

Speakers

Steven L. Allen, MD

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Jayshree: So this afternoon session is actually dedicated to you guys as patients and caregivers. I want to just mention a couple things. Deborah Murray in the back, she represents the MDS Foundation. She is being a representative, she also is in possession of a cookbook if anybody's interested in learning some interesting recipes. MDS Foundation is selling it for \$10. If anybody's interested in buying something or breezing through it and also, again, use her as a reference in case you have any further questions or future questions to help you get your answers. Again, feel free to reach out to me as well. I'm in Hackensack. You can use MDS and just say, "Jayshree. I have a question for Jayshree," or whatever and they'll E-mail it to me and I'll answer them back or I'll call you or whatever the case may be. There is a survey in your binder. If you haven't done one online, it's a survey just because we want to know you as a person and a caregiver. It is pretty lengthy and the reason we ask those specific questions in that long survey is, again, we're collecting data. If we have data to identify how many patients exist, what are those patients' and caregivers' needs, we can share that with the government and say, "I need resources. I need money. I need funding." Right? If you don't collect data, we can't prove it to the government and say this is an issue. This is a concern. So we're collecting the data for that purpose. If you get a chance, please fill it out. If you don't, feel free to go online and fill it out and there's also an evaluation form regarding Dr. Allen's presentation, my presentation and what else can we offer you as patient and caregivers in the future because we'll be hosting this again in the future, maybe a year or two from now, again, in Long Island probably or in New York City. Again, there will be new speakers, new information, hopefully, new drugs, hopefully. Hopefully. Again, that's what clinical trials are all about and research. So, I'm going to turn the floor to you. Please move the microphones closer to you. I want you to introduce yourself if you can. Tell me where you're from and what brings you here? What do you want to gain from here from this session, this conference? So, I'll start with you, Miss Monica. Go ahead.

Monica Carey: Hi. My name is Monica Carey. Most of my friends and family call me Mona. This is my husband, Tom.

Tom: Yes.

(Laughter)

Monica Carey: I was diagnosed with this about eight months ago. So, I'm new to this. I found this very informative today. Most of you people here are much more knowledgeable than I am. I'm just learning how to even say what I have. I just tell everybody it's MDS. I don't know. It's this long name. I don't know what I have. It has something to do with my blood. Okay? Listening to you people, I was very impressed. I guess I have a lot of reading to do when I go home to catch up halfway to what you people know. Okay. And I'm just hoping to learn as much as I can about what we have and hope that we're in good hands.

Jayshree: Very good. Thank you.

Monica Kerry: Thank you.

Jayshree: Tom? I actually made your introduction, but do you want to share anything as a caregiver?

Tom Carey: I'm still Tom, her husband. Again, I'm just here to drive her here.

Jayshree: You're good support.

Tom Carey: To help her. I... to learn what we can about it and get some... do the right thing with it.

Jayshree: Do you mind if I ask you how did you hear about this conference?

Tom Carey: We got something in the mail.

Monica Carey: Deborah.

Jayshree: Deborah.

Tom Carey: She's talking to me.

Jayshree: Did you research it online and found out that it's...

Tom Carey: We don't have no computer. We have no stinking computer. No, we don't have one.

Jayshree: I know where you're going after this. Did your oncologist tell you about this program?

Tom Carey: No, a friend of ours looked it up on his computer, gave us a phone number and my wife called and I believe she spoke to Debbie.

Jayshree: Deborah. Okay. Oh, very nice. Good friends connection.

Tom Carey: Yes. Debbie's French?

Jayshree: Your friend.

Tom Carey: Friend. I thought you said French and that's pretty much it.

Monica Carey: Get the microphone away from him.

Tom Carey: Did you hear the one about the rabbi?

Monica Carey: He'll go into his Henny Youngman...

(Laughter)

Jayshree: Alright. We have Mike over here and Cindy. Go ahead. Please speak into the microphone, introduce yourselves. What brings you here?

Mike Ying: Okay. Yeah. My name is Mike. I'm really come with... it was my wife. Her father, my father-in-law has MDS.

Jayshree: Where is he?

Mike Ying: He's in Beijing, China. So, he couldn't be here. So, we're trying to...

Jayshree: You're representing.

Mike Ying: Yeah. We're trying to hear, learn as much as we can and identify some resources that we can use to help formally diagnose the issue and see what are the possible treatments.

Jayshree: Awesome. Well, welcome. Thank you.

Cindy Lu: My name is Cindy Lou and my father was diagnosed as MDS. I think my mother said about one year and a half ago and but he had felt tired for many, many years. He came over in 2009 when my daughter graduated from college and he came here, but he always said he was tired and only I think about 1 ½ years ago they diagnosed him as MDS RARS and also he also is diagnosed with MPN and so he's in the hospital right now and the reason he's in hospital, I think in April they checked his blood count. It was... and hemoglobin. He was like a 6.3 or number, so they said he needed red blood transfusion. After that he felt better. It went back to 8. So, we went back then back in August. So he went to the hospital again. They check it. It was 6.3 or whatever. So he got the red blood transfusion then he got some lung infection. So, he's coughing a lot right now. He's very, very tired. So in August, I went back for 2 weeks. He was very, very weak and he's in the hospital. I tried to get as much information as possible because the doctor over there she never seen this disease. She heard about it, but she doesn't know how to treat him. So basically, she's not treating him and she just give her... transfusion as supportive care. She said that there's no better way in the whole world that can treat this kind of illness. That's what she says. So, I tried to get information. My mother is also doctor and she was a doctor. She was a pediatrician. Of course, she doesn't know all this, but she is reading as much as she can. I send all this information to her. So, we try to learn as much as possible to see how we can... how maybe pass the information to the doctor.

