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Speakers: Jayshree Shah, APN-C, RN, MSN, BSN, BS Tracey Iraca Deborah Murray

Jayshree Shah: So, let's just get back. I want to have enough time for lunch and discussion and to kind meet each other at some point. My name is Jayshree. I'm a nurse practitioner at Hackensack University Medical Center in Jersey, but it's a pleasure being here at Fox Chase Cancer Center and the invitation from you, patient and caregivers, to have MDS Foundation be represented here. So, thank you and thank you for Dr. Kropf and her chairman for the facility and to sponsor this lovely function today.

My presentation is is basically just discussing *Building Blocks of Hope* which you may have gotten, obviously, with... I see a lot of booklets in your hands. It's a whole packet that was developed for you, patients and caregivers to read through in relation to what MDS is about and what MDS Foundation can offer as far as resources concerned. We have Tracey, who's sitting on the left of me, right of you guys and Deborah who's outside, part of MDS Foundation as support if you guys have any further questions or think about or future questions or whatever. You can reach out to them and they're at MDS Foundation.

So, my talk is discussing A Patient and Caregiver Guide for Living with MDS and it's represented by the International Nursing Leadership Board and board of directors at the MDS Foundation. So, I'm part of the Nursing Leadership Board, so that's why I volunteer to come to different organizations such as this to teach patients and caregivers about MDS. My background is one where I was in the working at Hackensack in the Leukemia Division for eight plus years with Dr. Goldberg and I basically worked with him to see patients of all different types of blood disorders and included a large portion of MDS patients and anything that looked like an abnormal CBC which is a complete blood count, we saw those patients and we took care of them and we directed their care whether it be with us or transferring them to another facility because they had another clinical trial or working with the transplant physicians who work next door to us and coordinating care for them.

So, this is a nice representation if you see there's a lot of names in there and really famous people there. Different nurses in all different areas as well as countries. So, that's why it's called International Nurse Leadership Board because we have nurses all around the world representing in teaching and being part of this leadership board and MDS Foundation.

So as you heard from Dr. Kropf in regards to MDS being and needing to be individualized treatment, it's very important to understand where you are with your MDS. I think that's the hardest part sometimes and it begins with knowing what the disease is, what does it mean to have low risk, intermediate or high risk type of MDS and to that effect, every person in this room probably who is a patient will have an individualized treatment plan developed for them. I have one patient in the back right here actually that I've known for, oh my God, 10 plus years now, more than that, 15 I think... 10, about 11 or 12 now who she's been our patient and she's had deletion 5Q and I know of this and that's a special type of MDS, special type of treatment versus somebody that's low risk. Gentleman



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over here that needs a specialized different treatment plan for him which may just mean monitoring and it becomes really important to have a keen physician that knows about MDS, developing that plan and knowing how the caregivers who also represented here how you guys can integrate help, resources for the family members and patients to get them through.

So, it's so important to look at different criteria that decide that individualized treatment plan which includes performance status. Comorbidities are different conditions that people have like heart conditions, diabetes, thyroid problems, do you have arthritis that you're dealing with that's possibly debilitating, maybe an autoimmune component that you may have? Is it primary or secondary MDS? Do you guys have brand new primary MDS or secondary like? You guys know Robin from ABC? Well, did you guys know she had breast cancer first, treated and a few years later her CBC, her complete blood count, went awry, went a little whacko if you want to call or just wrong. Something looked wrong in the CBC. The doctors knew there was a little bit of a problem happening here, did know what. They did a bone marrow and they found at that she had MDS. Luckily for her, she had a sister that was a complete match, 10 out of 10. I know, lucky for her and you guys see her now on television, you couldn't tell. Great care from both physicians, nurses, resources, caregivers. I mean without you caregivers that are represented here today, I don't know, it's really tough. You have to push your patients to get them through the appointments and transportation, food, nutrition, exercise, all those things that come into play, so important. So, that's secondary MDS. Let me backtrack here. Robin had secondary because it was a second malignancy that she developed.

