Courtney D. DiNardo, MD, MSCE
Jayshree Shah, APN-C, MSN, RN, BSN, BS

Q1: There's two different kinds and the problem was I was too old to get a transplant (inaudible) according to my (inaudible). Back then or now. Well, let's go back (inaudible). Go forward but I (inaudible)

?: But it's ten years.

Q1: It's 10 years. So, I was 67.

?: That's young. That's still young now.

Q1: Well, they didn't then.

?: There's no official (inaudible) certainly the older you are, the higher (inaudible). Certainly, I've' seen some people (inaudible) be in excellent shape and willing to (inaudible)

Q1: Well, I don't really whether I would have went that route or not. We talked about it. She (inaudible) my medical history (inaudible).

?: (inaudible)

Q1: Because some people when they get them it's like starting all over because you've got that transplant which is to make for that person whatever immune system they had, whatever history they had.

?: (inaudible)

Q1: I don't know if you recall Robin Roberts had that transplant. I was really disappointed because they did like an hour and a half to two hour program and it was all on her. They had a chance and an opportunity to make the people aware of MDS, the problems with it, the need for research and a lot of other things. They didn't even take one minute to talk about that. It was all about her and I wrote them a letter. I wrote them a really nasty letter and…

?: Who did you write it (inaudible)?

Q1: I wrote it to the station. I was (inaudible) people would have written a letter to the station. I mean, I didn't care about… Good for her if she got one, but if you spend five minutes on that and then spend another hour talking about MDS which is unknown to 200 million people and they need to know about it like they do other (inaudible). Anyway, it just irritated me and I got… I sat down at my computer and told them what I thought of them.

Jayshree Shah: That's why the answer is (inaudible).

Q2: Breast cancer is very simple. I mean, you cut it out. It's a hard tumor. It's solid and whereas the MDS is a chronic cancer. People don't understand the concept of chronic where it matches the (inaudible). So…

Courtney D. DiNardo, MD: Blood cancers are very difficult to explain to family members (inaudible) because, you're right, it's very different than solid tumors which (inaudible). You can't see MDS really or leukemia (inaudible) you have them. (inaudible) MDS is not as we know it not be curable (inaudible). So, everything else is (inaudible)

Jayshree Shah: I want to (inaudible) Dr. DiNardo. I'll let her do some (inaudible). I am out from Jersey. My name is Jayshree and (inaudible). This is very informal. Kind of like your special day. We're here because you guys wanted 1) to have us come over and speak with you concerns, costs or ideas or how to be more understandable. So whatever questions or concerns or just tell us your story. Whatever you want to do today it's up to you.

Courtney D. DiNardo, MD: (Inaudible) have folks go around and just introduce and say… you guys feel comfortable. If not, we can just (inaudible) say who you are and what you want to (inaudible)

Q2: Well, I'm (Attendee) and I was diagnosed in '04. So, I've been living with it for 10 years now. The first eight years, I was with a well-known Houston hematologist and my treatment basically was with a shot called Aranesp and it's something that stimulates the bone marrow in producing additional red blood cells and what happened to me over the first eight years is the frequency of me going to Methodist Hospital to receive the shot, you couldn't get them in the doctor's office because Medicare forces you to go to the hospital rather than a doctor's office. So, the frequency increased as well as the dosage. So, it got to the point where I was going every two weeks at a maximum dosage and at that point…

Courtney D. DiNardo, MD: And still needing transfusions?

Q2: Pardon?

Courtney D. DiNardo, MD: Where you needing red cell transfusions also?

Q2: No, this was just… this was off campus and at that point the hematologist mentioned chemo and because I've been here before for another situation, I looked up MD Anderson and I did an analysis of all the MDS doctors that were practicing here.

Courtney D. DiNardo, MD: And I wasn't here by 2004.

Q2: And I researched Dr. Garcia Manero, and I wrote him a two page letter telling him why I needed to come over here and see him personally. So, he accepted that and we got together and talked and so I've been his patient for two years now.

Courtney D. DiNardo, MD: Were you at least were working with (inaudible)

Q2: I'm retired. I was in the oil industry. The oil service sector, not a Shell or Exxon but a service company, Baker Hughes (inaudible). So, we provided the tools and the means of getting the oil out of the ground. So, I was in manufacturing, marketing, finance and corporate assignments. So, I was in all facets of the business and I trained people around the world.

Courtney D. DiNardo, MD: Are you still able to work?

Q2: Oh, yeah. Well, I don't. After 30 years on the merry-go-round as a consultant for 10 years and then I decided that was enough. So, I've been retired now for, I guess, 15 years.

Q3: (inaudible) retired.

Q2: Yeah. It's nice. My wife works part-time. She's a realtor. She's been a realtor for 35 years and that subsidizes our living in addition to Social Security and retirement. So, that enables us to do the things that we used to do when we both worked.

Jayshree Shah: I do want to tell you that this meeting is recorded for the purposes of (inaudible) there as a need for MDS (inaudible) number one, and also to… We share our communication forums all around (inaudible) and we get all the (inaudible) and things from patients and caregivers and we like to collect those tickets and put them on file and then kind of develop a presentation for whether it be for patients or other organizations. So, I hope that's okay with you guys. I wanted to tell you that. It's (inaudible) for information. Just for reference. (Inaudible), it's nice to meet you. Thank you.

Q2: I'd like to make one more comment. If you don't have all of your E-mails you should because I filled out those surveys that you always send out and that's got a lot of interesting and valuable information time wise.

