

**Speakers:**

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

Jayshree Shah: I'm going to reboot again in regards to just finishing up for the afternoon portion of this forum. As I introduce myself, my name is Jayshree. The rest of the time I do have a presentation, but I'm kind of going to go breeze through it, but at the end of the day I really want to hear from you as patients and caregivers. I did miss you two ladies. We actually went around and introduced ourselves and I think you needed to step out to get some... it was cold in here. I'll call Engineering to raise up the temperature. They should be up to doing that. It may take a little bit of time. There is also I do want to remind you a survey. If you can fill that out. Your feedback is very important and feedback is important in the sense that you also have to let us know if you enjoy coming to this forum here in Hackensack in the future if you want another patient forum to happen and if Hackensack is a convenient site for all of you to come. If you can help us fill that out and, again, please include Dr. Goldberg and myself as a reference in case... in regards to your thoughts of how we could improve this patient forum in the future. We hope to have another one in the next maybe year or two again as long as the funding and stuff happens from the MDS Foundation.

So, I want to hear from those two ladies. I think I missed them and missed next to her as well. I didn't get to know your name. So, if you could introduce yourselves and how long you've had MDS and any summer plans.

Q1: I'm (Attendee). I'm from Boston and I'm a caregiver.

Jayshree Shah: Thank you. Any summer plans?

Q2: She's not my caregiver.

Jayshree Shah: Supporter.

Q2: She's my traveler and the driver. She's my daughter and I'm (Attendee) from Boston. I had laryngitis. I lost my voice. I think I'm just kind of in the early stages of being diagnosed with MDS.

Jayshree Shah: Any summer plans?

Q2: Any summer plans? Going to the Cape, Cape Cod.

Jayshree Shah: We have another one going to Martha's Vineyard.

Q3: Hi. I'm (Attendee) and I'm a patient of Dr. Andre (inaudible 2:57). I'm a patient here and I'm just here because I'm interested in knowing about other blood cancers and their new treatments and how we can increase the quality of living and all that.

Jayshree Shah: Thank you. Thank you for your support. This is great.

In front of you, you probably have a lovely binder called *Building Blocks of Hope, a Patient and Caregiver Guide for Living with MDS*. So, that was developed by Sandra Curtain. We call her Sandy and she developed this in lieu of patient and caregiver responses back after they filled out a survey saying that we need this information, we need that information, we don't understand this and that related to MDS. So, she got the idea of making a book pretty much and saying let's combine all of this information, let's teach anybody and everybody who wants to learn about MDS and put it together. So aside from having a hardcopy, we also have it on our website on the MDS Foundation website. You can go on it and download it for your reference or share it with a, I don't know, a friend, a family member, whoever else wants to learn about MDS. It was... I do want to tell you our MDS Foundation has an International Nurse Leadership Board which includes nurses from all over the world not just United States that we pretty much get together, we try to, in learning and sharing information about MDS and running these patient forums like this one to get experts like Dr. Goldberg and other physicians to share their knowledge and updates.

So, why was Sandy inclined, again, to develop this *Building Blocks of Hope*? Well, patients and caregivers said that we need to understand the diagnosis of MDS. I need to know more about it. How is MDS diagnosed? What are the consequences of getting blood transfusions? How can I maintain myself healthy? Nutrition. What can I do to keep my stamina up? All those things come into play. So hence, this book came about. It has tools and strategies for success that we hope will help you as patients and caregivers, driver, whoever else is here to learn about MDS and who to ask for help. We don't want you guys to Google everything related to MDS. We want you guys to hopefully have some means of direction to go to such as, again, the book that was developed and a plan, an MDS plan of how your journey will float. For some patients have been on Revlimid for seven plus years going further on and who's doing well. Some is new, newly diagnosed MDS. For some it's beginning stages. Don't know yet what's going to happen next. So, if you go around this room we introduced ourselves and we learned that everybody has been diagnosed at different times, but in addition to that if we went around the room again and asked... we missed you guys. We'll come back to you. We missed you. I'm sorry. What type of MDS you guys have. Everybody in this room that has MDS will probably have a different form of MDS. Not one person will have a similar kind. Why? We're all genetically different. That's what makes us so unique.

Go ahead. I missed you guys. I apologize. Please introduce... Yes.

Q4: (inaudible 7:15) I have no vacation plans.

Jayshree Shah: Well, there's time.

