I'm realizing I really wasn't present enough to her over the years to... and I'm kind of excited now that I can be more invested in walking with her.

Q5: He was fine and you know what? Once I got on Revlimid and things got better, I wouldn't even think about it. I have to even stop and think what is it I have? Somebody will say to me, "What is it?"

Jayshree Shah: Well, she's definitely living.

Q5: I have to stop and charge my memory to even know what MDS means sometimes.

Jayshree Shah: Well, you have him now to talk about and discuss. It's great that he was able to join us. That's great. Anybody else? No? Wow. This is the quietest forum I've ever had to run. I guess Dr. Rossetti 1) he did an excellent job in explaining about MDS and treatment options and what's to look forward to. The book that you have in front of you, again, has great information, but the nuts and bolts about MDS as well as great resources besides MDS Foundation to look to for guidance and assistance, but I would say what facility you're at if it does not have, say, social worker or nutritionist, reach out to the university level. Call them up. Say you're not a patient there, but I want to find out how I can hook up meaning to get more information. How can I meet a nutritionist? I bet you they'd be willing to spend some time to spend with you to explain to do something in related to questions or better care or better... whatever that you have in regards to answering anything. So, I've had as many patients reach out to me, "Jay, I don't come to Hackensack. I'm from a community hospital. I have this, this, this. Where can I get the information?" So, use us to guide you to where to get your answers which is why you're here today. So, I hope this was helpful that you guys came. You learned and, again, as a nurse, I commend you that you're here and you're learning and keep living and keep the hope alive which is the most important to me. So, thank you again for coming and sharing your Saturday morning with us. Appreciate it.

Q6: We just learned something from her about this. The bag and the scale when you give blood. We didn't know that will help. Now we know.

Jayshree Shah: There you go.

Q6: We see she's there every Monday getting blood through her port. I think everybody that's got a needle should have a port seeing as people trying to find it, but anyways what is too old for a transplant?

Jayshree Shah: Oh, that's a great question. So, the question is what is too old for a transplant. Well, it depends on the facility that you go to, number one, and how they do the evaluation and it can vary and it begins with the type of MDS you have, the other things that I mentioned, your age, your comorbidities, your type of insurance and what kind of brothers and sisters do you have meaning are you in communication? Will they come in to be tested? Do you have donors, possible donors? There's many risks involved with going through an allogeneic transplant and that could vary from not developing, say, graft versus host disease which can affect your gut, your skin, all different things, but that conversation should be done. That consultation should be done with a transplant doctor. Old is relative. It can vary. Somebody that's 70 – 80 years old that's very active and healthy, good performance status and they have MDS, they may be wanting to take that risk in going through the transplant. Somebody that's 60 or 50 and very sick, have heart condition, kidney issues, liver issues, they may not be the right person to go through all of that. So, it varies. Every person is an individualized patient and needs to be evaluated in an individual way.



Q6: Her sister would have to get the bone marrow.

Jayshree Shah: Not a bone marrow biopsy. No. Blood testing. The sisters, the brothers, the way they test them is by blood or swab and we can actually find out your DNA, your DNA, anybody's DNA by doing swabs to send it to National Marrow for Donor Evaluation and that's, I believe, in Wisconsin. So, that can be done through a transplant doctor and they will set you up, but go for the consultation first and have that discussion. Is my wife a transplant candidate or no?

Q7: Did I hear Dr. Rossetti right saying that for this particular situation unlike in some leukemias though a donor could be a pain from some... from outside your blood relatives.

Jayshree Shah: Yes. Robin Roberts was lucky. She had a sister that was a perfect match. She was super lucky. Some people don't have brothers and sisters maybe not alive or none to be just known. They go in the National Donor Bank of, say, 10 million people and they find a common (Attendee), similar (Attendee) that may have the DNA makeup of (Attendee) similar as close as possible. Ten out of 10 match to say that donor, 10 out of 10 match, (Attendee), the stem cells are going to go into (Attendee) and she's not going to react. We're trying our best to match the donor to (Attendee). Example, I'm giving you an example, as close as possible. So, there is a bank available for like 10 million people. There's 10 million plus people that have donated... I myself am registered as a potential donor if there is another Jayshree, Super Jay, available or a need for my stem cells to donate. So, they do have that available.

Q7: What is the risk to the... if you choose to do what you did become a potential donor, is there... and then I get a call a year later that somebody in Oregon and I match and they need me...?

Jayshree Shah: Again... Is that what you're saying?

Q7: Is there any risk to me in that process?

Jayshree Shah: Not at all. You can probably donate... I don't know how many times, but yeah you can donate more than once. You would probably want to space it out, obviously, and that person would be very lucky if there are to be a match. You had a question?