Jayshree Shah: (inaudible)

Q3: My name is (Attendee) and am I guess, a caregiver. My husband is the patient who was diagnosed last October and he has been on the (inaudible). He is our doctor's star patient on Vidaza. He has responded to it extremely well. He had one blood transfusion right after he was diagnosed in October and has been doing just really, really well. I call him my cat with nine lives because he's had five stents, he's got a stomach aneurism, a knee replacement, two knee

replacements, a hip replacement. He's had lung cancer (inaudible). He has COPD and emphysema. So, he's my cat with nine lives and somehow he's doing well on this Vidaza, very, very well. He just got out of the hospital this past Tuesday. So, that's the biggest thing that… (Inaudible) he was hoping to come today, but he just got out of the hospital. He just (inaudible) I need strength. (Inaudible) Vidaza is wonderful. His doctor and oncologist how long (inaudible) as long as it works. So, it's working (inaudible)

Courtney D. DiNardo, MD: That can have a very difficult concept, I think, for patients and family members is that we don't stop the Vidaza or the Dacogen or just (inaudible) that's working. It becomes your… You were explaining it to a chronic disease… It becomes your insulin if you have diabetes. It keeps going because you know because if you stop it, almost invariably within a couple of months (inaudible). So, it's not cure it, but it's teaching the bone marrow to make the cells correctly again. So, it's a modulation process that keeps going.

Q3: (inaudible) Well, I'm just sending you home with your antibiotic (inaudible) three weeks and he just went crazy. He kept waiting (inaudible) hematologist and oncologist so he could talk to them and because the pulmonary doctor (inaudible) says, "Well, if I give you the antibiotic and you're taking the Vidaza that's just going to counteract. We're not trying to (inaudible)," and this oncologist said, "No, we're here (inaudible) seven days on, 21 days are off.

Courtney D. DiNardo, MD: And so a lot of people who are not involved in blood cancers don't realize that Vidaza and Dacogen aren't really intensive chemotherapy agents that (inaudible). So, a lot physicians are thinking I'm going to start doing therapy. It's going to drop his immune system and pneumonia is going to come back. In some patients that happens the first couple of cycles, but other patients are…

Q3: It pisses him off. (inaudible). He said once if you were not to take the Vidaza, we'd never get you back to that level. (Inaudible) So, I'm just kind of here to (inaudible).

Courtney D. DiNardo, MD: Thank you.

Q4: Good morning. I'm (Attendee) with Diplomat Specialty Pharmacy and I've only been with the company a few months and I was coming to learn about the disease and little did I know my father-in-law was diagnosed with MDS a little over a year ago and my wife is a pharmacist and his wife take very close care of him. Of course, we live in Michigan, but from what I understand that Aranesp is what he's taking and he only gets a shot once a month if he needs it and he doesn't always need it. So, it seems to be working really well for him so far and he feels much better since he started therapy, but it hasn't been that long and I'm… He's about 87 and kind of stubborn. He's been through liver cancer, heart disease, so many surgeries I can't recall. Each one of them could have been very fatal and he's bounced back with flying colors just like he bounces back again. So, he's quite (inaudible) man and I really have full interest in this disease

knowing that (inaudible) was diagnosed with it and how our business might be able to be beneficial in the future. So, I'm just glad to be here.

Courtney D. DiNardo, MD: I'll make a comment based on what you said. So when we talk about MDS, they have (inaudible) I'm seeing a patient for the first time is going to be what is MDS. MDS is the cancer of the bone marrow and your bone marrow is in charge of making (inaudible). It's in charge of making your red cells which is what circulates your oxygen, gives you energy. It's in charge of your platelets which is what keeps you from bleeding. So people with MDS have low platelets, a low hemoglobin and then your white cells which is your immune system. So, that's what your bone marrow is in charge of. So, that's what is affected in people who have MDS.

Why do people get MDS? Sometimes it just happens. It's as we grow older and as your bone marrow has been in charge of making all these cells (inaudible) a lifetime. Your bone marrow can just get tired really and it can just stop making cells the right way. MDS, dysplasia, just means abnormal looking. So, it just means you're making funny looking cells. You're making them. You're making the red cells and the platelets and the white cells, but they're just not functioning the right way on your bone marrow and sometimes they get stuck in the bone marrow and don't circulate as well, the circulation, so that's why the counts are lower in the peripheral blood even though we have it's called a hypercellular marrow and you got too many cells in the bone marrow, but they're not working the way they should and they're not being released and so some people get MDS as a consequence of a lifetime and exposure and some people have benzenes or certain occupational exposures. We see a higher risk in airline pilots who have been exposed to a lot of radiation. Sometimes it's chemotherapy for other cancers. You mentioned (inaudible), so I don't know what he was treated with but a lot of times the chemotherapy that you get for other diseases we know it affects the bone marrow because the counts drop after chemotherapy, but it's affecting the bone marrow and it's making it… more damage really so that decades later now that we've done a good job at treating the primary cancer, we're (inaudible) secondary therapy related (inaudible). When we have a lower risk MDS where you have sometimes an isolated low blood count. So, red cell counts, the growth factors, Procrit or Aranesp sometimes do very good and all you need initially and it just improve the counts enough that you're not needing transfusions. So, that's a very effective strategy for some people with lower risk MDS not so effective in higher risk MDS. So someone who might end up on high risk (inaudible) but that wasn't offered to you and there's a reason. There's a population that it is very appropriate for and there's a population it's not.