Q5: (Attendee). I'm (Attendee)'s wife who has MDS and as far as vacation plans, I hope we do have some soon.

Jayshree Shah: She's waiting from a surprise from you.

Q6: We're taking our granddaughter to Disney.

Jayshree Shah: Nice.

Q7: I'm (Attendee) and I'm here to escort anybody who need an escort.

Jayshree Shah: He's everybody's supporter here. Well, we have two lovely ladies in the back that you met signing in. You guys know Deborah and Janice and her daughter that's... they are here from MDS Foundation. Feel free please after you fill out this survey to give them the survey back so that goes back to the head office for downloading information and updates as far as your feedback.

Alright. So, what is MDS? I don't want to repeat what Dr. Goldberg already went through because it's repetitive. MDS is a cancer. It's broken bone marrow. It's not functioning like he said, related to a garden collected with weeds and the weeds are just growing out of control. We need something to stop the weeds from growing. Hence, we have different treatment options available such as Vidaza, Dacogen, Revlimid, ATG and the grand cure for MDS we know is as a bone marrow transplant. That is the only cure. MDS as I mentioned is not one disease. It's a group of different diseases originating in bone marrow and that's what I meant earlier that in this room everybody has a different form and different kind of MDS. Not everybody's MDS is the same. Your MDS is different than hers, his, you kind of go around everybody's is different and we know that MDS cells are abnormal in shape and size. They become dysplastic meaning they're not normal looking. Hence, resulting in low blood count, but different kinds whether it be white blood cell or platelets.

This is a nice slide because it gives you a visual perspective of what's happening within your bone marrow. This is your bone marrow. This is your stem cell and it differentiates between a myeloid and a lymphoid and the myeloid is the one that makes, again, your neutrophils, basophils, eosinophils, monocytes, platelets and red blood cells. So, it makes up your system in regards to white blood cell, red blood cell and platelets and if it's not functioning properly then it becomes abnormal and abnormal meaning it creates immature cells related to exposure possibly from chemicals, age. Mutations that are happening within your DNA that we sometimes don't have any control over. Hence, peripheral cytopenias develop and that's developed and visualized on a regular CBC, a blood count that you guys get when you come in for your reports to look at.

So, how do we diagnose somebody with MDS? In the book it gives you a nice overview of all the different testing that we have to do to make sure patients truly have MDS and not something else like maybe vitamin B12 deficiency that may look like MDS, but they don't have MDS. They have a vitamin B12 deficiency with a hemoglobin of, say, 5 and they're saying, "Wow. Is that possible?" It is. People can come in with a bad hemoglobin and they think, "Oh, my God." They have MDS. Give me a bone marrow transplant tomorrow like on the show "House." That doesn't happen. We have to do the proper workup and that includes a whole bunch of testing and making sure that patients actually have MDS.

Q8: Why is (inaudible 11:54 – 12:02).

Jayshree Shah: That's part of the rule outs to make sure your levels are within normal limits. The hematologist (inaudible 12:08) is make sure you don't have another form of disease called red blood cell dysplasia which can happen. There is other forms of hemolysis like ITP. Patients may have that in lieu of having MDS. We have to make sure that the patient truly does not have a breakdown of red blood cells. So, that's part of that. TSH is a thyroid panel. So, sometimes patients present on initial diagnosis in addition peripheral cytopenias, blood counts being low, a thyroid problem, a testosterone problem. So, we want to make sure that those levels are fixed because if you fix those levels sometimes the patient may feel better

Q9: (inaudible 12:57)

Jayshree Shah: MDS itself.

Q9: (inaudible 13:02)

Jayshree Shah: Renal is kidney function and hepatic a liver function. We need a baseline assessment. When we first meet a brand new patient for a consultation, we like to do those testing. Why? Because we need to know where you are on initial point of meeting. If we're going to know you for say, eight years. I want to reflect back and say, "Joe had a perfect kidney function when we met and his kidney function eight years later is still perfect," so we have something to compare it to.

Q10: (inaudible 13:39)

Jayshree Shah: No.

Q10: B12.

Jayshree Shah: Well, that's a different issue. That's a different issue.

