Speakers:

Richard Helmer, III, MD
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Jean Ridgeway: I think we'll get started for the afternoon. So, people are straggling in. Chop chop. Get to your seat. So, I'm going to talk to you on what was started this morning, but I'd like to be a little bit more personable and hopefully I don't want to say MDS for Dummies, but I'm going to tone it down a little bit. I have a doctoral degree and his talk was like not so bad for me, but it probably glazed a lot of folks over. So, I'm going to… I think it would be nice to start out with an introduction if you let us know who you are and why you came, but you have to give an elevator speech. This is not the 24 hour filibuster. Okay? So, you can't do that and then I have to remind you… So one of the things that the MDS Foundation does it is collects a lot of "data." So everything can be captured as data. So, this handy dandy little instrument in front of you called a microphone has a middle button and it says push and when you push it you talk into the thing. So, (Attendee) is on now. He wanted to say Hi, I'm (Attendee) that would be great. So when you speak if you could kindly use the microphone so they could capture your questions, etc. So, that'd be really helpful.

My name is Jean Ridgeway and I'm a nurse practitioner. I work at the University of Chicago. The University of Chicago is located in Chicago. We're about 10 miles south of downtown. So, I have a beautiful view of the skyline. I live 30 miles north of there in the city. So, like Austin that's experienced a lot of growth, Chicago has experienced lots and lots of growth over many years. So, I've been at the University of Chicago for about 15 years. I'm the lead nurse practitioner and the lead person in stem cell transplant and malignant hematology. So, we'll talk if we have questions about transplant. We can talk lots about that. I spent the majority of my clinical time with the transplant program. We have a special program for "older" patients. So, there's two type of stem cell transplants. Like in myeloma folks give their own cells. That's called an atalogous transplant and when the cell source is someone else be it your twin brother, an umbilical cord or an unrelated person that's called an allogeneic transplant. So, I work the majority of folks that I care for on a regular basis have had allogeneic stem cell transplants. We do do transplants for people over the age of 70. Those are my babies and I care for them quite meticulously. They come and see me three times a week for the first 100 days after transplant and so that's because we need a little bit more care. The side effects for older patients can be a little bit more difficult to deal with. So, we pay lots of close attention and we know as people get through the first 100 days their chance for outcomes are improved. So, that's one of the reasons we do that. In my early career as a nurse, I've been a nurse for over 30 years and I started out working in malignant hematology on a floor. So, it's a floor nurse and MDS at that point in time was kind of an enigma. People called it smoldering leukemia. They didn't really know what to call it. Nobody wanted to pay much attention to it and so they really didn't. About 10 years into my tenure there and even at the beginning I used to work at the University of Illinois, 10 miles north of where I am now, and we were part of what was called a cooperative group. So when

researchers go to do clinical trials or studies they oftentimes they cooperate and they can use lots of different sites all over the country because MDS is a rare disorder so in order to get information you're going to need to collaborate with your colleagues in order to get enough patients enrolled to see if you can verify what's going on and we were part of a large cooperative group that actually did the licensing study for 5-Azacitidine. So, that was back in the '90s and so I got very interested in that and I think blood is kind of interesting. So, I've spent my career did my doctoral work looking at patients over the age of 75 with acute hematological malignancies, AML and then MDS. So, that's what I do. I'm married. I have four kids. One of my daughters is nurse. My son's in medical school. One of my sons graduated from UT. And so I'm not a stranger to Austin, but I'm glad to be here. So, I'm going to go around. Tell me your name and some people are a caregiver. Some people are here because they're interested because of a family member. So, let us know who you are, why you're here and we'll go around and we will… I'm kind of like a nut about schedules. So, we'll end up with lunch at noon. So, we're good to go. (Attendee), press the button.

Q1: (Attendee) and my wife and caretaker, (Attendee), and she's putting up with me. I had non-Hodgkin's lymphoma in 2011. Was chemotherapy for that and bone marrow showed no lymphoma the first year and then 2012 it showed no lymphoma but MDS and so it was secondary to me. I've been gong a long unusual. I've taken no treatment and it's been pretty steady. Less than one percent blasts and they got to investigate them, others more. The only thing I've had is last year I had from January through August I had a high fever and bronchitis and we tried everything and he sent me even to a PET scan and that threw me back to my oncologist and went there and found out I had an ulcer. So, that may have been my problem. I've been taking Darbepoetin Alfa from time to time to bring up my red cells. I've been having anemia nearly all my life, but that's how they found this. They went in there… the lymphoma. They went in there just to see why I had anemia and they found lymphoma.