Q5: Good morning. I'm (Attendee) from Celegene. I'm just really interested in opportunity to hear to your stories and your (inaudible). It really helps me learn about you guys. I really mean that (inaudible). I have not had any personal experience with MDS with regards to the family perspective, but I have had friends that have been diagnosed with MDS. A friend's mother was misdiagnosed in… 10 years ago and we had a lot of therapy (inaudible) now. My family has been touched with other forms of cancer. So, I'm always just… I feel so… I don't know…

(inaudible) your experiences that I know what really mattered and so I (inaudible) particularly know what is important (inaudible). Nurses, pharmacists, (inaudible) my healthcare providers that need to know more information about products that we have and so I just really (inaudible). If you have any questions, (inaudible)

Q7: Are you with Celegene over at (inaudible)?

Q6: No. I'm with Celegene Biotech with the pharmaceutical (inaudible) Revlimid. They're (inaudible). I'm not here to discuss… We do have a new online system now which will fully… You guys are able to do your patient surveys online now. So, that's just quickly… that's very helpful. (Inaudible) made a huge impact (inaudible) where they are (inaudible). Does anybody know why you have to go through this grueling process?

Courtney D. DiNardo, MD: So, Revlimid is Lenalidomide which is another appropriate agent for a subset of MDS patients which tends to be people with isolated chromosome change that's called a deletion 5Q. So, there is a cohort of MDS patients who have an isolated 5Q deletion. They tend to have a very low red cell count, but sustained platelet count, a white cell count and so there's a cell called Lenalidomide or Revlimid that is very effective for that subtype of MDS. So, that's what we're talking about, but it requires a lot of back and forth getting approval for it because… I'm going to steal your thunder (inaudible) generation of Thalidomide. Thalidomide being the drug that many of you may remember called (inaudible) baby syndrome when pregnant women took it for nausea and so it's very carefully distributed to people at any age, but in particular patients of child bearing potential. So, there's a lot of checks and balances in the distribution of that drug.

Q6: Thank you for coming.

Q7: Good morning. My name is (Attendee). I'm a librarian in the Learning Center here at MD Anderson and actually I wasn't supposed to be here today. I came in to catch up on some more (inaudible) and I thought my God, how did I miss the patient conference and I'd like to come to these patient conferences because I always like to keep updated in what's going on in a particular disease and also because like (Attendee), I realize that a person (inaudible) once you're face with the disease when (inaudible) some of you really want to know the disease and so we impact the family, caregivers, how to deal side effects, how people deal with a chronic disease and I really get a feel for that allows me to be in contact with the patients and the caregivers. So, that's why I like to come to these. I really wasn't on your list, but I figured since I was downstairs I would come up and I'd find out as much as I could, but the Learning Center is actually a consumer health library here at MD Anderson. A lot of our patients that come here for years don't know about it. We are currently located on the fourth floor across from the A elevator. I don't know how many of you are MD Anderson patients, but what we do is we provide people information. We do database searches. So if you wanted to come in and you wanted like the most recent paper

that (inaudible) that for you. A lot of times the docs will (inaudible) and then we also provide people supportive information. So, I just wanted you to know about that.

Q8: With all the information (inaudible)

Q7: It's called the Learning Center as opposed to the patient family or a public library. That's where people get their (inaudible) and they come here and there's also another Learning Center in (inaudible), but we tend to focus on MDS and the blood cancers because actually those clinics that (inaudible) and then the Mays Learning Center focuses on the (inaudible) that are located (inaudible) whereas (inaudible) cancers, but please do come by. We're open Monday through Friday 9:00 to 4:00 and we're happy to help you in whatever way we can.

Jayshree Shah: Do you have a contact phone number or have to (inaudible). Maybe you can give it to me during the lunch hour?

Q7: Absolutely. Also, we also have a new reference service that people can actually (inaudible) information.

Jayshree Shah: (inaudible)

Q9: I actually had a question was for providing contact information. It's (inaudible)

Q7: I'm trying to think of our reference service. It's www.(inaudible) MDAnderson.org at TLC Staff@MDAnderson.org. Can you just put a phone number down there (inaudible). It's (713) 745-8063 and that's the number of the library here in the main building. Thank you so much.

Jayshree Shah: Thank you.

Q10: I'm (Attendee). It's her story to tell, but I just wanted to comment. I appreciate your definition of MDS a little while ago because I'm one of those that if you give me things to read and I would read (inaudible) it's too much and then always (inaudible) percentages and I didn't want to read percentages. So, I just put the book away because they're not (inaudible) necessary to read are not that great. So, I let her just…

Courtney D. DiNardo, MD: Especially why I don't really want to (inaudible) because there's an understanding of the disease and there's… and so in some people it's very helpful to know all the numbers and I'm happy to give that to patients who are interested, but some people don't really want to know that and again remember that odds are population based. You know, looking at thousands of patients and saying what we think (inaudible) for our general (inaudible) but every patient is very different and so who's to say that you're going to be that person. So, I dare not (inaudible)

Q10: And then the other thing is during this discussion, the one thing that's being… I consider myself a caregiver, so I'm not that… but anyway, (inaudible) that the year since she's been diagnosed, one of the issues that we (inaudible) MD Anderson (inaudible) so it's like this is where we're going to go (inaudible). At Methodist was diagnosed, but so we have two premier doctors on the MDS side and on the transplant side, but some of the discussion about when to go and not… that was very stressful watching blasts versus cytogenetics and I'm talking like I know what I'm talking about, but the point is that was probably one of the more stressful and difficult times from last year. Anyway, that's just… take the discussion, but I'll let (inaudible). She's the one who has the story to tell.