Now, Dr. Goldberg mentioned about the different classification systems that exist and, again, we have to know which category of MDS we fall into to understand what type it is and how we are going to address it for treatment which is the FAB, WHO. There's a WHO updated 2008 and these are the different kinds of, again, breakdown of MDS, different subtypes. Now, we have the IPSS and we have the revised version of IPSS. We here at Hackensack follow the revised version, but we've used definitely still as a basic understanding still use the IPSS, the regular IPSS, as a basic understanding of MDS, in understanding prognostic factors. So, this is a nice reference it can anybody wants to go on the website of Foundation. IPSSR-calculator. If you put in your information, it will give you a prognosis IPSS score.

Q11: What is that address again?

Jayshree Shah: It's right here. Sorry. It's not clear. It's [www.mds-foundation.org/ipss-r-calculated/](http://www.mds-foundation.org/ipss-r-calculated/) and you plug in your information, the necessary information, like your platelets, your white count, your cytogenetic information. If you have that basic information you plug it in, it will give you a score and that is your score that you will have a discussion with your physician about and understanding your prognosis, what treatment options you will be going through or consider.

The facts about MDS which Dr. Goldberg also mentioned earlier. Average age at diagnosis is 73. MDS remains an incurable malignancy for majority of patients. We know transplant is the cure. You guys are familiar with Robin Roberts. I use her as a reference because she developed breast cancer first, received treatment and then she went into remission with that. A few years later, she developed MDS. She received a few doses of treatment while she was awaiting transplant to be considered and luckily her sister was a perfect match. So, she went through the stem cell transplant as an option and hopefully she's in the cure zone, cure mode. The leading cause of death is the disease itself for roughly about 80 percent. Stratified treatment strategy are key to optimal therapeutic options and outcomes.

Q12: Jayshree, I thought that mostly people don't die of MDS when they're diagnosed. The infections, those (inaudible 17:07) strange results (inaudible 17:09).

Jayshree Shah: It is. The leading cause of death is the disease itself in addition to the comorbidities that the patients have. So, it's hard to differentiate sometimes which one is causing what. Patients may have, say, heart disease, diabetes or some kind of autoimmune component. It may be one triggering the other meaning the heart disease is what caused them to go in with a heart attack, but while they were hospitalized dealing with the heart attack, they developed an infection, but because they have MDS it could be a causality of a triggering effect. So, majority of the time patients who have MDS, most of the time they have multiple comorbidities that they're dealing with. So, it's so important for all of you aside from MDS whoever your primary care doctor is or other physicians that are following you for other things like cardiac, kidney or other issues make sure that you are communicating what your oncologist is doing more of a

reason, (Attendee) for you to make sure, again, communication with other physicians to know each one if they're not communicating with each other, you let them know what treatment you're getting and how it's impacting you. Again if your hemoglobin is trending low to 6 – 7 and you have a history of a heart attack and your cardiologist doesn't know that you're dealing with MDS, your cardiologist... you will have to be your advocate making sure your levels stay above a certain level that your cardiologist would want you to be. So, you prevent another heart attack.

So, individualized treatment is important because, again, everybody in this room has an individualized plan. Your plan is different than his because you may have a combination issue you're dealing with potentially, don't know yet where you're standing, but you may just have MDS. Again, it's an individualized plan because everybody's MDS is going to be different and knowing what types you have is going to be the key starter in understanding how you're going to take care of yourself.

Performance status, comorbidities which we just talked about, primary versus secondary type of MDS. So, similar to Robin Roberts, she had breast cancer first and then developed MDS. Well, did you have prostate cancer first and then developed MDS. Lifestyle, what cytogenetic abnormalities do you have. We talked about... Dr. Goldberg talked about transfusion supportive care, growth factors, Revlimid as an option, Vidaza as an option, Dacogen, chemotherapy. Now, there are certain patients that may be eligible to receive chemotherapy or want to get chemotherapy because they're pending stem cell transplant next as their option. Investigational agents. Now, Dr. Goldberg gave a website to you guys as a reference – [www.clinicaltrials.gov](http://www.clinicaltrials.gov). Feel free to go on the website to get the most updated information and then contact the facility if you're interested and if you think you're eligible to participate for the trial.

Now, mechanisms and action and therapies under investigation. These are bunch of different things that are available and available except some are done with as far as clinical trials, but this is what clinical trials is investigational. It's still in the running. It's not approved by FDA yet. So, that's where you as patients sometimes come about and say, "Oh, I want to see if I'm eligible to participate."