Jayshree: How wonderful and I wish him well. I think you have captured all of the necessary paperwork to share with the physician in China and hopefully as you learn today, there are treatments available and maybe they'll be able to institute it and offer that therapy. Good luck. Go ahead, Mark.

Mark Maimone: Okay. I'm Mark.

Q1: Isn't there a center of excellence in China?

Cindy Lu: Yeah. I did reach out. I talked to MDS... Andrea, Andrea in the MDS Foundation. She give me the phone number in China and I called. They just told me the patients have to go to the center of excellence to see the doctor, but my father is too weak to go there. So...

Q1: Because I was doing some research and actually the longest amount of research connecting benzene and MDS has come out of China.

Jayshree: Interesting. I think the connection she... Cindy is definitely going to make that connection with centers of excellence which we spoke about and she's going to work on that and see how MDS can be the intermediate party to feel it out a little bit better. Yes, Mark.

Mark Maimone: I was diagnosed about a year and a half ago. The bizarre thing, of course, is I don't feel anything. So, it's a cytogenetic diagnosis. My blood levels are all a little bit low, but perhaps not enough to feel anything. So, I'm basically here to learn more about the disease, the treatments and what I can expect and when I can expect to have to intervene in some way in any fashion. So, that's basically my story right now.

Jayshree: Okay. Go ahead.

Samuel Manoharan: My name is Sam Manoharan. My wife is the patient. We know, Jayshree, we go to her many years now. So, she will expect the disease.

Ambuja Manoharan: My name is Ambuja. You can call me... the call me Mona, too. Yeah because I'm a nurse. I was a nurse. I have a (inaudible 10:29) 2 years ago, but when her, she works with Dr. Goldberg, very good doctor. I miss him. She said that he's going to leave. I'm so sorry. I hope... give him my... Say hello to him. I'm going to miss him, but when they diagnosed it in 2004 with 5Q- and I was at that time I was very scared what is it going to be, leukemia or this but then they assured me this is not leukemia, but it's kind of... Well, anyway, I got into that and I'm okay so far and I come to the meetings whenever I can to see what's the new medication, what's the new therapy, what is anything new there. So, that's why I come for new information and I'm doing okay. No medication. I took Revlimid med for 3 months and then after that they stop it. It was okay. So everything, blood count is stable and (inaudible 11:41).

Jayshree: Yes. You're status quo and the best part they're going on vacation tomorrow. I'm jealous.

Q2: Where are you going?

?: We're going on a cruise.

Ambuja Manoharan: Bermuda.

Samuel Manoharan: Bermuda.

Jayshree: Bermuda. Is that Charles? I'm sorry.

Charles: Charles. Yes.

Jayshree: Charles. Go ahead.

Charles Avalos: My name is Charles and I live in Patua (sp? 12:02) in Suffolk County, the lower end. I was first diagnosed about 2 ½ years ago with a hemoglobin of 11 during a routine physical and I was with the routine and the hematologist and the bone marrow test and everything else and it was determined that I had MDS with RARS and the first 6 months I was given the Erythropoietin, which...

Jayshree: (inaudible 12:36) of Procrit or Aranesp.

Charles Avalos: One of those which did nothing for me absolutely. Finally, the hemoglobin dropped down to about 7 and I started taking Revlimid 2 years ago which got my hemoglobin up to 11 and I've been doing quite well with it except that during the last 3 months or so it has dropped down to about 8.8. So maybe, we're reaching the end of the Revlimid deal which probably the next step would be one of the drugs that we spoke about, Vidaza or something like that.

Jayshree: Okay. Well, we wish you well. I hope that you attained some information about potentially maybe even considering clinical trial or looking into it as an opportunity.

Q2: Excuse me. Charles, you said you were diagnosed a year and a half ago?

Charles Avalos: Two and a half years ago.

Q2: Two and a half years ago and regular routine blood... that's what happened with me and you were an 11 at the time?

Charles Avalos: Right.

Q2: How long did it take to drop from 11 to an 8 you said you went down?

Charles Avalos: Just gradually over time.

Q2: Like how much time?

Charles: Two years, two and a half years.

Q2: Okay. Interesting. Okay. Thank you.

Randy Genet: Hi. I'm Randy. I am the patient advocate for my husband who is... who had anemia for a number of years before he was officially diagnosed in 2009 with the official diagnosis and he'd rather be watching the football game, but I think that these are very important moments because if you learn one thing at a meeting it's important to go forward, to have information.

Jerry Genet: My name is Jerry. I am of an attitude that life takes its chances. I was anemic many years ago. I've been off... I have not been on any drugs. We were about to go on a protocol when my wife says not for me and she marched me through 3 doctors. The third doctor said, "Let's monitor you." I'm being monitored going onto the fourth year. Am I right?