Q11: Okay. So, I'm (Attendee) and I'm the patient and I was diagnosed on September 6th a year ago with MDS, but (inaudible) whole had MDS (inaudible) because I was seeing hematologists in med centers (inaudible) for what appeared to be a low platelet count and he had diagnosed me with idiopathic thrombocytopenia, ITP… and that just means a low platelet count and the way he described it I never remember being frightened or afraid that it was going to be cancer or none of that and he had been treating me with Promacta which is supposed to simulate…

Courtney D. DiNardo, MD: So, a platelet growth factor (inaudible) Aranesp or Procrit which is a red cell growth factor.

Q11: So, yeah. So it was stimulating my platelets and so as long as… I mean, he gave the option. He highly recommended that I had a spleen removed, my spleen remover, and or and I said (inaudible) medication and he did a bone marrow biopsy I guess that he gave at that period, but he never did a biopsy, but anyway…

Courtney D. DiNardo, MD: Did the Promacta work?

Q11: It was stimulating it. I mean, it wasn't like… (Inaudible) any doubts (inaudible) so it was probably… He said this is fine. Don't worry about it. It's supposed to be in 154,000 (inaudible). So anyway, so this (inaudible) and I wasn't feeling bad at all. I didn't really have any symptoms. So, we were just kind of… I was kind of was plugging along and a lot of times I was like do I really have to take this medicine? It's so expensive and so then finally I saw him in April of that year and he mentioned this splenectomy and I was like… and I left there and I told him well, I just want to really consider that. So, I left there thinking you know, I really should get a second opinion before I have the surgery. I just don't have surgeries without getting second opinions. So, that was when I reached another doctor (inaudible), another hematologist and she looked at my blood work and she had to get… she wanted me to get her all the background information and she was the one who said, "I'm really concerned about your white count not just your… and when you saw the doctor back in April," (inaudible) by then it's August, my white count was (inaudible) low, real low too. So then she was wanted to get another bone marrow biopsy and she diagnosed the MDS. Lo and behold looking back, I went back to the first bone marrow biopsy, which I never received a written copy of. They told me over the phone it looked fine. That's

what I remember, but when I looked back at that biopsy and said under the diagnosis it said indicative of MDS, but I was never told that I had MDS all along. At that point, it's probably low risk MDS I'm assuming. That's only one (inaudible) just being affected. There were no chromosomal issues, but by the time that they get the MDS that second time in 2013 there were no chromosomal issues, but the platelet count was down to like 12 percent and under my (inaudible) said it was 12 percent. So, in that short amount of time I had… well, short amount being three years with MDS, I guess, that could be a long… but and then when I got that diagnosis I sort of researched it and found Dr. Garcia Manero and so that's how I ended up here because I wanted to get a second… Now, I had two opinions. One being that I didn't have MDS. Another one saying I did have MDS. So, I needed to get somebody else confirming that I do have MDS and what their opinion would be and that was Dr. Garcia Manero because he was here and close and he had done some research on it and anyway that's where I had stayed and by then when he did his initial… when we did the initial because they wanted to do another bone marrow biopsy here (inaudible) so and that was just maybe three weeks later it was already showing a chromosomal issue. I don't know which puts me at a higher risk of MDS which meant I cut off a year and a half of life expectancy. It was really a concerning diagnosis at that point, but they all geared me towards having a stem cell transplant because of my age and the high risk factor. So, that's where I went and had my stem cell… I had pre-chemo with Vidaza for about three, four, five months (inaudible) and then I went in to the… had my stem cell transplant. Now, I'm five and a half months… five months and 26 days post-transplant.

Courtney D. DiNardo, MD: (inaudible)

Q11: I'm really great and I haven't had any blood (inaudible) since I left the hospital. I had (inaudible) and the doctors were all very happy with the (inaudible), but Dr. Garcia Manero… The first doctor at the other hospital medical center had said that you're prime candidate for a stem cell transplant. I was (inaudible) result at the time, but and she said the only chance of cure, but when I got to Dr. Garcia Manero he was like, "Well, I don't like to use that word 'cure' with MDS." He says, "I'd be like it always come back. It's just the fact that you're so young," he said, "It could likely come back (inaudible)." So anyway, so he gave an excuse that (inaudible) whereas other places I was hearing (inaudible) transplant would be the cure. That might be a different (inaudible) also if you (inaudible) Robin Roberts they say cure (inaudible) stem cell transplant and so I think that (inaudible). It's a tricky word because I always and even my stem cell doctors will say 'cure.' So, there were different… One of the big…

Q10: I use cure. I'm good with that.

Courtney D. DiNardo, MD: It's really hard to explain to people who don't have a lot of understanding if you don't use that word 'remission' or 'cure' because people just never really understand how am I… How do relate? It's challenging.

Q11: Yeah. Well, and so I do like to get every time I ask somebody or hear that come out of the doctor's mouth a lot of times they would say what do you mean 'cure.'

Courtney D. DiNardo, MD: And then they probably hem and haw.