Cytogenetic status. It's so important to know if you can besides knowing if it's low risk, intermediate or high do you have a cytogenetic abnormality that is specific to a type of MDS and, for example, if the patient has a deletion 5Q, well, we have a great drug to combat that and to shut off that mutation. So if you have that we have basically a drug to stop and change and help the patient through.

And to know your lifestyle. What kind of lifestyle are you maintaining or able to maintain? Key principles of therapy in MDS, what is your goal? Is the goal going to be getting to an allogeneic transplant? Is the goal going to be maintaining a good quality of life that you want? What are your goals? Again, it's an individualized treatment plan for every patient that's represented here and it's going to be different.

Age alone should not exclude active therapies which is so important because we have at our facility alone, we have 90 year olds getting treatment for MDS. Again, a 90 year old could be very active or not and it's a variable. Again, every person's different. All active therapies, again, for MDS require time to work. So with MDS, I can tell you the key words that I tell all my patients is 1) be patient. It does not work like a solid tumor cancer type of therapy where you somewhat see it because this is a blood cancer and when you're seeing a solid tumor cancer where you actually see it on films, on a CAT scan that the doctor shows you. "Oh, my God. I have a lung mass that I can actually see a six centimeter mass right in the lobe in the lung," and all of a sudden three months later they repeat the CAT scan and it's gone. Wow. It shrunk. You actually visualized it. With blood cancer, it's hard because we all depend on numbers that creates unnecessary anxiety with it along with it so I tell patients be patient, be patient and everybody's numbers are going to be different. Your number 10



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for hemoglobin is different than your number 10 for hemoglobin because everybody has different tolerance to number 10.

Proactive management of side effects in the early phases of treatment are key to obtaining the best response. That's where you caregivers come as a key players in helping patients through. Knowing what phone numbers to reach out to when a patient gets sick, what to do, who to call, is there somebody to call, are you at the best facility possible? I think we're at one of the best over here at Fox Chase. If not here, Jefferson. I've heard of a couple other, Temple, UPenn, all different places up here in Pennsylvania. You guys are very lucky to have a bunch of cancer centers, academic cancer centers, being represented that focuses on learning about MDS.

Now, blood counts often get worse before they get better. As Dr. Kropf, you heard her say it involves a lot of support in the beginning for patients to get through and to see if the response will come through. Why? Because, again, MDS is like you're cleaning out the bone marrow in a slow fashion. So, I always give this analogy to patients and caregivers, so they can understand it a little bit different or better or in a different way. MDS is like think of it as a garden. Your garden is your bone marrow where you plant your seeds where we have white blood cell seeds, red blood cell seeds and platelet seeds. When those seeds are broken, you're not going to have those fruition of tomatoes, peppers, eggplants, all those things that we want when we plant a garden, but within the garden itself, there's going to be weeds. When you have weeds, those are blast cells. Those are the cells that don't belong there. So hence, you need medicine, weed killer, to kill those weeds. So, the seeds grow into fruition. There's enough space in the garden and it doesn't overtake it. Hence, the fertilizer we call it Vidaza. We call it Dacogen. Those are the fertilizers we call different chemotherapies that are out there. The different trials that Dr. Kropf mentioned. Those are the weed killers. That's what I call it. So, that's what we need. So, we need to clean out the garden so that there's room and once there's room then the seeds will grow into fruition to the vegetables and plants that you want.

So, this is a nice representation as far as visually what happens what happens to blood counts as they drop as MDS progresses and normal blood counts, again, are crowded out because the weeds are coming through by abnormal stem cells in the bone marrow and blood. So once you begin treatment, you're starting to clean it, but again the one shot fertilizer doesn't work all the time. You got to keep on hitting it with the fertilizer. Think about it as similar to, again, a garden. That weed will come back. So, you got to keep on hitting it every two weeks to make sure that weed doesn't come through. Similar concept. The Vidaza, it's given every month. It's the same concept. You want to keep it down. So as the treatment cleans out the marrow, blood counts may drop further, patients my experience hematologic toxicities. So, there's side effects with that when you give this fertilizer. So, it's important to monitor those patients very closely and they may need blood, they may need platelets, transfusions. They may even need some antibiotics during that process to get them over the hump until there is room for, again, your seeds to grow into fruition. Once you get those weeds taken care of completely and say now there's room, the new stem cells, the hemopoietic cells basically are growing into fruition to your red blood cells, white blood cells and platelets to be normal and functioning to doing their jobs then you have a nice clean bone marrow coming through and hence you will see a response. How? By looking at your CBC. You can actually see your blood counts