Randy Genet: (Agreement sound)

Jerry Genet: I had to ask permission. My attitude is a little different than others because of my age. I'm 80 years old. I'm going to see you next year. Will you take me on the boat? I think this is a wonderful situation whereby you learn some of the things in the experience of others. You're very fortunate.

Jayshree: Can you speak a little louder?

Jerry Genet: You're very fortunate that the nurse practitioner you're seeing right now is one of the best and that's because we've been to about 6 different sessions such as this. Sometimes it's confusing with some of the doctors or how they speak or their attitude. You're going to go to more than one. You're going to meet more than one doctor and each one is going to tell you something that you can grasp and take home with you, but you grasp a lot from the people you're with because of their experiences and your experience. Randy, my wife, is very curious and speaks to people and picks up information and that's why she'll march me to every meeting that we can get to because there's 1 inkling of information that might make her comfortable or open the door to something. At 80, there are not many doors that'd be open, but she's still trying. Thank you.

Jayshree: Thank you.

Allen Schnurman: Hi. I'm Allen. My wife is Judy. I'm the caregiver. The decision that we have to make is because they haven't had a definitive diagnosis of MDS, but they have diagnosed Judy as aplastic anemia some days and some days it's MDS and we're going over whether or not to have a stem cell or transplant and when you hear how scary it is when a doctor stands up there and says it's like being hit by a truck and then he says that one out of every two patients does not do well. I mean, this is an enormous decision and he actually said you could die from the treatment, not necessarily from the disease but from the treatment. It's truly a family decision that we're going through and it's a very hard decision for us and we're just trying to get as much information as possible. We'd like to speak to people who have actually went through the transplant process. That would be very helpful for us and that's why we're here.

Jayshree: Definitely reach out to your oncologist. I think he or she would be... and the coordinators from the transplant department would be happy to hook you up with the ones that have gone through it to talk about their experience.

Judy Schnurman: Hi. I'm Judy and I think a lot of you heard when I asked the doctor the question earlier. For me, I was diagnosed with lymphoma 5 years ago and went through a course of treatment. What was the...? ICE. I ended up with ICE, intensive chemotherapy, 3 sessions.

Each one was 48 hours of straight chemo over a 3 month period. Anyways, my lymphoma is cured, but unfortunately through a routine physical exam I had my primary doctor had retired and we had come home from a vacation in California and I developed a cough/cold for 2 weeks and I said, "Gee. I better go find a doctor in case I need an antibiotic," and through a routine blood test, she called me to say I was anemic and my platelets were low. So, I called my treating oncologist who did a bone marrow biopsy which came back negative and I just 2 weeks ago had my fifth bone marrow biopsy which came back negative. My chromosomes are normal. The biopsy is... you know, there's... is normal, so they've been going back and forth whether I had MDS which was the sort of the prevalent thought until last week I met with the transplant doctor who had done the last biopsy and now they feel it's aplastic anemia because my chromosomes are normal. So, he felt that the conservative approach right now is to do Cyclosporine and see how that works and leave transplant on the table for the future. So, it's a hard decision. When you sort of have a diagnosis, it's easier to make a decision when the doctors aren't really sure what you have you feel like, well, it's a little bit of a crap shoot. So, we're trying to get everything... learn everything we can about it. Now, we'll have to learn more about aplastic anemia. We've been focusing the last 10 months on MDS. So, that's why where here. We found out you wanted to know. I had Google bone marrow failure and came up with an organization that was called the Marrow Forum and signed onto their website and under Conferences, I found this conference and that's how I signed up.

Allen Schnurman: The only thing I'll add is if you look... you look healthy. You feel good yet they're telling you that they have this situation which is extremely serious, but you feel good. You're doing everything. You're living your life and they recommend to you to go through this procedure that they're telling you you're going to be hit by a truck. What do they want us to do?

Jayshree: It's very tough to process that. I think it takes time, but at the end of the day it sounds like you guys are still in that phase of identifying exactly what you have and that in itself is very complicated and time consuming because in the beginning I could tell you most of my patients and other patients have shared just understanding what if you have MDS or aplastic anemia or MPN, whatever three letter name or whatever you have, it's a big change, big change.

Judy Schnurman: I have a question. Do you find the doctors that specialize in MDS also specialize in aplastic anemia?

Jayshree: They do. They do.

Judy Schnurman: So, it would be the same specialty.

Jayshree: It is. It is. As Dr. Allen mentioned earlier, it does overlap. The two... three diseases, they tend to go in and out kind of, but I think ultimately it's looking at the bone marrow now which you just had and identifying what it is, what chromosomes, issues if there are any and how do you feel and coming up with... I think they suggested probably transplant as an option is because they want to have something in the back pocket in case plan A doesn't work, but you have plan B to go to and ready to go if need be.

Judy Schnurman: What I also want to add is right now I'm basically... when did we start the transfusions? I go for a transfusion pretty much like every six weeks. Six to seven weeks my hemoglobin goes below eight.

Allen Schnurman: In the sevens.