Q101: Just what you're saying (inaudible) one of the very big challenges in that (inaudible) period where I was going through the chemo and going through to try get my blasts down. That was a big… because I tend to delve into the facts and I like to know get literature and he kept on saying, "Will you stop? It's just making you depressed," but the chromosomal issue I had was Trisomy 8. So, it's not that bad of a deal of a chromosome issue, but it's there and so it was… and so Dr. Garcia Manero said, he's wonderful (inaudible) trying to get the blasts down as low as he could whereas the stem cell doctor the only thing I wish there was more of a meeting of the minds. What they felt like and what the leukemia (inaudible) they kept (inaudible) the chemo doc kept on saying let's go for… let's get the blasts low as possible, low as possible. I don't know if he ever thought that (inaudible)

Courtney D. DiNardo, MD: Sometimes. Not always.

Q11: I was on actually a study with Vidaza and Vorinostat. I don't know if I was (inaudible) I didn't have any side effects.

Courtney D. DiNardo, MD: So, It was the Vidaza plus/minus Vorinostat. So, some people, 50 percent of people got Vorinostat and some people were getting placebo and it was completely blinded. So, two physicians and patients didn't know what they were getting or not.

Q101: But that was another reason why I chose this facility because they might (inaudible) the other hospital (inaudible). That center (inaudible) I would have just gotten Vidaza as the standard protocol, but that hospital was also recommending let's go as quickly as possible to go to the stem cell (inaudible), but on the other hand here, we were kind of in a stall pattern and doing the chemo month after month and yet I had a stem cell doctor here on the same floor saying we're ready to go. We found your match. I had four (inaudible) I didn't have a stem cell transplant just to get a match, a donor, because none of my relatives were matches. So, my sibling. So, it's something to just find a match and I had four luckily that were (inaudible) matches. So, I was very, very fortunate and the first one had to back out (inaudible), so I was very, very fortunate to have another backup to do the stem cell transplant and anyway once we (inaudible) that with the stem cell ready to go to do it and also I think it was also because my blasts got below 10 percent. They went from 12 to say, eight. Well, they ended up at four, but they were still at eight.

Q10: (inaudible)

Q11: So anyway, there were so many things to look at and once they got below 10, I think the stem cell team was ready to go. The doctor here was still wanting to getting lower because he (inaudible) and so that was a big thing (inaudible)

Courtney D. DiNardo, MD: So, a couple comments about that experience. One is MD Anderson is fairly unique in the type of other places that… There's a couple of other places (inaudible), Sloane Kettering where there's leukemia teams and there's transplant teams. A lot of institutions go to (inaudible) physician (inaudible) and so it was actually a unique scenario that a few of the top largest centers where you have that kind of inter play, the chemo doctor and the transplant doctor because I think, honestly, is helpful because you have two experts. One's a transplant expert and one's a leukemia expert really, but you're right. There's always a… like when we talk about risk and benefit a lot with MDS and so certainly a transplant has a better chance of working the less disease you have and it's part of your transplant because you're focusing on this new immune system of someone else coming in and taking over and the more it sees you have (inaudible) it's going to attack where let's say you want a lower burden of MDS at the time of the transplant if you're close to (inaudible), but then there's also the more time that passes, the more cycles of therapy you get, the more times that maybe your counts might have done (inaudible) the higher transplant you're at risk at some infection or complication and you might lose the opportunity for a transplant you need. Transplanters, they have the transplant, they're ready and they don't want something to happen that prevents you from getting to the transplant and we're saying well, we know it's going to be a little bit better, but what's a little better? The transplant population that we talked about (inaudible)

Q11: (inaudible) the transplant doctor is saying it doesn't matter what we give you during the stem cell transplant. So, wipe out all the cancer cells and all the good cells anyway, so you're good enough and then also I was going to be on an experiment… another (inaudible) I forget what its' called that was for (inaudible). That would involve some (inaudible), but anyway or my donor cells (inaudible). So, but anyway that's (inaudible).

Courtney D. DiNardo, MD: I'm going to interrupt for one second just to show on the board. So when people are talking about the blast percentages and the cytogenetics so the IPSS is the most common tool. There's a revised one now (inaudible) the easiest one just to kind of know in the back of your head is the IPSS. The three things that have the most impact on your MDS is the percentage of bone marrow blasts, which you were talking about. You were somewhere in this range. You were 12 percent, I think, initially, the karyotype which your chromosome changes and so down here defines go to normal, -Y, isolated deletion 5Q or a 20Q intermediate is anything else except for poor which has more than three changes or chromosomes that affect. So, the chromosome risk factors and the cytopenias meaning of those three cell lines that we talked about, do you have just one cell line that's affected like just your platelet count which it sounds like you were maybe at the beginning, just an isolated platelet or is it two or three cell lines, the white cells and the red cells and the platelets are all lower than they should be and then you add the scores together, you add it together and then you get this total score and that defines whether

you're low risk, Intermediate 1, Intermediate 2 or high where the median survival, but these are patients that were not treated. So, the important thing to know when you're looking at these percentages or the survival times in the IPSS score, this is if you don't receive treatment and so treatment in the modern area with Vidaza and Decitabine and Lenalidomide and all these things impact this favorably and that's not something that a lot of patients actually realize. So, very important that you realize that survival is better than most (inaudible) IPSS score.

Q11: The median age of survival for people you're saying they didn't get any…

Courtney D. DiNardo, MD: Correct. These were all people that were moderate (inaudible) these numbers.

Q12: (inaudible)

Courtney D. DiNardo, MD: That's the whole point. Right? That's the whole point of (inaudible) with Vidaza. You get improved counts.

Q12: I seen the life expectancy was that with (inaudible)

Q13: My (inaudible) I've got data on charts that show all of this and everything else, but in my case, my blast counts eight years apart from a bone marrow… I've had two and I have the deletion 5Q from 2004 and 2012 yet I think my question to you would be what causes the bone marrow to change because I didn't see any change between those seven or eight years and now I see a change. So, is it the treatments that are impacting the bone marrow to change or is it just time?