Jean Ridgeway: And what brings you here today?

Q1: Say again.

Jean Ridgeway: What brings you here today? What are you happen to learn?

Q1: Oh, I just want to find out what's new, what's going on with it and just more details. I get very little from my doctor. He's just happy as a lark that I'm not having treatment.

Jean Ridgeway: That's a lot to be thankful for.

Q1: That is a lot to be thankful for.

Jean Ridgeway: Well, welcome. Welcome. (Attendee) has something called therapy related MDS. So in the world of Myelodysplastic Syndrome, it can arise with no predisposition. You

didn't have a first therapy, but what we know about some of the medications and chemotherapies that we give to lymphoma patients is it can cause damage to the bone marrow and then people can develop a myelodysplasia afterwards and they call that therapy related MDS, but many times you'll see that all MDS patients get grouped together, but as we go around the circle you'll find out that not everybody's the same. People can be very different. Next to, (Attendee) has to use the microphone, (Attendee). You can't like hoard it all day. Pass it over.

Q2: I'm (Attendee)'s wife and just came here to learn some more because we have no idea what kind of treatment, what kind of help and we were so glad to find out this foundation.

Jean Ridgeway: It's a great place to get reliable information. If you're new on the MDS front, you have to be a little careful and cautious where you go on the Internet. Don't go to Susie's MDS page. Go to places that are reputable. So, this is one of the best sources and then you have the book which is great.

Q2: Thank you.

Jean Ridgeway: Welcome. (Attendee)'s next.

Q3: Hi. I'm (Attendee). I live here in Austin. I was diagnosed with multiple sclerosis in 2000, was on treatment for that and it was the neurologist who coaxed me to see a hematologist because of my counts dropping, my white count in particular, and that's when I was diagnosed in 2009 with Myelodysplastic Syndrome and came off of MS medications and because MDS trumped MS. So, I learned MDS and I was going back and forth between Austin and Houston to MD Anderson and I'm still doing that, but at a slower pace. So, I was 5 ½ years blood transfusion dependent monthly.

Jean Ridgeway: Dependent.

Q3: Dependent. Five and a half straight years dependent and all the medications which were many and varied did not slow the progression of the blood transfusion dependency and so MD Anderson switched me to cyclosporine which is an immunosuppressant.

Jean Ridgeway: And it's a pill or a liquid.

Q3: It is a pill. They're horse pills and so I take the cyclosporine for 18 months. Now, I have been transfusion free.

(Applause)

Q3: And I am here, me too, I am here because you are here and I wanted to meet somebody in Austin or the surrounding area for all these years who was a patient of the same thing I'm being treated for and I have never met one.

Jean Ridgeway: Who else lives in the Austin area? One. (Attendee), where do you live?

Q3: San Antonia.

Jean Ridgeway: That's not so far. I mean, I live in Chicago. Is San Antonia far? Well, welcome and that's not unusual. People come to these forums and you'll hear comments like the only MDS patient that my doctor sees and it's a rare disorder. It is a rare disorder, but welcome.

Q3: Thank you.

Jean Ridgeway: (Attendee).

Q4: Hi. I'm (Attendee) and I'm (Attendee)'s husband. Yeah. I'm here… The more we learn, knowledge is power and she's such a trooper. She's been through all of it and we're glad the cyclosporine and that's what my concerns are. These long term effects of these medications does that trump the… the benefit… I mean, we're glad to be transfusion free and the chelation and all that stuff and so… Here to learn some more.

Jean Ridgeway: Great. Welcome. (Attendee)'s next.

Q5: My name's (Attendee). I'm married to the man who has MDS who couldn't make it today. Other things going on, but we've been looking for a program close to us and we're just here for more information. I'm just here. I've been preferring denial since the diagnosis. So, I'm not as well informed as my husband is. I like denial a lot better, but anyway I'm here to learn what I can. So, I appreciate ya'll.

Jean Ridgeway: Do you mind if I… So, your husband has MDS.

Q5: Yes.

Jean Ridgeway: And is he low risk, high risk, treatment?

Q5: I don't' know.

Jean Ridgeway: Does he get any treatment?

Q5: No.

Jean Ridgeway: No treatment.

Q5: We've just been told that and wait till he starts falling apart and then they'll start doing something.