Jayshree: I'm sure that's something that you may want to, again, talk with your oncologist about to make sure. I'm sure they're monitoring your iron levels, your ferritin and making sure you don't have iron overload. Any potential patient that is considering transplant as an option, they've done enough studies to prove that patients that have iron overload meaning too much iron deposits in different organs can result in poor survival when they get to transplant. So, that's something that they have to think about before they get the patient into transplant because, again, we want them to have the best chance if you were to go through that big procedure of going through transplant and getting hit by the truck. You want to have the best odds going in. So, that's something that they definitely look at very closely. Yes, Jerry.

Jerry Genet: Has anybody suggested hypobaric chamber treatment for the patient who has low hemoglobin? It can't hurt. It'd help and is any temporary that (inaudible 24:15) then it blows out.

Jayshree: I don't know too much about the correlation or if that's something that's offered. Right now, that's not the standard, but that's something that I'm sure maybe an oncologist or hematologist may be willing to want to look at. I think it's hard enough trying to find a place that has that available. There are...

Jerry Genet: (inaudible 24:34) New Jersey.

Jayshree: Yeah, I know. In Hackensack they just open it up actually, but I don't know if they'd be inclined to want to try it. Again, it's something of an experiment somewhat. So, just know that. It's not a standard.

Jerry Genet: But it's not an evasive experiment.

Jayshree: Correct.

Jerry Genet: So, it's something that before you go through all the steps you could take a shot at if your doctor will go along.

Jayshree: I think it takes a trial, a clinical trial of some kind for patients potentially like yourself to want to participate and consider in doing it ultimately. Hey, you got to add the legality component because safety is an issue. Yes.

Jerry Genet: Think about it.

Jayshree: Good thought though.

Mary: I'm Mary from Long Island. My husband Angelo, he's the patient. I'm here to support him but also to just listen to all you guys and see if there's something that might help him down the road in the future. He's been on just about all the medicines. He's transfusion dependent, every 10 to 14 days and he's been doing that for how long?

Angelo: Six years.

Mary: Six years. So, every time he goes I say let those veins work, God, please. So, where do we go from here? That's the thing.

Jayshree: Again, use MDS Foundation as a resource if you want to go on to see if there's any trials or something that you may want to consider and participating or looking through it. It's very tough and I think everybody that has ever gotten a transfusion or two or whatever they know how long and tedious it is and it does impact your quality of life, but...

Mary: You don't travel. You really can't... try to schedule a vacation. It's like hello because you might need it on a Monday or Tuesday, but then the next time will be on Friday. So, how do you do it?

?: (inaudible 26:42).

Mary: It's every 10...

?: They tell you every 10 days. It's not like (inaudible 26:48).

Angelo: No. You go through blood tests and you go through what you're feeling at the time. If you got absolutely no energy it's because you're... it's time for you to get some blood.

Mary: And sure enough he'll go to the doctor and he'll say, "No, no. I bet you you're 9," and he does the test and he's like 7.7 and another thing. Why is it that you have to be above 8 to get a transfusion? I mean, below 8? Excuse me, to get a transfusion? Isn't it if they made it 9 at least you'd have some sort of quality where you could think. I mean, I see times he's been as low as 5.7 and walking to my amazement, but I see how... it's hard to focus when you're that low. I think that if the people in the hospital or the ones who made this determination worked on 7.7 they'd say, "Maybe we should raise this to 12," because they'd realize that it's you can't think. You can't function at that number.

Jayshree: Right because, again, when you think about what hemoglobin is it's iron and it needs oxygen. So, a combination of it working together for you to function. It depends on the institution. At our institution, we have a different cutoff, but we also make exceptions. So, I think it goes by case to case. It goes by institution to institution. I think it's something that your institution wherever you're going to will have to consider that Angelo is special. He's different. His comorbidities, his issue of having MDS is where you know what? Having a 8.5 is low for him. He needs a boost. But again, I think it's a balance of resources. Sometimes the blood transfusions, people have antibodies. It may take 2 days, 2 or 3 days before they find a match and over time there are lots of implications of when you get so much blood that you build up those

antibodies, you build up more reactions. So those are things that we as practitioners think about. That's where we come from, but we never want to impact quality of life. I think we want to offer that and take it as, again, person to person.

Randy Genet: Your patients who get blood transfusions, if they don't get them as often as what's just described can their family members donate blood for them to get?

Jayshree: Yes. We welcome any... The patient that is not first degree relative that's not going to transplant, yes. So, if you, Randy, where to donate blood for Jerry, yes, you can and we welcome it.

Q3: Does your doctor that you work with recommend vitamins without iron or multivitamins at all?

Jayshree: We do. As a basis for... my role as a nurse practitioner is to screen and identify patients that are... identify patients that need treatment, what treatment, the schedule of treatment and monitor their safety and the side effect profile and in regards to vitamins and stuff, I have to go through the med list. That's my main priority and information because I can tell you what the patient has diagnosis wise. What am I going to be looking out for? The drug to drug interactions. A multivitamin is not going to hurt you. It's a water soluble type of a therapy, but it's also very important that you as patients and caregivers that share any herbs, any vitamins, anything else that you may be taking and letting us know. I'm surprised every day that I practice that when I ask the question, "Can you give me the list of medicines that you're taking?" and they give me the list. My next question is can I have a list of vitamins and herbs or anything different? And here comes another list.