Courtney D. DiNardo, MD: So, the question is you had kind of a stable, low risk MDS.

Q13: I've got a blast count of two ever since the inception.

Courtney D. DiNardo, MD: And then all of a sudden things…

Q13: Well, I don't know. The blast counts probably still two or lower, but other things have changed when he's done… because I've had like three bone… I just had one Thursday, bone marrow and a biopsy Thursday. So, that he can go over them with me again to see where we are.

Courtney D. DiNardo, MD: Usually, there are… So cancer, any cancer, is kind of… is genetic changes that happen over time. There are these mutations or chromosome changes or some sort of abnormalities that happen and it starts as one of the normal stem cells in your bone marrow. Those are what are called hematopoietic stem cells that are in charge of (inaudible), the white cells, the red cells and the platelets and then acquires a change that makes it work better than the others and replicate faster or it's stronger and outlives the others. So, it happens for growth

advantage. So you have these cells in your bone marrow that are functioning just a little bit better and it's actually not cancer yet, but then maybe one of those lines it's another genetic change in an area that makes it outgrow in faster. So then this bone starts growing more and at some point an average MDS patient has six to eight genetic changes and so you acquire these changes in these cells over time and then at some point it becomes a cancer or my suspicion for you is that there was this abnormal population that some additional had whether it was acquired in other chromosome change or another genetic mutation and that's why we always for people that are (inaudible) mutations, genetic changes that happen to try to get a sense of what the specific abnormalities of your MDS are. So, this is to show you kind of what I'm talking about. So, this is all within the past 10 years that we've identified all these different genetic changes and so MDS as an average person has like six mutations and so we're realizing that there are these genes some of which we know a lot about, some of which we don't really know much about at all are abnormal and that the combination of different things that happen kind of tell us a little bit about the biology of MDS, but it's just now starting to impact treatment decisions. So, we now have some (inaudible) we have ideation (inaudible) that have just hit clinical trials. They've been developed. We have (inaudible) inhibitors, those tend to be (inaudible), so to answer your question a little bit, I don't know your specific story, but certainly something is happening. If your disease is changing. It's most likely maybe more of these (inaudible)

Q13: It probably has. I do recall some changes, but the specifics I can't recall.

Courtney D. DiNardo, MD: And so when you're thinking about this is (inaudible) how he was at a low risk for a while with your low platelet count and then you said you developed that Trisomy 8. That's a marker that your disease is becoming more aggressive.

Q14: Plus the blasts (inaudible)

Courtney D. DiNardo, MD: Plus the blasts are (inaudible)

Q14: Because I don't think the blasts… there were blasts (inaudible)

Courtney D. DiNardo, MD: But certainly that…

Q14: But it shouldn't be done more often. There should have been more often than a three year period according to the first doctor.

Courtney D. DiNardo, MD: Yes.

Q14: That he wouldn't diagnose me. It sounds like because that's a risk that it should have been monitored.

Courtney D. DiNardo, MD: We typically monitor… and there's actually no great evidence, but we typically monitor people with counts every so often that are low risk like every three months or so with a bone marrow every six months or so, six months to a year to see if there's any changes, but that's practice. That's not (inaudible).

Q15: (inaudible). We're coming here for our treatment. So up until April (inaudible) and in April, we moved to Huntsville and we are now five minutes from the hospital that's close to 25 minutes, but I got (inaudible) and I retired from my career and then went to nursing school and I'm a registered nurse. (Inaudible)

Q16: (inaudible) What is the average hemoglobin when somebody is first diagnosed with this?

Courtney D. DiNardo, MD: A normal hemoglobin on a average person is somewhere between like 13 to 16 or so. So, that's normal and most people with MDS when they're diagnosed are quite a bit lower. It's probably on the order of like eight to 10. Some people are diagnosed… it just depends because, again, remember MDS is a constellation of a lot of different diseases from a lot of different genetic changes. There's different types of MDS. Some people are diagnosed because they are so short of breath that they can't get from one side of their house to the other. They go into the hospital and they have a hemoglobin of four because they haven't realized that it's been a very slowly progressive thing over probably six months and we see that fairly frequently.

Q16: I probably had it for (inaudible) and I was just plain (inaudible) tired and weak and…

Courtney D. DiNardo, MD: We hear that a lot.

Q16: I put up with that for a long time and are you're a doctor?

Q17: Pardon?

Q16: Are you a doctor?

Q17: Yes. I was. I was too. Pretty good at it too, but after a couple of surgeries I quit.

Q16: That's where I'm at now trying to decide. I was (inaudible).

Q17: Oh, really? Okay.

Q16: And that's when we first figured out something was wrong. New Year's Eve I guess it was…

Q18: Two thousand twelve.