Key principles of therapies in MDS. Allogeneic bone marrow transplant remains, again, as I mentioned only potential cure. Age alone should not exclude active therapies and as Dr. Goldberg said give at least six months to see if the treatment is working and in the world of MDS, its stable is the end product. It's a good thing. Like Martha Stewart said, "It's a good thing." It's a great thing. Stable is a good thing. Proactive management of side effects is in the early phases are very important because it will deter you from stopping therapy and helping you stay on it to get over the hump, if we want to call it. Why? Because if you stay on it then we will at least know whether or not the therapy's working or not.

So, this is what happens in your bone marrow when you have a disease (inaudible 22:16) very high and the bone marrow, as Dr. Goldberg mentioned, you're cleaning out those weeds in the

garden which is your bone marrow and then as you're cleaning it out slowly, you're replacing it with good stem cells and cleaning it out for you to have good stem cells that are functioning and doing their job that they're supposed to be.

Toxicities may be difficult and/or discouraging for the patient in the beginning and say, "Oh, I want to give up. This is too much." That's where you as caregivers, supporters, daughters, wives, friend, whoever, your cheerleaders to help you plug along and pull through because that's what's going to keep you going. Going shopping, taking a walk, anything, traveling if you can, doing day trips, going to functions, enjoying some gardening, simple things like gardening, anything that you enjoy doing outside of your home setting sometimes is good to move and keep moving. Time is required for the best response as I just mentioned. Setting expectations is very important. Understanding what you're going into in the beginning is also important. You don't want to go in and say, "Oh, yes. I'm expecting a response in two weeks. Where's my result?" You have to make sure you communicate what your expectations are. Say for example, having a grandchild. I want to make sure I'm there for my grandchild's birth. That's something of a goal. Fine, we'll see how we can work on it and to help you to get to that goal to make sure you're there for the grandchild to come about or graduation, wedding, whatever.

This is a slide that Sandy's patient actually put up as a response to patient who tolerated Lenalidomide which is Revlimid for over 10 years and just showing the response of how the patient did so well with it and the patient had a deletion 5Q as a cytogenetic abnormality.

What can I do to stay healthy and that was one of the questions that was asked earlier. Having a balanced diet, daily activity, keep moving. The longer you stay still the longer you will want to just not want to do many things and you will become stagnant with your body itself. I tell all my patients whether they have MDS, lung cancer, GI, any type of cancer and even if they don't have cancer I tell them keep moving. Keep moving. That is your activity. Exercise. It could just mean a walk around the block, walk in the house. Avoid infection. Use common sense. Somebody's sneezing, coughing and they don't look well, stay away from them. Carry a Purell with you. Simple thing like that. Avoid bleeding. Again, you're not going to go jump off a plane or do some hacking of the trees or something like that and making sure you prevent that from bleeding especially if you have low platelets. Continue to enjoy doing things that you love. Say for example, know your limitation. If you're able to just do, say, gardening alone that takes a lot of your time and energy and you enjoy it stay with it. At the end of the day we want you to live and have a great quality of life. Get enough rest and if that means taking two naps a day go for it, but if you're recharged and you're ready to do more activity go for it. Ask for help when needed. Take advantage of available resources and they're all included in your book, *The Building Blocks of Hope*. Be an active participant in building hope. You guys are your best advocates. We're here to ride your journey and help you through that.

This is additional information for your reference, Healthy Body Health Mind which is important for you to if you want to go on the website feel free to browse through it. Becoming a partner in

your care, developing an MDS plan and this is included, again, as an online patient advocacy initiative. Interactive online format for you guys buildingblocksofhope.com so you can actually go on the website and develop your plan and create personalized MDS plan for you. Tools for tracking your progress are included between pages 85 and 91 and, again, online resources are great for people that are computer savvy or they want to use computers in addition to paper and patient and caregivers, again, may contact a patient liaison by calling again MDS Foundation. Audrey Hassad as a reference along with Deborah and Janice. So, this is the tabs that are included in your booklet, tab one through let me go through six. All the way to six and it has a whole plan for you as patient and developing your own MDS plan and now we leave the forum to you guys.

Q13: By the way, are these slides on the website?

Jayshree Shah: Yeah. I think so. If they're not Deborah can E-mail it to you. If you give her your E-mail, she'll E-mail it to you just let her know who wants these slides. She'd be happy to E-mail it to your E-mail address. Not a problem. There's no copyright on these. We only love sharing. So, the forum is left to you guys. Do you guys have any questions or any thoughts? Yes, Mr. (Attendee)?