Q4: (inaudible 31:06) without iron work with the (inaudible 31:09).

Jayshree: Not really. Every patient is different. I do look at that for patients that have iron overload that I know that's an issue then I do recommend multivitamin without iron. Majority of the time, the iron is such a small component of it in the multivitamin that it does not matter.

Q4: And in your experience D3, vitamin D3, what is your experience about that with MDS?

Jayshree: I'm all for it. Any person that lives in the East Coast or actually southern part, we don't get enough sun and, of course, everybody says wear sunscreen, sunscreen, sunscreen. If you checked everybody's vitamin D level here, probably about 75 percent of all of us have levels below the norm and that's just because we live in this area. We're indoors all the time. We don't get enough even from the food, dietary wise, so I welcome any number of people that want to participate and take a vitamin D medication in addition to calcium to go ahead and do so. It's not going to hurt you.

Cindy Lu: I have a question. (inaudible 32:21) treatment, blood transfusion, do you have the iron overload issue?

?: Yes. I treat that with Exjade.

Jayshree: With an oral chelating medicine to take daily to take the iron out.

Cindy Lu: Okay and that drug is very expensive. Right?

Jayshree: It is.

Cindy Lu: You need to pay by yourself or it is covered?

?: I'm on Medicare. It has some partial coverage. I think it's been estimated my cost is going to be around \$2,000 a month.

Jayshree: So knowing that these medicines do cost significant amount of money it leads us to the next person that's going to be talking. Her name is Lauren and she works for Diplomat Pharmacy. Additional to you. Yeah.

?: I think it's important for me to just give you a synopsis of where I've been and where I'm at at this point. I was diagnosed when I was 60, 12 years ago, and at that time I was able to be treated with Procrit as the only treatment source that worked effectively very well for a period of 6 years. I had no transfusions whatsoever. Whenever my blood level got low enough, give me a shot of Procrit and it boost me up to a condition where transfusion was not needed nor recommended by the health community. Six years ago or so, I started requiring transfusions and up to this point I have tried every one of the treatments that Dr. Allen spoke about to no avail for my particular case and at this point I'm waiting for Mr. (inaudible 34:29) to come out on the board and see where I go from there. The important thing about me is not me, but the fact that I've already outlived all the expectations. I think it's important to give people hope that that will work.

Jayshree: And I welcome that and I think that sentiment is shared by everyone that is here. So, thank you.

Lauren Ganapini: Hello. My name is Lauren Ganapini. I am here on behalf of Diplomat Specialty Pharmacy. As Jayshree was kind of mentioning, our pharmacy does a lot more than just dispense your oral chemotherapy medication. As Dr. Allen had touched, some of these chemotherapies are very expensive and they (inaudible 35:21) very high copays. So what Diplomat does, we see if you guys are available for any copay assistance. There are third party foundations that are available that have funds in place to hopefully alleviate you from that high dollar copay. So, I'm really here representing Diplomat and letting you guys know that there are resources available to help with those high, high dollar amount copays and if I don't know which... most likely I won't because there's so many different avenues that the script can go down, but I'm a resource here to at least take back and help find an answer and see if we can help in any way with your oral chemotherapy prescription.

Q5: Do you have cards?

Lauren Ganapini: I have some. I do have some brochures if you like for you right now and if any questions afterwards, I do... I can share my information and we can follow up with you afterwards.

Jayshree: Thank you.

Richard Feller: I guess I'm up. My name is Rich and I live in Huntington right here on the Island, so this was easy to get to. I was diagnosed with MDS about 10 years ago. Routine physical, well actually it had gone on for a few years before that where the doctor kept saying, "You're anemic go see an oncologist," and the first time I ignored it then a year later I went and she said, "Well, some people are just anemic," and then I went to another one a year after that after he told me again and she did a bone marrow test and said that I had MDS Trisomy 8. It was a variation of it that I have. The longest time it was watch your weight. I think my hemoglobin was 11. something at that time. It got down to... I don't know, I guess in the 10s. I ended up going to Sloan-Kettering and Dr. Clement is my doctor there. It went down into the 10s and they put me on RB, Erythropoietin and I got those shots for awhile. They did a little bit in the beginning and then they tapered off on what they were doing and the dosages were increased and whatever and then I got down to a point where my hemoglobin was in the 8s and I was offered a clinical trial and I chose to have transfusions and I've been on transfusions now, I guess, for the better part of a year and I get 2 units of red blood cells every... It started out at 7. That was too far at 7 weeks. It went down to 6 and lately it's been 5 weeks and the last time I went in there, my hemoglobin was 7.6 and so I'm in between transfusions now. I'll see what it comes out to next time. That's where I'm at.

Q6: What were you feeling like at 8.5, say, or...

Richard Feller: I didn't feel bad. I didn't feel bad. As a matter of fact...

Q6: When did you start feeling bad?

Rich Feller: When I get into the 7s but I got to admit that the last time I went into the... You know, part of it is a psychological component to this, too, and I went into the City which has become quite routine now and I'm going in there and I'm saying, "Well, you went from 6 to 5 weeks then I feel pretty good," and then they did the blood test and it was 7.6 and then I felt pretty lousy and then I got (inaudible 39:16)

Q6: Just after the blood test.