Jean Ridgeway: Oh, that's very reassuring. How long ago did he… were you informed of the diagnosis?

Q5: About four years.

Jean Ridgeway: Four years. Okay.

Q5: So when I see 8.8, I'm not happy, but I'm also optimistic. After the denial I'm going to be optimistic.

Jean Ridgeway: Good. Very good. Next to you?

Q3: Where are you from, (Attendee)?

Q5: Houston.

Jean Ridgeway: Huston. Oh, you came a long way.

Q5: Not as far as you, but...

Jean Ridgeway: Well, welcome.

Q5: Thank you.

Q6: I'm (Attendee) and I'm traveling with (Attendee) whose mother's MDS. So, I have a blood disorder and this interests me.

Jean Ridgeway: Very good. Welcome.

Q7: Hi. I'm (Attendee). My mother has it. My mother is 86 now. She was diagnosed with it in 2012. She was sent to the cancer specialist blood doctor in 2012 because of the anemia and about two months into it I think is when they gave her the bone biopsy and diagnosed it as MDS and like I was telling the doctor the only thing that she has had is that Procrit as a treatment and when you said when I see 8.8 you're not happy. What kind of count are you talking about?

Jean Ridgeway: So, hemoglobin is measured in grams per deciliter and 8 grams per deciliter, it varies. At ours, I can speak to our center and I can tell you what the American Society for

Hematologists recommends as far as when to transfuse. It's seven grams per deciliter. Now if you're a healthy person, your hemoglobin is going to be anywhere from 13 if you're a woman up to 17 grams per deciliter. That's a normal hemoglobin and in Myelodysplastic Syndrome what we know is that 90 percent of people have anemia, but the onset of it is very gradual and folks learn to accommodate and you kind of don't notice until you get to this tipping point about seven grams per deciliter, seven to eight grams per deciliter. So, sometimes patients will get transfused if they're a little higher than that if they have heart disease or have had a heart attack, if they have chronic obstructive pulmonary disease. They may need a higher hemoglobin because hemoglobin is the mechanism that carries oxygen in our body. So, we all function better with oxygen going to all of our organs which is why you get transfused. So, but everyone's got their own threshold. Some people do okay at eight. One of my patients yesterday she was 7.4. We don't transfuse her until she's mid-six and she's like I'm fine.

Q7: She's never had any transfusions.

Jean Ridgeway: Your mom's never had any.

Q7: Uh-uh and her underlying other diseases, diabetes which she's always taken very, very good care of herself with the diabetes, but her problem now really is she's got… being 86 she's got that… spinal stenosis and the pain from that is what's hurting her more than this, I believe.

Jean Ridgeway: You heard the physician talk about something called comorbid burden. So, that's a fancy way of saying that… So comorbid burden is a medical way of saying that when people come to treatment and they see a hematologist that will often have other concommonent medical issues like diabetes, spinal stenosis, arthritis. So, that's what comorbid burden means and what we know in the world of MDS is that oftentimes the MDS is an issue, but the comorbid burden and the symptoms from those can sometimes tip the scale in a negative way with the MDS. Well welcome. We're just introducing our self. Next.

Q8: Hi. I'm (Attendee). I'm here on behalf of my father-in-law who was diagnosed in early this year.

Jean Ridgeway: Twenty sixteen.

Q8: Or probably December actually just before with MDS and he really had no other previous things. He was having blood pressure issues and then one day he just like fainted and fell down and his blood pressure was way low and they took him in and found out that he was anemic and did transfusions and lots of tests and finally diagnosed that and at the time he had two granddaughters who were about to give birth, about four months apart and they both were wanting to donate their stem cells, the cord cells, and his doctor said they wouldn't do it because he was too old.

Jean Ridgeway: How old is he?

Q8: He is going to be 90.

Jean Ridgeway: Yeah. He's too old. I'm sorry, but that's really true. Did they donate the cords anyway? There are these agencies… you have to have it well set up before the woman delivers.

Q8: No, they didn't. Sorry.

Jean Ridgeway: That's okay. There's always next time.

Q8: Yeah, but the…

Jean Ridgeway: He's 90.

Q8: Yeah, 90 and they wanted him to do chemotherapy and he said no. He couldn't… So, they're just doing transfusions when he needs it every two or three weeks, but we were just interested in finding out what other options are, why they would even want to do chemotherapy because it doesn't sound like it's specifically cancer. I mean, I guess chemotherapy isn't just for cancer.