Q14: Something comes to mind. Being a 17 years survivor, I have several doctors. I would recommend if possible to have all your doctors affiliated with the same hospital. I ran into a terrible problem with kidney stone situation where I was admitted to a new hospital and when they saw my MDS, the blood readings, they got very excited and I ran into dealing with infectious disease doctor and spent several weeks getting additional treatments and it was a nightmare. So, that's something that I would recommend.

Jayshree Shah: It's very challenging, Mr. (Attendee), you're right. When it comes to physicians or practitioners that are unfamiliar with learning about MDS or knowing about MDS and when they encounter it it's a new world to them and that's where you as advocates of yourself as well as caregivers that are with you here today carry this book with you and tell your physicians, "Here, you need to learn this disease process after you finish taking care of me," and it's more of a motivation because there are physicians and practitioners out there that do not know about MDS. It is still new.

Q14: Even practicing hematologists.

Jayshree Shah: Yes. Yes. And it's scary, but that's where you're going to give them the reference and say, "Go on the mdsfoundation.org website to learn about it." Use your book as a reference to say, "Here, this is your homework because I'm doing my homework, you do yours and learn about it and then we can have a conversation."

Q14: And they shouldn't feel insulted. Right?



Jayshree Shah: No, it's not about that. It's not about that. It's about sharing information. I don't know a lot of information about certain things, but that's where I go to learn about it. I research it. I need to find out. That's why you guys are here today to listen to Dr. Goldberg to learn more about it. How can you learn more to improve or to change or change a treatment plan or whatever you need to do? There's a reason why you're here today for support even just to get hope. Something like that. That's why it's very true, Mr. (Attendee) to keep all of your physicians informed what you have. If there's a new drug, new medication that you've been prescribed make sure all of your doctors know about it. You'd be surprised how helpful that is. Often it just takes a few minutes to pick up the phone to speak to the nurse or whoever and just say can you add that to my medication list because that's what I'm taking and can you pass on the information to the doctor so that he or she knows that I'm on a new blood thinner.

Q15: Excuse me, Mr. (Attendee), did you use the same doctor over the past 17 years and where are you being treated now?

Q14: Well, we're in central New Jersey. So, I got to Robert Wood Johnson and I try to have all my doctors affiliated with that hospital.

Jayshree Shah: Does anybody else want to share anything? Any other questions?

Q16: Is MDS broken down by country, certain populations have more MDS than others?

Jayshree Shah: That's a great question. The question is is MDS broken down by countries in regards to the incidence. I do not know of any data like that per se. I know they discuss... there are certain areas that do have higher incidence than others and it depends on... there's certain countries that are more focused and learning more about MDS and doing more work with it than others. For example...

Q16: Do you know which ones that have more incidence?

Jayshree Shah: Well, no. I do not know them number wise, but there are countries like Italy. There are a lot of physicians that do a lot of work with MDS. For aplastic anemia, Asian countries tend to have a higher incidence. That I do know of aplastic anemia versus us, meaning the Western countries. So, they have more research that they've done with aplastic anemia because their incidence is higher. So, we get a lot of... not a lot but information-wise for research regarding ATG, we get information from them as well and what treatments they use for aplastic anemia. Thailand, Korea. Yes?

Q17: I'm sorry I'm having a little trouble hearing. (Inaudible 34:55) is my problem. What did you say about Italy (inaudible 35:00)?

Jayshree Shah: There are a lot of physicians from Italy that have done a lot of work, research on MDS. So when we have an MDS meeting which just happened in Washington, DC, about, what, a month ago or so I think. Deb, right? Yeah. It was an International MDS Symposium meeting. That's for physicians and healthcare providers. So, they hold that meeting every year and... every two years, I believe. One every two years. So every two years, but the next one will be in 2017. This time it happened to be in Washington. So, physicians from all over the world wherever they're doing research on MDS, aplastic anemia type of diseases, cancers they come over and they present their research.

Q17: (inaudible 35:59) have the Italians come up with (inaudible 36:03).

Jayshree Shah: You know, I don't have the updated information from that meeting as far as the new updates, but they will be published soon. You know what? The best person to reach out would be Deborah, MDS Foundation. So, put that on your hot list if you're interested in getting the updates. Every meeting that's ever run in the United States especially in the science world, they have updates. So if nobody...if physicians or practitioners are unable to attend, you can go and research to find out where there's an updated information. It's more of a synopsis type of information session that they can give you or inform you to learn about what the meeting was held on and is there any updated research.