Richard Feller: Just after the blood test. So on the other hand when I leave there, I catch a bus and I go out the side door when I go to the hospital and quite often I'll run for the M4... the M66 bus.

Q6: Run?

Richard Feller: Yeah. I can... it's downhill and that last time I was moving a little slow going down to the bus. I just think there's a lot to this and there's a lot... there's a psychological part.

When I get down into the 7s, I can feel it... I don't get winded. I can feel it in my throat. I can feel throbbing in my head, but... when I exert myself, but that's kind of the way it is. That's where we're at now.

Jayshree: Have they offered any therapy to you that you aren't considering or is what made you want to do transfusions and not consider a clinical trial?

Richard Feller: They offered me a study that was... that involved Revlimid and something else. APL? And I read that. The APL I'm not worried about. The Revlimid thing, I read that and all the side effects for this stuff and I said, "I can have all these problems or I can have a transfusion." I had like no life and I decided that I'll save the problems for later and but by the way, my iron is now up to... it was 1,100 or 1,200 or something. So, I didn't see the doctor last time. I saw the nurse or the nurse practitioner and in 3 weeks or so I'll see the doctor and I wouldn't be surprised if we had a discussion about... I will have a discussion about the iron.

Jayshree: Overload.

Richard Feller: Yeah. I'm very... That's where I'm at.

Jayshree: Yes, ma'am.

Q7: I've been hearing that can do the transfusion because I'm still (inaudible 41:32) I'm like six weeks (inaudible 41:34).

Richard Feller: I think it's been about a week... about a year. I haven't really kept track of that, but I think it's been...

Q7: Did Dr. Clement recommend any type of transplant or (inaudible 41:48)?

Richard Feller: She said I'm not ready for that and that if I was in need of it, this was probably 6 months ago, she said that if I was in need of it, she'd recommend it, but she didn't see me as being ready for that now which since I was 67, I thought it was encouraging that she thought I was that healthy. I don't know whether for another 3 years or something which she recommended then I don't know, but that's where I'm at. Right now, my concern is the iron and that those intervals are getting to be shorter between transfusions. It's always 2 units of red blood cells. It's a day.

Jayshree: Go ahead, Caroline.

Caroline Feller: I'm Caroline. I'm married to Richard. I came just for more education and to find out what was new in terms of treatment and so I'm here.

Jayshree: Welcome. Go ahead, Toby.

Toby Cohen: I'm Toby and I originally before I got sick, had a hemoglobin of 15, which I had my entire adult life and then in 2002, I was feeling very fatigued and I went to the doctor and my

hemoglobin was 10 and from 2002 until 3 years ago, my hemoglobin hovered between actually 10 and 11 and then within the last 3 years, it started drifting down or it didn't drift down. It sort of leaped down to 8 and for the last 3 years it's been hovering between 7 and 8. So I'm fascinated by the fact that you say you felt absolutely no symptoms whatsoever because my initial symptom was one of the longest fatigue and it felt different than the fatigue of depression or just general stress or exhaustion. It was a very specific kind of fatigue and I noticed that when my counts go low, my legs start feeling very heavy. You feel that? Yeah. Like each thigh feels like it weights 300 pounds and then I get a transfusion and that sensation goes away. I have some questions if you don't mind.

Jayshree: I do want to get to the last three over here. Do you mind if you wait for two more minutes?

Toby: Sure.

Jayshree: Regarding the questions and I'll them... I just want to cover everybody because I want to... Go ahead.

Betty Popp: Hi. My name is Betty. I'm here with my daughter, Elizabeth, and my son, Frank, and this is a couple of one liners, I think. You mentioned it's difficult to remember what you have, the name of the disease. The way I finally remembered it was another thing we say about a doctor is he's an MD. So, MDs now... that was the way I finally remembered that. I've had... but I never forget it now. I... about two years ago was when they first diagnosed through a routine physical and starting in the beginning of 2012, I started under and remain under Dr. Allen's care and I, too, felt fine all along and thinking, "Oh, this is... This is no big deal. I can live with this," and I worked part-time four days a week until September of this year. I didn't have any... I probably had transfusions over that period of time, but I did not start taking Vidaza and every once in awhile my daughter will say Viagra, but I know it's not. I didn't start taking Vidaza until...

?: You've been on three treatments three months ago.

Betty: Yes. July of this year and I deliberately did it on my vacation because I wanted to make sure how am I going to feel after it, right, and just take needles in the belly. That was no big deal. Be conscious of nausea and what they do, they'll give you a pill in case you feel nauseous but now I have them trained that they give me a pill before I take it and I have my own supply of pills that I take one later on in the day because that first night nausea was horrible. Be conscious of other medications. I had breast cancer... stage 0 which if you want a stage that's the best stage you could get and it was a lumpectomy and they put me on Tomoxaphine. Tomoxaphine, they give you for 5 years. I thought that was wonderful. They expect me to live 5 years. So you stay on the Tomoxaphine for 5 years and that's supposed to guarantee you don't get breast cancer again and by the way unlike Robin, on mine had nothing to do... there was connection with the 2. However, the write up and I read these things religiously on your medication said that Tomoxaphine and, aside, all my counts are lowered. My white, my red, my platelets. They said for Tomoxaphine, in rare cases but especially for someone with low infection fighting which would be white counts can cause you to lower your platelets and lower your white cells. Those 2,