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slowly starting to fix itself. It's because the cleanup is happening in your bone marrow and it takes time. So, be patient.

Time is required for the best response. Again, a minimum of four to six months. I've had some patients not respond for a good eight to 10 months, but it takes time. Some patients take longer than others. So, you kind of have to know your patient, what's happening to them.

Cytopenias often gets worse, as I just mentioned, before they get better. Again, there are strategies for getting through the initial cycles of treatment, which may involve dose modifications or delays.

Supportive care is so important. That could just mean getting maybe a nap every day. That's all. Maybe that's what it takes. So be it. If you're very active and all of a sudden you require a nap to recharge your batteries, that's okay. It's a new norm for you and you may have to fluctuate for the time being until your blood counts come up.

Setting expectations. I think that's a really hardcore discussion that you guys will have to have with your physician at some point in understanding where you stand with your disease. What grade are you are at with your disease? In the beginning, middle, the high risk end? Where are you so you can understand what expectations to come with.

So, trilineage response following four cycles of Azacitidine. This is actually, I believe, Sandy's patient. Sandy is one of the nurse practitioners that works in Arizona Cancer Center and this just shows your nice response with, again, going through using Azacitidine with referral evaluation and diagnosis and observation. Now if you look in the beginning, the white count and the hemoglobin are low and then slowly they start trickling up. It's because, again, this takes time. This is just to give you a nice graph perspective if you want to... for some engineers and teachers that like to graph everything just to visualize it just how Azatadine, it just takes time for it to start working.

So, this is also Sandy's patient response over 10 years of Lenalidomide treatments sustained moderate for asymptomatic cytopenias, a new norm. Again, everybody's norm count is going to be different. Yes. It is going to be different because every MDS patient is going to be different because we're all unique people. We're made differently.

So, what can I do to stay healthy? These are just some suggestions:

Balanced diet. Fox Chase, I'm sure, has a great nutritionist to work with possibly. If not, call up Jefferson. Call up, I don't know, Temple. They have nutritionists. Call them up. Get some advice. I'm sure they'd be happy to get you the necessary information. Call up MDS Foundation. We can hook you up with a resource or two.

Daily activity and exercise. I tell all my patients if you can and you're able to keep moving. Move your arms, move your legs, keep moving. If it just means walking, it's perfect. I'm not expecting a marathon. I'm not expectation a 10K. Keep moving.



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Fatigue. You will offset fatigue in that way. I know you're probably saying, "Jay, I can't do it with the hemoglobin at seven." Okay. What can you do? Maybe if you can just the normal activities of daily living and if you can do a little bit more, believe it or not it will perk you up.

Set goals. Set expectations. Set what you need to do. If you get one unit of blood, say, every month. See what you can do with that unit of blood to see what activities you can offset to do with that transfusion.

Avoid infection. We're not expecting every person that has MDS to be in a bubble. That will make you depressed.

Keep moving, keep interaction, but use common sense. Somebody's coughing, somebody is sneezing. Again, keep your distance, carry Purell with you. Simple things. Basic common things.

Flu. Flu is coming around the corner. Vaccines are out. Consider it. Have that discussion with your doctors. Is it necessary? Is it nonnecessary? What are the complications? Should I get it? Should I get it now? Later?

Pneumonia vaccines. Talk with your doctors. It's a live attenuated vaccine. Should I get it? Should I not get it?

Avoid bleeding. Again, common sense. Don't go out there and start cutting up wood over there with the big axe. Be conscious.