Q16: It was maybe two years ago I was playing with some guys that never play and I was playing good. We had about five (inaudible) landed in a bunker or something and I had a hard time from the bunker back to the (inaudible) so I can stand still and hit a golf ball, but after that it was tough. So, I was around number 12 and I told them I was (inaudible) at the time. I told the guys that I had to go in (inaudible). One of the guys said let me call my wife. She's a nurse and let her come out there and check all your vital signs. She came out on the next train and checked everything. She says you need to get to a doctor. She said everything's out of whack. (inaudible) You're not going to get too many doctors on a Saturday morning (inaudible), so I waited till Monday morning and told… No, I waited…

Q17: He waited to (inaudible)

Q16: I called them and they said the first (inaudible) would be Thursday of next week. So, I said, "Okay." So, the (inaudible) I get over there and tell him what happened and this doctor has a real bad reputation. You go in there and you tell him (inaudible) he'll give you a shot or a pill and send you home. That's about all he's good for. (Inaudible) So, told him what happened and said, "Well, it sound like we need to do some blood work." So, I went in to (inaudible) a bunch of blood (inaudible). We'll call you when we get some (inaudible) so it was about seven o'clock. (Inaudible) and he said you have a 4.8.

Q17: Hemoglobin. Actually, the blood test it was a five on that day. If he didn't call us (inaudible) they didn't call us that afternoon (inaudible). He called the next day and said, "You can continue taking B12 or iron." It was 5.6 at that time or you could get a blood transfusion and I'm like well, B12 and the iron, (inaudible). He didn't tell us the numbers. He just said it was low and I said well, (inaudible) taking B12 and iron for months. That's not going to work. So, we couldn't get a hold of his office and we just showed up because it's right next to the hospital (inaudible).

Q16: Well, they set it up and I can go ahead (inaudible)

Courtney D. DiNardo, MD: You probably felt quite a bit better.

Q16: So, we go in and we set up for two units and the nurse got the board and she's looking at it and looking at me. She said, "You're a 4.8. I said is that what that says. So, most people come in on stretcher that are (inaudible)

Courtney D. DiNardo, MD: This was a very slow process over time because if your body goes from a normal count of 15 to four, (inaudible) and that was to happen over like a week or two, your body wouldn't be able to tolerate that and your circulatory system would have collapsed. So, it must have been a very slow process that allowed your body to kind of…

Q16: Now that I look back, I feel like I've had this or the symptoms for years.

Jayshree Shah: Probably and you didn't realize it (inaudible) that your body was kind of adjusting to your symptoms that you were dealing with. Ah, I'm tired. Let me take a nap.

Q16: I didn't want to go get a physical or none of that.

Q18: You only go to the doctor when something's wrong, right?

Q17: What happens to you over time is your body gets accustomed to a lower level of hemoglobin. In other words, you can have MDS and have a 12 count. A normal adult male has 14 to 18 and female 13 to 16, but you can operate on 12 and if you're lower and it takes another year to get down to 11 then you maintain a pretty stable 11 number your body gets accustomed to that because most of us that have and the multitude of people I know here run counts in the nines and you can operate pretty good on a nine. You get a little out of breath if you walk too fast or you exert (inaudible).

Courtney D. DiNardo, MD: There's different thresholds. There's some people… We don't transfuse them till their hemoglobin drops below seven and they function just fine. Some people it's eight, some people it's nine. So, it's…

Q17: I came in at 5.4 one time because I was losing blood from another reason and they rushed me from the clinic to ER. I mean, I had two guys. We were on a race track. I was at home. I couldn't move. I had a friend come over that whose wife was on oxygen and he came over and gave me oxygen and I stuck my finger in. We couldn't get zero. So, it was scary really. So, when you're at 4.8 what I worried about if you don't have enough blood flowing to your brain, it's going to affect cells in your brain. So, four and five are pretty low counts.

Q16: But I'm going in to get the blood and the nurse looks at me and says, "You shouldn't be walking," because I've been getting about (inaudible). So, we go in and get the blood. This was in January and it was cold outside and she said… the doctor said go home. He said (inaudible) go home. You should stay here over night (inaudible) set you up for two – three more units and then we'll see what it goes up to and I was telling the doctor and the doctor says, "Send him home. If he doesn't call me next week," and we're out to the car and the nurse runs out there and before I drove off and she said, "Look," she says, "I know I'm just a nurse and have been for a long time, but I'm going to tell you right now that this is… go get you another doctor right now."

Courtney D. DiNardo, MD: (inaudible) for what exactly happened is that you had a really good advocate speaking for you additional to your (inaudible) of thinking what's going on. It did not make sense. I think that's important. I think we all need that in our lives. You have him plus others, caregivers and other professionals and so you're going to be the (inaudible)

Q18: I think it's a golfer syndrome because as long as he can play golf he's fine, but when it starts getting (inaudible) get out of the bunkers and walk to the green and he's out of breath, take him home something must be wrong.

Q19: It must be because I had just learned golf.

Jayshree Shah: It's so funny though that you guys are… you discuss golf as your means of understanding what your symptoms are related to. It's interesting because (inaudible) goes back and tells me it goes to another patient forum because each place they see his different ways of identifying (inaudible)

Courtney D. DiNardo, MD: The number of pills they give him.

Jayshree Shah: Yeah. It's interesting.