Q17: (Inaudible 37:02)

Jayshree Shah: So are South Americans, too. Don't get me wrong.

Q17: (Inaudible 37:11)

Jayshree Shah: I think there's a lot of people here that drink a lot of wine.

Q17: I was just wondering how many people here who have MDS are bothered by really (inaudible 37:42) fatigue. I mean, so dreary and fatigued. I was absolutely stunned by the fact that you were playing softball with teams (inaudible 37:55). I mean, (inaudible 37:57) hemoglobin falls to eight and (inaudible 38:01). Do muscles (inaudible 38:06).

Q18: (inaudible 38:09 – 38:22)

Jayshree Shah: Everybody does build up a tolerance of some means in what their threshold is. So his threshold is different than yours and it, again, it varies differentiating to the type of MDS everybody has.

Q17: I'm just curious what the experiences (inaudible 38:46).

Jayshree Shah: With fatigue? Well, we can go around and if anybody wants to share or comment on how impactful fatigue has been towards your diagnosis.

Q19: Just clarify one thing you just said. You said the fatigue factor varies with the type of MDS that you have. Now, by that do you mean whether you have refractory (inaudible 39:10) RCMD or just RA or excess blasts?

Jayshree Shah: Correct. So, your subtype is different. That's what I meant by earlier. Your type of MDS. MDS is a clonal... bunch of different subtypes of different variation of MDS and what I meant was the subtype differentiate and how your disease is progressing or presenting... not progressing, but presenting. His MDS is different than your wife's.

Q19: I understand that part, but is there a correlation between the fatigue factor and the generic tag that's on the MDS, i.e. RCMD, RA, etc.?

Jayshree Shah: Yes, there is and I think Dr. Goldberg can definitely expand on that more. I don't know if there's any specific research done with the different variations, but there is a direct correlation because one requires... not one, but there are different types that require more transfusions than others like RARS. They require a transfusions pretty much on a regular basis versus RCM. It does vary.

Q20: Did Hackensack (inaudible 40:33).

Jayshree Shah: They do. I'd have to ask Dr. Goldberg if he went or not. I don't know if he want this year, but I know he does get invited because...

Q21: Could people please use the microphones because you guys are having a private conversation.

Jayshree Shah: I apologize.

Q21: We don't know what the heck you're asking.

Jayshree Shah: She asked whether Dr. Goldberg went to the international meeting that was ran in Washington just two months ago, end of April and I'm not sure if he went or not, but I know he gets invited. I hope he got a chance to go because it's very informative in learning updated research whether it be only if it's a lab kind of based knowledge or research.

Q22: Were you there, Jayshree?

Jayshree Shah: I was not able to make it that weekend. I had another engagement, but I'm hoping maybe in the next two years. I did go to Germany, the one that was held two years ago in

Germany. That was really nice to learn kind of like a combination therapies that were coming about.

Q23: I think Dr. Goldberg went to that.

Jayshree Shah: He did? He told you?

Q23: I think so.

Jayshree Shah: Well, I guess we'll have to have another forum to learn about the updates from him.

Q24: Follow up on that. I have not had a fatigue factor, but I do get transfusions when the hemoglobin's eight. That's my cutoff.

Jayshree Shah: So, does your hemoglobin... if you didn't get your check up for your CBC, does your fatigue come about?

Q24: After 17 years, the body accommodates. I think at times it drops maybe to 7.5 and then I feel more exhausted.

Jayshree Shah: So for you, the number correlates to the symptom when it drops. Anybody else want to share?

Q25: I just wanted to mention a couple things (inaudible 43:02). He worked until... you were what? Not that long... He worked a good 10 years after he was diagnosed and occasionally his numbers would go down to 7... You were in New Jersey you could go into New York to work and he also played tennis in the early part of it and he did alright with that and then finally the doctor said I don't think you should play tennis anymore. It would be too taxing on you. (Inaudible 43:30).

Q26: Mr. (Attendee), was the decision to treat your kidney stones was it determined by the fact that you had MDS? In other words were they not do lithotripsy because they were worried about something or did they do an open surgery so that they could remove the stone which would have been less dangerous for you.

Q27: That was a separate situation. The kidney stones I've had through the years much younger... The treatment didn't have nothing to do with the MDS.

Jayshree Shah: Do you want to tell us about your fatigue, sir? The one in front of you?