What are your platelets? Know your numbers. When you go to the doctor's office, if you can get a copy of your CBC. I always give a copy to my patients. Why? Being informed will make you feel like you're in control. I always give that information to my patients because they at the end of the day understand what we're dealing with for that day and that visit. Your white count is this. Your hemoglobin is this. Your platelets are this. If you know those numbers then you know what you're working with for the next, I don't know, three weeks, four weeks before you come back.

Continue to enjoy the things you love. Live. Keep moving.

Get enough rest. Again if you need a nap here and there, go for it. It recharges your battery. Turn it up.

Do what you need to get your activities, keep moving, be interactive. Again, go to your functions that you would normally. Go to church. Whatever makes you happy and you want to live with that.

Take advantage of available resources. Again, explore *The Building Blocks of Hope*. We have a website on the MDS Foundation that you can log in. You can use that as a resource for guidance. Again, you can always call us, MDS Foundation, and we can guide you through with whatever questions you may have.



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Be an active participant in building hope for you, as a patient, caregiver, general person that just is interested in learning about MDS. Whatever the case may be.

Becoming a partner in your care is building your own MDS plan because it's an individualized treatment plan. Every plan will be different.

Tools and strategies for success. Again, explore *The Building Blocks of Hope*. You guys have a great book in front of you, some great weekend reading to go through. There's lots and lots of information which starts off with Understanding Your Disease, Know Your IPSS Score, What is Your Survival, where do you fall through with... what is your risk category so then you can know what expectations to start off. Ask questions about treatment options, Schedule, Possible Side Effects, Strategies for Managing them. Again, consider lifestyle. So, you're running marathons before and now you're able to do only 10Ks. Okay, it's a lifestyle change, but that's something your body is telling you that you may have to modify for the time being.

Transportation. Seek friends, family, whoever can help you to get through to get to your treatment so you get it and you feel better. Hopefully you have a good result with it.

Ask for help. Become a partner, again, in your MDS journey. Build your MDS plan. You guys are here today to do that and to learn. So, build it, grow with it and explore what other resources are out there to implement it with your plan.

So, tab five within your booklet that you guys all have is My MDS Plan, Understanding the Diagnosis. Again, several tools to allow you to track and manage your journey. You want to make extra copies so go ahead and make that before writing on them so that you can track your progress.

And, again, MDS patient Outreach and advocacy program is available. Patient direct liaison. There's a phone number out there and A. Hassan is Audrey Hassan. She's one of the personnel that works at MDS Foundation that can assist you with, again, grouping you or assisting you with getting you the resources that you may need and this phone number and stuff, I think it's including in your booklet, but I'll leave this up there.

I'm kind of open to any questions or comments or if you want to share something, feel free. This forum now is open to you.

Yes, sir?

Q1: I would like to say in behalf of MDS Foundation when I was first diagnosed, my wife investigated it and she pulled up MDS. In the beginning, no one really tells you anything about MDS. Well, once we got these six booklets and we've read these, both my wife and I, it explains everything and I would just tell people definitely read these booklets because it will help you a lot to understand what we have



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Jayshree Shah: Thank you. That's helpful to know. You'd be surprised and you probably... When I started learning about MDS, believe it or not, I think I was a novice back in the day and there was lots of other healthcare professions that were in the same boat as myself. I still... I'm learning. I just learned a lot from Dr. Kropf today about the different trials that she and Fox Chase are proposing. That's awesome. So MDS, if you can think about it, it's kind of new. Kind of new is because we didn't know it as MDS. What they called it if you... I don't know if you know the prehistory, but they called it preleukemia. That's what it was known for. That's what it was called for a long time. Just beginning in the 1990s or so give or take, it started taking its form and group of doctors kind of got together and said there's some commonality with these patients that have this type of not really leukemia, but something else that's wrong with their bone marrow. They didn't know what to call it and they developed these classification systems called FAB; French, American and British if you can tell those different countries kind of got together and they developed this classification and they called it a FAB classification to develop and understand what MDS is about. So, it's still new. It's not like breast cancer.

Q1: Read the booklets.