Q20: I'm (Attendee) and I've had MDS probably since 1998. I had a breast (inaudible) and I can pinpoint that because I had a breast biopsy in 1997 and all three (inaudible) okay. In 1998 when the doctor checked my blood work, I was (inaudible) and so we started off with every kind of iron known to man including liquid iron which is the vilest stuff in the world. You take it by the teaspoonful because if you mix it with water it still tastes as bad as the concentrated stuff, but and it took them about till 2002 before I had a diagnosis. At the time, I was working as a school business administrator which is a pretty high pressure… keeping lots of balls in the air. By 2002 about the time I was diagnosed, I just couldn't do my job anymore. I elected to retire on disability. My hemoglobin was running around eight or ten. I chose my original… medical technologist because the laboratory worker by training (inaudible) and I wanted to stay transfusion free as long as I could because I was aware of antibodies and the transmission that was just kept trying (inaudible) diagnosed (inaudible) figuring the West Nile Virus was being transmitted by blood transfusions and all kinds of other stuff. So, I elected to stay away from the blood transfusions. I then went home to New Jersey to take care of my parents who were aging. When my mom passed away in 2005, I no longer… or shortly after that I could no longer handle my life as hemoglobin was eight. I just cannot do this anymore. So, I went to have transfusions. That's when doctor who I was dealing with who was also a… the hematologist that I was dealing with and in Philly at Penn said, "Okay. Now, you're starting to need treatment. Now, we're going to have to start looking for (inaudible)." I do have an (inaudible) which is monochromal (inaudible) of unknown significance which is kind of like… it's possibility it's making myeloma, but it may not be, but when they did the bone marrow aspiration before they started treatment I did have some (inaudible). So, my… the treatment of choice at that point was Thalidomide because at that point that was 2005. That was just when Revlimid became (inaudible). It was not available everywhere and it was much more expensive than Thalidomide. I was on Thalidomide for 3 ½ years until just after (inaudible) here. The reasons for wanting to go off of Thalidomide was that I was having trouble getting out of my own way. It's a depressant. So, it's just… I was (inaudible) even though I took it in the evening, I was having trouble getting (inaudible) and it

really takes a lot of out your physically. Also, I decided I wanted to go to the gym and when they did some testing on balance and that sort of thing at the gym and I finally went to the neurologist. I had lost like 75 percent of my sensory (inaudible) in my feet and my lower legs.

Courtney D. DiNardo, MD: Those were caused neuropathy in some people. (inaudible) leg loss function.

Q20: So, at that point in 2008 I went on Revlimid which has been, again, the second miracle drug. My last transfusion was in October of 2005. I started the Thalidomide in September of 2005. So and the… I've been running 10 – 11 (inaudible). I don't have any 5Q- or any of the things that would normally predict that it would work and it was… the Thalidomide was an experiment to start with and it was mainly because I also had the (inaudible) and they wanted to start to control those abnormal proteins that they… that the (inaudible) cells were putting out. The last bone marrow that I had, which was about six years ago was (inaudible). I have a hyperplastic marrow, which means that they can do the biopsy when they do the (inaudible). Take a piece of bone that's not a problem, but they'll pull the aspirate out is like pulling cement through the tube. You know, aspirating cement through… So, that normally is… that's normally a tough one to get out. I have had the ferrotype done a couple times. The last time was in Philly and the guy that did the (inaudible) chromosome was the guy whose wife was the one that just (inaudible) retired. So, I (inaudible) and I've been here for…

(inaudible)

Q20: He was my doctor at the time and I've also done… I'm good at name dropping. I saw Dr. Garcia Manero when I (inaudible) and… but he shipped me out to Dr. Alex (inaudible) because of the Thalidomide and (inaudible) all that stuff. I also was part of the study that's lost its funding in Tampa at (inaudible) and just looking at long term what people with MDS look like over the long term and unfortunately that's not (inaudible) my sister and (inaudible)

Courtney D. DiNardo, MD: Well, I apologize. So, it's about 10 minutes after the hour. I have to leave, but my E-mail I'm going to put back up for a minute or two. So, any questions. Does anyone have any? It's really lovely session. So, I have done too much of these patient forums. This is really nice. So, thank you all.

Jayshree Shah: (inaudible) any questions for Dr. DiNardo.

Q21: How long have you been here?

Courtney D. DiNardo, MD: Almost three years. (inaudible) a relatively new (inaudible).

Q22: Bone marrow biopsy is something that patients do not look forward to. I read (inaudible) that at some point in the future, they're thinking we may not be able to have to do those.

Courtney D. DiNardo, MD: It depends on the type of bone marrow problem that you have. If you have, for instance, CML which is characterized by that 922 (inaudible) we can test that in the peripheral blood using molecular (inaudible). So, those patients no long… you can be… having your surveillance over time with one. So, yes. At some point they're supposed to be an option. We can do a lot of the testing through peripheral blood. We're not anywhere close to that for the majority at this point in time. We… a lot of patients have very traumatic bone marrow experiences when they come to MD Anderson or an institution where they do a lot of bone marrows. That's much more evasive procedure that (inaudible) a procedure most of you are very familiar with and they tend to be… you can never (inaudible), but in general people tolerate bone marrow much rather that are familiar with bone marrows.

Jayshree Shah: And they are (inaudible) successful, too.

Courtney D. DiNardo, MD: And we do offer a sedation. We have different levels. We have (inaudible) which means you get people that (inaudible) twilight sleep. There are people who really have trouble tolerating it and in certain situations we can actually knock people out to sedation for bone marrow. So, that's always… We can always figure out a way to make it not so distressing for patients.

Jayshree Shah: Thank you so much for coming.

Courtney D. DiNardo, MD: Thank you.

Jayshree Shah: (inaudible) for a few minutes and then come back. It's at 11:15. Maybe at 11:25. You have five – ten minutes to stretch. I do want to tell you that I unfortunately have to end this forum a little bit earlier only because we all need to catch a flight at 3:30 – 3:40, but we want to make sure we get there on time. So, is it okay if we finish around 1:30 for you guys? Is that okay? Alright. And we'll have lunch at 12ish. So, we can just finish chatting (inaudible) for break and then come back and then I can do my spiel and my presentation and we can chat. Okay?