Q8: In speaking about a stem cell donations, my perception is that seems like a very easy thing to do. For example like I'm an organ donor on my driver's license, but that's once I've already passed away, but stem cell donation it's probably something that I could do very simply.

Jayshree Shah: It is. Let me explain. He's referring to people have this perception of stem cell donation like you go into the operating room and they kind of poke you or take the bone marrow out and then reinfuse it into the donor, the actual patient, to reinfuse it. That's like the old school Frankenstein version. No. The way they do it actually is you literally sit for about give or take maybe four hours or six hours in a chair, a comfortable chair and you get hooked up to a dialysis machine, type machine, and what it does it actually takes your stem cells out of your blood and it collects it and... collects it into a bag similar to like a platelet transfusion or blood transfusion bag and they

hold it. Those are your stem cells and they get reinfused, say, into (Attendee) on the day of the transplant day. Now before the patient, say I'm using (Attendee) I hope you don't mind as an example. Say she was planning on going through transplant and there was a donor available, another (Attendee). This other (Attendee) has to get a whole workup done. I mean, I'm talking about lots and lots of blood work, HIV, hepatitis, all kinds of evaluation before they're cleared to be the donor. Once they're cleared then they go through a rigorous evaluation to make sure physically and everything that they're okay donating. They set up a protocol with that donor getting medication. The shot's called Neupogen which is a growth factor. What it does it actually stimulates the bone marrow to grow extra white blood cells. Why is that important? Because you're collecting stem cells via veins to extra to collect it in a bag to give the patient, (Attendee), those stem cells. So, you give those injections for a give or take about four to five days. You will give those injections and then day six or seven you collect those stem cells via infusion and you collect a million plus and blah, blah, blah. There's a certain amount of stem cells and then you hold it, refrigerate it, you process it to make sure it's free of bacteria, infection, virus, anything related to that. Make sure it's processed sterilely. That's stored. In the meantime, (Attendee), the patient is going to be hospitalized, say, day minus five into the hospital, given heavy duty chemo and I'm talking about heavy duty chemo. This is harsh stuff. Why do we do that? We give chemo, specific different kind regimens, to wipe out her bone marrow to a level of zero. Why? Because her stem cells are no good right now. Want to wipe it out and give her donor's (Attendee) stem cells into her infusing via catheter, the Hickman catheter. Give those stem cells and what it does it actually... those are seeds. Think about it as seeds. Now, they're planted in her bone marrow, those seeds. Isn't that cool? That's cool and bone marrow is now going to grow the normal stem cells. The problem is as soon as they start growing, they realize this is not (Attendee). This is somebody else's cells in (Attendee) and it starts attacking. When it starts attacking it can come out with different infections, all kinds. It could be gut infections with diarrhea, skin infections with different changes that happen. The way that we reverse or combat is by giving them autoimmune drugs to balance it out so her donor (Attendee) stem cells don't reject. They stay within her and they grow to fruition. Hence, we have a (Attendee) and that's where Robin Roberts is now. She's grown her sister's stem cells within her body to Robin Roberts now. It's mutated. It's changed and it stayed. So, that's how they go through the whole process and then they monitor. We monitor by bone marrow, by blood. We keep a very close eye on the patient. The patients usually for transplant, they stay in the hospital for about one month. One month.

Q9: Is there a website to go to if you want to look into being a donor?

Jayshree Shah: You mean a donor for... Yeah. It's National Marrow for Donor in Wisconsin, and MDP.

Q10: Be the Match.

Jayshree Shah: Be the Match. Yup. Be the Match and you can donate any time meaning they'll send you the swab. It costs money to do it blankly like if you're interested in doing it. The way best to do it is finding out where they're holding kind of a forum for free kits and you go there and you do it and it's sent out for free. So, find out where they're holding different free kind of drives for bone

marrow drives, for, say, other patients or whatever and you can go there and do the swab and it's free.

Q10: And would this donation then would also be available for other...

Jayshree Shah: Yes.

Q10: ... other diseases or would it just be for MDS?

Jayshree Shah: No, not for MDS. It could be any bone marrow.

Q10: Any bone marrow issues...

Jayshree Shah: Correct.

Q10: ... where the match would work.

Jayshree Shah: Yes. Even leukemia, lymphoma, anything, but the patient is registered to go a bone marrow transplant. If your stem cells or DNA matches somebody else's, they'll call you and reach out to you

Q10: You're saying there's 10 million people right now.

Jayshree Shah: Registered at Be the Match. Yes. That's nothing. We have, what, 300 plus people living in the United States. It's nothing.

Q11: Around (inaudible 40:45). I'll be glad 10,000,002 after today.