Jayshree Shah: I know. So, breast cancer. You guys know. Everybody knows breast cancer, but if you ask a physician what MDS is like an older possible... I don't know, any physicians, they may say, "It's too new, I don't know too much about it because it is." We're still learning and it's so awesome. We're still learning because it's kind of something that is growing to develop its own kind of answers and develop a treatment plan and all kinds of things with different trials that, again, all different organizations are proposing. To hear Dr. Kropf present just a few, those are encouraging, very encouraging and it's nice to know that there's something going out there that they're going to work on.

Q1: Can I say one other thing?

Jayshree Shah: Yes, sir.

Q1: A lot of people don't know this, but I was shocked how MDS was a financial burden. I mean, it really is. So, there is a thing out there called Patient Access Network that people can sign up for to help pay for the drugs that we get for MDS and it's very helpful. It'll help a lot of the people.

Jayshree Shah: So, I don't know if everybody heard what he said, but there is an organization or support kind of a financial area called Patient Access Support Network and for people that are in dire need or don't have health insurance or the copays are high companies, pharmaceutical companies, will work with your organization to see possibly they can offer the drug for free, but you will need to reach out to a social worker, a finance counselor to explain what's happening with your financial status to see what kind of things that can be assisted with resources. Thank you for mentioning that because it's very true.

Q1: It's really important. I'm telling you.



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Jayshree Shah: For people that need drugs, simple drugs, also people can go on a website called needymeds.com and you can apply for different copays, different drugs for free possibly and companies will have different things available possibly if you need them and the high copays they may be able to help you out because these drugs are expensive. They're not cheap.

Yes, miss?

Q2: September was Blood Cancer Awareness Month and you didn't even hear hardly anything. Nothing.

Jayshree Shah: I know. So, you can understand October you guys know October. Everybody knows October because it's Breast Cancer Month, but that does not mean we don't represent. I think it does. I think slowly and progressively it will with Robin from... I forget her name, last name.

Q2: Roberts.

Jayshree Shah: Thank you. I knew it was RR. Roberts. Robin Roberts with her as a voice because sometimes you need a celebrity unfortunately to develop some kind of disease to kind of advocate and say there is a push for it. There's a learning curve that needs to happen. There needs to come with a treatment plan. Research, clinical trials. All of those things need to come into play. So, it's so true. So, I'm hoping Robin Roberts has stepped up and she's done a phenomenal job, but I hope that she even pushes other celebrities to come forward and help with that and it's so true, but you as a patient, caregiver can also represent and teach others about that there is something called blood cancers like MDS. Thanks.

Q3: Is it a rare disease? I read somewhere where they're not as common as other types of blood cancers. Is it rare? They're also saying there's a lot of people getting it because the population is aging.

Jayshree Shah: Correct. I don't know how you would define rare. I don't think this is rare. I think it's there to some degree. There has also been... Think about it this way. People have in the past been getting medication to treat MDS, but they never called it MDS. They may have called it iron deficiency anemia, but they never did a bone marrow because the hemoglobin was just low. So, that's a possibility. The thing that now is happening is that cancer centers, academic places are actually evaluating why you're having the low hemoglobin and by doing a bone marrow. The bone marrow will tell us different things like identifying whether or not the patient has MDS. So, people... again, we are aging. There's a couple factors with this – aging. We're coming up with so many different therapies now. Think about it. We have patients and people that go through not just one cancer and surviving. They go through two, three, four or five different cancers. As you get different therapies to treat those cancers, your DNA is also changing with that and with that there's going to be a high probability possible of mutations developing. Hence, this may come about as a cofactor or whatever the case may be and that patient in the back there she apparently has CLL and MDS. Did I understand you correctly back there?



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Q4: Yes.

Jayshree Shah: Right. So, it's a combination factor. People can have combination things. So, it's hard to say how that comes about, but I think we're... As a science, we're getting better at diagnosing people with abnormal CBCs. Yes, ma'am.

Q5: (inaudible 31:59) how do you tell people?