Jean Ridgeway: Well, it's interesting. The nomenclature with Myelodysplastic Syndrome has evolved in these past few years. Some people used to shy away from it saying that it's cancer, but now I would say that the parting line is that it's a malignancy. It meets the criteria. It's clonal. That means that all the bad cells look like each other and it does evolve more naturally into acute leukemia. So, people do see it and when you say chemotherapy I'm not sure if you're referring to Azacitidine or Decitabine. You could figure that out. You could get the names of it and we use this generic term for chemotherapy. Most people think about like (Attendee) had chemotherapy for lymphoma. You think about these really hardcore drugs make you lose your hair, you're vomiting and the drugs that are used with Myelodysplastic Syndrome, Decitabine and Azacitidine, are the hypomethylators. So, they're a different… they use a different mechanism and actually they're pretty well tolerated even in… they're not benign and people have to be watched closely, but the medications themselves can be tolerated. At our center we treat people in their late 80s and 90s. We have a gentleman who's like 92. He gets Decitabine for MDS and he's actually doing quite well, but it's an individual decision.

Q8: Thank you.

Q9: My name is (Attendee). I am an oncology nurse for 28 years and I'm a sales specialist for Novartis.

Jean Ridgeway: Welcome.

Q10: I'm (Attendee) and I'm with Celgene. I worked with Celgene for 15 years in hematology. I'm just here to hear from the patient's perspective and learn more from you and Dr. Helmer.

Jean Ridgeway: Great.

Q11: I'm (Attendee). My wife, (Attendee), she's the patient. I'm the caregiver. I'm her advocate to the insurance company, to the doctor, to now my congressman, to lots of different things. It keeps her stress level down which helps her feel better and I let her describe her drug. We live in San Antonio. We struggled the beginning with the doctor that we were not happy with. So, I'm going to tell you anybody, (Attendee), find the right doctor. Find the right doctor. Get a second opinion. We did and we've been very happy. The last year we've been able to see the doctor every other month instead of every month. So, we're making progress.

(Applause)

Jean Ridgeway: I will tell you one of the things about this MDS Foundation is the foundation itself was a grass roots organization, was founded by a patient. Right, Audrey?

Audrey Hassan: Yes, a patient (inaudible 21:22) decided that there was a need for a foundation and that's how it (inaudible).

Jean Ridgeway: So, Dr. Bennet is a hematopathologist. So, he's the guy who could read and interpret the slides and so he's been working with MDS for quite a long time and about, I don't know, five or eight years ago Medicare, we've talked a little bit about this drug, Erythropoietin or Darbepoetin, the red cell hormone injection and so we all live with rules and regulations and so Medicare the drug was being used in the '90s and there were some bad things that happened anyway. They came down with a very difficult decision that said we don't want to allow this being used and so it was really groups of myelodysplastic patients that went before their legislators and, I think, did they go to Capitol Hill and they made an appeal and said this is one of the things that makes the difference in our lives is quality of life and helps us stay away from transfusions and it was because of their petitioning with the government that there's a special exception carve out that it's allowed to be used in Myelodysplastic Syndrome. So, it is important to get involved with local officials because they do listen. I'll tell you that I contact my local official pretty commonly. I go into his office. I know Illinois has a bad rap, but you have to live with it, but they do listen and they're our employees. So, you should be involved with them and it does make a difference. If they don't hear from us they don't know what the issue is. Next.

Q12: My name is (Attendee). I was diagnosed with MDS in 2010, February 2010. So, it's been about six years. I went to a doctor that I just didn't have a good feeling about, but I went to him for a year before I made the decision the last time… when I left his office and my red blood count was 8.8 and I was… could tell I was starting to feel not great and I just had to make the

decision. I had made my appointment when I left and I walked out and said this is it. I'm done with him and so I started researching and trying to find somebody, of course, in my network.

Jean Ridgeway: You have to do that.

Q12: And I was so happy that I did because I love who I go to now, but my doctor… I have the 5Q- and my doctor… the doctor I was going to did not want to put me on the Revlimid and I had already seen the transplant doctor in San Antonio just as a second opinion or what have you and he's the one that kept trying to push my doctor to do the Revlimid and he wouldn't do it and it was… just started infuriating me, but then I went to the new doctor that I go to now he basically that was the first thing he said why are you not in Revlimid and I was like oh, my God.

Jean Ridgeway: So, how long have you been on it?