right, and so I thought maybe this is the perfect storm. I'm getting Vidaza which is lowering my counts. In the meantime, I'm taking the Tomoxaphine which is also lowering those counts and I said could it be that for me it's the perfect storm. So, I spoke to Dr. Allen and we agreed that for 2 months I stopped now, just recently, I stopped taking the Tomoxaphine. Oddly enough, oddly enough, but anyway, my platelet count is normally... if it goes 15 then they give me platelets, right, but and I save all my sheets. I make sure I get a printout every time my counts come in, right, and so I had a printout of this day and it said my platelets were 41. Forty-one. I was all excited and it isn't that I had a... it isn't that I had platelets. It's that I had stopped the Tomoxaphine for about a week. The next day, it was like 15 and I didn't speak to Dr. Allen about that yet, but I said, "How was it possible to go from 41 to 15 in a day?" So the nurse practitioner said, "Well, maybe it's just you're picking it up." I said, "Yeah, but something dashing it right down," and so I have a suspicion that Tomoxaphine could be making this worse, this count, and those are the things you have to... It's kind of insist upon. I'll say, "Well, read this. What does this say?" and then explain it to me in another way. Okay and my biggest thing right now, again, I felt fine in the beginning and say, "Oh, I could live with this." My biggest thing is shortness of breath because, again, I just left work recently. So of course, I have chairs all over my house because if I go 3 feet and it's too much, I sit down in a chair. It's like musical chairs all by myself. So anyway, that's my story.

Jayshree: Thank you. Go ahead, Toby.

Toby Cohen: I have three questions for you and one for Cindy. How much vitamin D do you suggest?

Jayshree: Sure. So, the recommended dose for vitamin D for any patient, any person, is 800 units... 8 or 800 international units. You can take a higher dosage for different reasons. Now, the best way to analyze and figure out what dosage you should be taking is by making sure your physician or somebody checks your level first to determine what other dosage. For now though, you can do 800 and then still have your doctor check out the blood level, the vitamin D level, and then determine another dose. There's no side effect.

Toby Cohen: Second question. Should we be taking vitamin B6 or B12 or a multiple of B complex?

Jayshree: Sure. So, I think if there is a concern about vitamin deficiency, I think that conversation should be definitely done with a practitioner and going over your concerns and have them evaluate what medicines and vitamins you're taking currently to come up with a treatment plan for you as an individual because Betty may not have vitamin B12 deficiency versus you may. That can be checked by blood level.

Toby Cohen: Because my first hematologist at Memorial felt that regardless of one's blood level of B12 or B6 that every patient who had MDS should be on Pyridoxine but then other hematologists have said to me at Memorial, "I've never seen it work."

Jayshree: I think taking a multivitamin for every patient 1) if you're able to swallow and take it and remember to take it, it's sufficient. I think if you have a good diet in place, that's also good,

but if you have other comorbidities such as an inflammatory problem like rheumatoid arthritis, lupus or some other issues that may be depleting your vitamins potentially then it's something of a conversation that you should definitely have with your practitioner about it and say that do I need to? Can I? He or she may not know the answer, but they may refer you to a dietician or a nutritionist to evaluate and figure out a treatment plan appropriate for you as a person.

Toby Cohen: And my last question for you is on one of the slides that you put up when you said that one of the blood tests or testing that should be done for somebody who first presents with low blood counts, is a renal profile. Now, what does that involve and why would that account for a low blood count?

Jayshree: Sure. So the renal profile is the part of the whole package of a workup for any patient that comes through the door in addition to a CBC. The renal panel, the renal analysis, is a kidney function evaluating and the two part deal for the kidney is the BUN and creatine. The BUN stands for basically an analysis of an immediate issue of the kidney if there is one. The creatine level tells you how good the kidney is functioning in the long haul. The BUN gives me a nice synopsis, oh, you know, Toby's kidney right now is working, but it looks a little dehydrated by a certain number with the standard level. The creatine is a longer acting analysis of the kidney and the long haul and I look at the numbers, again, range. Why? It's to determine whether the patient needs hydration, do they need an evaluation by a nephrologist? So why would those numbers be low or high, rather, not low, but high. The reasons could be because the patient has had anemia meaning low hemoglobin. If your tank is half full, if your hemoglobin is eight or seven or something, you're still stressing your entire body, your other organs and saying keep on working, but you're running at half the speed and the kidney is saying I'm tired, give me more, give me more blood, but there is no blood to go around. So, it's stressed out. So, that's why the number shows up the way it does. So until it's fixed by either a treatment or a transfusion or some other modality maybe even just hydration. If I asked around the room how much people think they drink water or fluids, you'll be surprised. "Jay, I drink enough." Okay. Well, let's look over here. We got one can over here. Mona might say, "Jay, I drank..." maybe it's not a can of water pretend. She'll tell me, "Oh, yeah, Jay. I drink about three cans of water a day." That's certainly not enough a person at her size and her stature for her to be drinking. Again, that's something simple, but it's meaningful for the kidneys, other organs, to have to consider and have. I'm going to go... You have a question?