Jayshree Shah: How do you tell people what? That you have MDS? So, her question is to everybody here in communication or communicating how do you tell family members, just anybody that you have MDS and I think it begins with sitting down and telling them that yes, I actually...

Q5: I don't know how to (inaudible 32:39).

Jayshree Shah: So, is it somebody specific that you're concerned about or are you scared of telling them? What is your...?

Q5: I don't want anyone to (inaudible 32:54)

Jayshree Shah: Feel sorry?

Q5: Yeah. (inaudible 32:58)

Jayshree Shah: I think I have patients that say, "Jay, don't tell my son. Jay, don't tell my daughter because they're going to be worried," and I tell them I said, "It's up to you at the end of the day," but I think knowing sometimes will ease people's mind of why you're feeling what you are and it's hard. This is not easy. This is a long haul. This is a long road. It's a day to day, but I tell people keep moving, live, be happy, communicate because once you share what you're feeling there is hope, there is survival and there is research. You guys are at... like I can't explain to learn about different trials that are now available. We didn't have that. We didn't have Vidaza, we didn't have Decitabine. We didn't have hope. The treatment was blood transfusions, platelet transfusions and hospice. So, we've come a long way and we got a long ways to go.

Q5: You know what interesting is that (inaudible 34:25) what it is. Working for a hospice a long term (inaudible 34:31). So, this is a wonderful, wonderful opportunity. I always felt that people (inaudible 34:39) work in hospice were very professional. So, 1) I don't want to share this, but yet I have to be the very best that I can be in this situation. So, what kind of...

Jayshree Shah: Kind of (inaudible 34:53). I think you may need to talk to somebody to be able to communicate in the way that you'll want to share and how much you want to share and when you want to share. Everybody's sharing may be different. Some person may like to talk. Some people may not like to talk. Everybody's...

Q5: I like to listen.



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Jayshree Shah: But I think at some point you will also may want to share because it sounds like you're holding some stuff within you and I think it's also important to just say release and you may be at ease as a possibility, but it may take time, but I think we have great social workers. I have a great team. I love my social worker. I work very closely with my nutritionist. People that I trust I work with. I spend more time which you can imagine and most healthcare professionals. I work more time at work than with my personal life. So, I love what I do and I think if you speak to who you need to in the way and work with the social worker, I think it will ease your mind and put you at ease.

Q6: Suddenly had a thought.

Jayshree Shah: Yes.

Q6: We have an autistic grandson. He's nine years old and I've been to many meetings about what (inaudible 36:21) and one of the things that I heard and I try and practice it as much as possible is to tell people that I have an autistic grandson because I think that the more people that know, this thing too, I can't tell everybody that I got. I really can't. I told my family. I have told a couple of friends, but it hasn't been... I haven't gone to work and said I have this, but maybe it's better if you do talk about it and tell people that... the more people that know about things like this the better it is.

Jayshree Shah: Maybe you guys can develop you being represented here. You can maybe start your own patient support group. I don't know. This may be a great avenue for you as a... I don't know the exact location, but Central Philly or something or Fox Chase Center support group maybe once every month. I don't know. Maybe you can work with somebody regionally to see if that would helped.

Q5: I haven't done it yet. I think there is a meeting that a woman who lost her husband to MDS. She has it at her house, a luncheon. I have not gone to it.

O7: Rochelle.

Jayshree Shah: Miss Weinberg. So, yes. Do you guys have the information?

Tracey Iraca (?): The information. It's out at the table. It's a coping and caring luncheon for families. It was originally started for spouses and then so many patients that patients also wanted to attend. So, Rochelle is having that in November at her house. So, if you have questions there is...

Jayshree Shah: If you guys want to get more information, stop over and Tracey and Deb will be able to help you with that information and it may be a great avenue for you guys to come and bring maybe a colleague or somebody to have them understand about MDS. The MDS Foundation, they hold meetings throughout the year and sometimes I tell patients if they are able to, just bring a friend and say, "Listen, I'm going for half a day. Come with me. I want you to learn about MDS. I think you'll get a lot out of it."