Q28: My fatigue is always with me, but interestingly Dr. Goldberg mentioned today that I should go get my thyroid checked by (inaudible 44:45) because my numbers are below the scale. It's been like all of them, red, white, hemoglobin and platelets, but I don't think it's the MDS at all.

Q29: I'm sorry. I'm not hearing. What did you say? I'm not hearing.

Q28: What didn't you hear? The whole thing?

Q29: After the thyroid.

Q28: I can't hear you now.

Q30: He wears hearing aids.

Q29: Can you hear me now?

Q28: I can. Verizon.

Q29: I didn't hear the sentence after the thyroid that you should get your thyroid checked.

Q28: I don't think it's the MDS. Like all my numbers are lower than the scale meaning all my numbers platelets, the red, white, the hemoglobin, but I don't know why I'm always tired.

Jayshree Shah: That's one of the differentials. That's what Dr. Goldberg was referring to you is that to make sure that you always want to rule out and not blame MDS, MDS, MDS. You want to make sure that other things are looked at. Again, that's the work... that's part of the work up. As practitioners, we want to make sure we've taken a look at a whole bunch of things. Is it vitamin D deficiency? Is it vitamin B deficiency? Is it thyroid? Is it testosterone? All of those things come into play. So, it's a little bit of a work up depending on the symptom that you may be presenting. Yes, ma'am?

Q31: (inaudible 46:25).

Jayshree Shah: And depression. And depression is a huge component. That's probably not included in a workup, but I think it's important to discuss and talk about how you're feeling and talk about your emotions, but it depends on the person, too. Are they talkative? Do they want to keep everything inside of them and that's where you as caregivers or supporters need to come with the patient sometimes to help us because it's a team effort. It's not just one person deal. One to one, it's the team component and getting your input believe it or not is as important as the patient's input about what's happening.

Q32: Do you believe that testosterone treatments are working?

Jayshree Shah: We've used testosterone treatments on occasion with a few patients and it has helped. You just have to be very careful about letting the primary care doctor know that we're instituting testosterone treatment.

Q32: He suggested I try that, but I thought of the (inaudible 47:37) it doesn't look too good to me.

Jayshree Shah: With any drug, whichever form you're going to take whether it be a pill, injection, a cream, any means, that's the medicine you're getting in your system and it's being absorbed. You're going to possibly have some means of reaction. It's a risk and benefit ratio and that's a discussion you should have with your practitioner before starting and I tell patients if you're going to take any vitamin, any herbs that you're not sure whether you should take it or not or buy, write down the name and information before you buy... spend tons of money. Don't waste your money. Get the information, get approval, get the doctor's or practitioner's approval before you buy to make sure it's okay to take in conjunction with the treatments you are going to be taking because they do interact sometimes and you don't want to counteract something that you're receiving for your cancer.

Q32: Am I to understand that any drug that you're going to try, it should run four to six months before you know or is there a specific... did I miss something?

Jayshree Shah: So, it depends on what drug you're referring to. If you're referring to Vidaza, Dacogen. Revlimid is different. Revlimid you pretty much know about two months into the starting of the treatment whether or not it's going to work. So, it does vary depending on the drug. The Procrit and the Aranesp, any growth factor we usually give about eight weeks. So, that's about two months.

Q32: Yes, my doctor gave it six weeks and it doesn't seem to be working.

Jayshree Shah: So then you have to go to plan B. Again, differentiating and trying it out. Sometimes we have used combination of different things to try, to tweak it. Yes, ma'am.

Q33: What is your input about the new mode of treatment which is called immunotherapy?

Jayshree Shah: It's a great question. So, immunotherapy is basically tricking your immune system to kind of kill the cancer or send a signal or send a message to kill the cancer. So, I know that they're thinking about it in means for MDS. I just haven't seen any clinical trial come about yet, but I think it's going to be in the works and it's a new field that is evolving in a blow up fashion for different other cancers specifically for... because I work in the thoracic and the phase one clinical trial we're doing a lot of work with immunotherapy with lung, pancreatic. Right now, so we're looking into those cancers. As far as MDS, I haven't seen any, but that does mean



that's not going to come about. They may be using that very much in the near future I hope to see if it works. Will be encouraging if it is and I'm sure we're going to get updates from Dr. Goldberg about that.

Thank you so much, again, for everybody for coming in today on a Saturday and please hand in your surveys. That's important.

(Applause)