Q8: ... just follow that up with why do people on dialysis get Procrit? I mean, what's the relationship between the kidney there and the blood count?

Jayshree: It's the same concept with the EPO. EPO is made in the kidneys and what it's telling is the body to churn out more red blood cells and saying let's go, pick up the pieces, let's get that...

Q8: But that's not MDS.

Jayshree: No. That's different. It's a kidney related anemia. It's separate than MDS because it's just a kidney related anemia. The white blood cells and the platelets, they're normal. If they did a bone marrow on that kidney patient, kidney on dialysis patient that bone marrow will look normal except for low hemoglobin. That's it. Go ahead.

Q9: I just wanted to share, I work for the same health system that Dr. Allen works in as well and as I go around and tell people about my mom's diagnosis and you might have had a similar experience, they'll say, "Is there anything I can do?" and right now you may or may not be aware we are critically low levels of blood in New York State, probably throughout the country. Donating blood is so easy. I've been donating for many, many years. I happen to find out recently that I'm pregnant and cannot give for the next couple of months, but I just want to say if you have people that really care about you and say is there anything I can do very simply to say, "You could donate blood." It makes such a... you can hear in this room how many people are dependent on those transfusions on a regular basis. If you have O negative, that's what I have. Right now, they are desperately looking for O negative blood. So, just one of the things to keep in mind and to share with other people that want to help you out. The other thing really quickly is that people feel differently about this, but my mom has decided to go ahead and do it. Donating your body, nobody really wants to think about the very end, but the (inaudible 59:35) Health System and many, many other health systems and hospitals have medical schools that they work with that can really learn a lot, the doctors can really learn a lot from using the bodies of people that do donate. So, it's just something to keep in mind and it's a very easy process. It's a simple, one form.

Q10: And it's nice. They'll either return the ashes to somebody or they'll throw it at sea. So, I picked throw it out at sea, but it's a good thing to be able to do that because it's so far away from a cure and they need to be able to work. So, I did donate to Hofstra.

Jayshree: Very nice. Thank you. Thank you for your comments and sharing ideas. Yes.

Q11: You gave a good point about the B when you said so when you have anemic, if you're anemic the BUN goes high up?

Jayshree: No. There's no direct correlation with that. The BUN tells us the body is stressed and it could be related to dehydration.

Q11: Like you said, if I'm drinking a lot of water, but still my BUN is a little high up.

Jayshree: A little high is okay.

Q11: And the creatine and is good. It's normal.

Jayshree: Then that's fine.

Q11: So, that's okay. It has nothing to do... because I'm the anemic, blood, hemoglobin a little low...?

Jayshree: If it's a little low then there is a correlation but the creatine is a long acting evaluation. Again, that we're looking at.

Q11: So creatine then is normal so it's okay. Alright. Thank you.

Jayshree: Yes.

Q12: Could you explain the relationship between the red blood cell count and the hemoglobin. Everyone talks about hemoglobin levels. I have low red blood count, but my hemoglobin isn't that bad. So, I get a little confused.

Jayshree: So when we collect a blood sample on a patient, we basically collect one tube. What we send that tube over to is a laboratory. The microscopic... the laboratory technician, what they do is they take one droplet or they really don't do that anymore. The machine does everything. What it does it analyzes one droplet and puts it on a slide. In the slide, it looks at basically an analysis of 1 by 1 centimeter. Think of it that way. It's a quick picture of who Mark is underneath and it looks at and figures out there is 100 cells of red blood cells. There and with that they have a formula to calculate your hemoglobin. So, it's basically a small synopsis of how many red blood cells in 100 cells or 1 by 1 centimeter picture.

Q12: So, they're directly related to each other.

Jayshree: They are. If they want to look at how many cells you're making. The other test that you should be considering and that was listed on the analysis is the retic count. That's a bigger picture. Don't focus on the RBCs. I know that people tend to look at the CVC and they're saying, "Low, low, low, low, low, low," focus on the three big things which is the white blood cells, hemoglobin and platelets. Ask your physician to do every now and then the retic... Reticulocyte something like that. I'm spelling it wrong.

Q12: Close enough.

Jayshree: Yeah. Close enough. Retic. R-E-T-I-C. Retic count. That's okay. I can repeat it. Retic. R-E-T-I-C and what that test is the blood test, okay, and what that is basically an analysis. It's a quick overview of how good your bone marrow is functioning in making your red blood cells. So, those are baby red blood cells. So if your bone marrow is not functioning and saying let's turn it up that number is going to be low, okay, and if it's making enough, it's going to be within the normal.

Q13: What's the normal range?

Jayshree: I think it's .4 to something... 1.6, but any laboratory that you go to will have their own range and just follow with that range. I truly apologize. We've run out of time. I think we have to actually exit because there's another conference happening in here. I thank you for your introductions, sharing your stories. Again, I know that we didn't have much time about questions and answers. I know we want to continue this conversation and I hope to share this, again, this conference in the future through MDS Foundation and maybe at that point we can just have Q&A and that will be good, but again, thank you so much for coming and attending this.

(Applause)