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Q8: (inaudible 38:31) not this meeting in particular centers around the psychological effect of MDS more so. That's what our speaker is speaking on the psychological... She's an oncologist psychiatrist.

Jayshree Shah: Oh, wow. What a great combo. I think I need one for our facility.

Yes, sir.

Q9: I wanted to ask a question about Vidaza.

Jayshree Shah: Yes, sir.

Q9: We have several different kinds of blood cells. Vidaza, I'd like to know if typically tends to work on all or just some or just one or none. I also hear how long do you take it. All I hear, well, until it stops working. She's not a terribly encouraging... If you can flesh out your experiences with that.

Jayshree Shah: Sure. So, I've had many experience with patients receiving Vidaza as well Dacogen. Vidaza is a hypomethylating agent that is given in two different ways - subcutaneously or intravenously. Now, the plan is sometimes intravenously can be given for five days, seven days or 10 days depending, again, on your treatment plan that your doctor devised for you. Either way the means of it is yes, you get this therapy, but you need it on a routine basis which means every four to six weeks for a lifetime until it stops working. Why is that? Because that MDS clone is there and it can't be deleted. It will possibly mutate, maybe not, but what Vidaza does it just shuts it down and says keep quiet. In respect to it working and how it works, it takes time, like I presented on the slides, between four to six months. You will see a response once it starts working. For what kinds of patients of MDS? There are certain types that it does work a little bit faster than others. There are subcategories of MDS that patients can get and we didn't really brief on that or didn't go through with the understanding, but I think in your booklet it has a breakdown of different types are RA which is refractory anemia, RARS. There is different RAB with transformation. There is just RAB. So, different categories. So, different types may do better. There's one type called refractory anemia. They may do better than others. So, I think I would have to look at the patient what type it is of MDS that the hematopathologist has classified you as. So with the hematopathologist, they actually look at the bone marrow, not just the liquid, but they also look at the bone. So, sometimes the doctors will collect a bone chip and identify do you have enough iron in your bone marrow, the chip. Does it have fibrosis? Does it have scaring? Where you stand with your iron stores? What are your platelets looking in your bone marrow? So, they look at the whole picture and then classify you. I think you need to have that discussion with your oncologist to find out what is your relatively... understanding as far as response with Vidaza that will happen with your type. I don't know your time and I think, again, I would have to look at your profile.

Q9: Thank you.



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Jayshree Shah: But it's well tolerated I have to say and, again, well tolerated because my patients have been on Vidaza for seven, eight years plus. Dr. Silverman is New York, he's had patients I can't even tell you, over 10 plus years. So, you're probably saying, "Jay, how do they do it?" Well, they come up with a game plan. The patients, they're very savvy. You guys are very savvy and I tell patients if you want to take a vacation, plan it on the weeks that you're off.

Q9: We're doing that.

Jayshree Shah: Exactly. You live. You guys plan it. We... We're only kind of just going with the ride. We will work around your schedule. Yes?

Q10: In your experience have you noticed that blood levels of hemoglobin as measured by this wonderful equipment that everybody has can be variable from one institution to another by as much as a gram or more.

Jayshree Shah: I don't know about a gram. We have a CBC machine that tells us results, no lie, in 10 minutes and you're probably saying, "Jay, how is that accurate?" Well, if I were to submit the same sample to drawing the sample through a venipuncture, actually, versus a quick stick over here through the capillaries over here the numbers may be just a skew off, points, a couple points. A gram, I don't know. That's a big variability there. I would probably have to do some analysis to compare how different...

Q10: Well a finger stick versus taking it...

Jayshree Shah: Venipuncture.

Q10: ... venipuncture. What's the difference there?

Jayshree Shah: Sometimes the levels may be... I don't know... Again, it depends on how it's drawn up or collected with the cells and the microscope and how to detect how many of red blood cells are there. I would have to say it's not in our facility, again, we draw it through the finger stick and then if there's a question or something then we draw it up venipuncture peripherally to see if there's a comparison and where the difference is. Most of the time, it's relatively equal and it's, again, points off. So, it's not too different.