Jayshree Shah: See, there you go. Yes?

Q12: I had an autologous stem cells transplant which is not the same. They used my own stem cells, but I've known many people who've had allogeneic transplants and they all... it's amazing once you're in that position to potentially need a donor how scary it is and I know that a lot of people can't find matches. It's not... Ten million sounds like a lot, but with the number of things you have to match, it's not like a blood type. So, I just know a lot of people who have donor transplants who are very appreciative of people who get swabbed.

Jayshree Shah: Who get swabbed and are registered and are willing to offer themselves in a different way.

Q13: How do insurance companies look on these transplants?

Jayshree Shah: So, le time give you a ballpark. Insurance companies for MDS diagnosis, I don't believe they're approved for Medicare. They are doing clinical trials to find out if Medicare patients

who have MDS, 65 or older is it worthwhile. So, they're evaluating. One allogeneic transplant can cost anywhere from 500,000 to 1 million.

Q14: Whoa!

Jayshree Shah: Yes and that's just one. So, you can only understand how complex, how detailed, how important things are to fall into place to go through any of that. The reason why it's all so expensive is because you pretty much have all the specialists on board to take care of you for you to be... to have a positive result meaning for you not to reject your donor cells. You have the GI doctor, infection disease, cardiologist, kidney, all of those specialists they're on board. As soon as you enter, they're on board to follow you if you develop a problem, they have to address it to help you through that. So, it costs... It's a team effort in a very multidisciplinary manner to make sure that you have a positive outcome.

Q15: You mentioned that Medicare won't pay for that currently? Do you happen to know about Medicaid? Is that similar to Medicare?

Jayshree Shah: Medicaid varies each state by state... State by state it differs.

Q16: My questions aren't related to the transplants, but does anybody else have bone pain in the legs or their arms as a result of having MDS?

Jayshree Shah: (Attendee) does. She's saying yes. Anybody else?

Q16: Is it mainly at night?

Jayshree Shah: What are your thoughts?

Q17: Dr. Liang (sp? 43:58) said it was a sign that the bone was regenerating and so it was positive in certain locations. Other locations it was inconsequential, but the right... (Attendee) was having them in the right locations after the chemo began and Dr. Liang was very happy by that.

Jayshree Shah: Okay. So, that was a positive outcome in regards to a response evaluation.

Q17: Other pains she thought neutral, but certain pains she believed could be regeneration of the bone marrow.

Jayshree Shah: So, that could be one relationship. I think what the person whoever's having the bone pain... Where are you having your bone pain at?

Q16: Between the hips and the knees, but I've had this since I was seven.

Jayshree Shah: Right. So, I think it's probably an underlying issue of some other kind issue besides MDS. It may be exacerbated meaning make it worse with MDS having on top of it. I think your

physician probably or... yeah, physician may have to evaluate and finding out what the underlying causality may be. Maybe orthopedic, maybe autoimmune. Maybe something related to that.

Q16: My mom had lupus.

Jayshree Shah: Right. I've had many patients who've had an autoimmune. Autoimmune is what I mean by autoimmune is your body attacks on its own in different ways. It could be bone pain, arthritic pain causing different things to attack. It would be red blood cells, white blood cells or platelets in different ways. So, that could mean lupus, rheumatoid arthritis or something of an arthritic joint pain throughout as a possibility. You may need a further evaluation maybe by a rheumatologist to make sure that it's nothing related to arthritis. Some patients of mine who have MDS and autoimmune, we've put them on a little low touch of steroid every now and then just to see if that would make a difference, causality change or the symptom to change for management and to maintain quality of life, but evaluation is the key first before people start taking medicine.

Q18: (inaudible 46:15)

Jayshree Shah: Anybody else want to share anything else? No.

Q19: How long do you take Azacitronine? Aza?

Jayshree Shah: Aza? Okay. So, Aza can vary anywhere from give or take 18 months to lifelong. For Joan's patients, she's had... She's gone already, but the other nurse practitioner that work with Dr. Rossetti, she's had patients for seven plus years. So, you can keep going for a long time. Dr. Silverman who did the initial trials on Aza had patients 10 plus, 15 years plus and it does vary. I've had most I've had patients go on for about four plus years and they've, again, stable. Stable in MDS is a good thing. Finding a new norm is different for every patient and trying to figure out how to balance with that.

Guys, thank you so much, again, for everybody, patient, caregivers, family members and (Attendee) for representing. Anybody else want to share anything? Last bit thoughts?

Q20: Just thank you.

Jayshree Shah: Alright. Thank you everybody. Thank you for taking your Saturday out.

(Applause)

Jayshree Shah: Get home safe, guys, with the traffic and all.