Q12: Almost five years. It'll be five years in July. My problem is now is it's which… we were just talking, (Attendee), it's very expensive and thank God I have insurance, but I'm going to this thing now recently because it's been this year that it keeps going up.

Jean Ridgeway: Your copay.

Q12: Not my copay, but the mediation itself and so the insurance wants to every month it's like a struggle with them approving it. It's just been a nightmare and that's what (Attendee)'s kind of been doing some other stuff trying to get… talk to other people about it and what have you. It's just a very expensive drug, but the thing is it works and to me it makes me what I call normal. My doctor says if somebody were to really look at my blood count if they didn't know my history they would think it was normal. So, I've done really well on it and I just wonder… I am very fortunate. I have two siblings that are matches and I have a twin sister.

Jean Ridgeway: I have a twin brother.

Q12: And so it's kind of like one of those things my doctor right now says because the Revlimid works he doesn't want to do anything else and I am a younger patient. I'm 55. I was 49 when I was diagnosed and I basically was diagnosed going and having a physical and my doctor said I was anemic and so they referred me to a hematologist which by the way I did not know are generally oncologists and when I went up to the door I was like oh, my God. I'm in the wrong place. This is an oncologist. You're thinking I'm anemic. There's nothing wrong with me. I've always been a healthy person. Very rarely ever even sick at all and then when they tell you you have something you don't even know what it is. You're like what? What did you even…? You don't even know what they said.

Jean Ridgeway: Were you by yourself when you got the diagnosis?

Q12: I was not by myself. I was by myself when I got… when I had to the first bone marrow biopsy. Oh, my God. That was…

Jean Ridgeway: Was it bad?

Q12: Oh, it was horrible.

Jean Ridgeway: Oh, I'm so sorry.

Q12: Oh, my God. Like the worse thing. I will not even tell you the things that I said to my doctor. I wanted to literally choke him when I was done. My husband was out of town. I had no idea. If I'd had researched it, I probably wouldn't done it, but I had three or four… three since then. The second one I was medicated.

Jean Ridgeway: That's the trick. There you go. I probably do anywhere from 10 to 15 a week.

Q12: Oh, my God. It was horrible.

Jean Ridgeway: I'm charged with… I help teach the fellows which are like the regular physicians who are training to be oncologists and then I teach all the nurse practitioners and physician assistants. Taking medicine is fine.

Q12: When my first doctor that I didn't like they did it and so…

Jean Ridgeway: Well, here you are. Now, you know the secret.

Q12: I had one from doctor that I go to now and it was not bad. I wasn't really medicated, but it wasn't bad.

Jean Ridgeway: Whatever it takes. Really. As the patient, you have your husband to advocate for you, but we all need to be our own advocates. If you feel uncomfortable and you would like you can take medicine at home, you can take something orally. Every center is different. I can't really speak to individual places, but you need to do what you need to do for yourself and…

Q12: I basically went the first year with my doctor doing nothing. I was taking B12 shots, B12 vitamins, not really doing anything and I just felt like every month my blood count was just going down. It wasn't getting any better and I would go in and they'd say well, now this month it's this. It hasn't really gotten any better. It's getting a little bit worse and it's like you're not even doing anything. Give me like a pill, something.

Jean Ridgeway: We talked about getting a second opinion. One of the things the MDS Foundation has is that it has a network of centers that are called Centers of Excellence and

physicians across… really internationally that they can recommend if you're looking for a name. So, the girls can help you. If you're interested in that they don't get… unlike Chicago where you get paid under the table and it's a lot of who you know. That's not true. So, these ladies just want to do the right thing for you and get you networked up with people who are competent and trained because everyone has an expertise and so having a rare disorder you need an expert.

Q12: I went and did my second opinion with Dr. Shaughnessy who is the transplant doctor in San Antonio only because my mother-in-law had a friend that's daughter was a nurse and she recommended them and so that's why I ended up going there. Love him, too.

Jean Ridgeway: It's hard. I mean, you know you begin on this journey. You've never heard of the disorder before. It's very overwhelming and so having the tools to network is quite an asset.

Q12: I do recommend always going and getting a second.

Jean Ridgeway: And you're in San Antonio.

Q12: I'm in San Antonio.

Jean Ridgeway: You're in Austin. Houston. Sorry. I'm really not that geographically challenged. You're next.

Q13: My name's (Attendee) and I'm a clinical nurse educator for Novartis. I cover five states in the Midwest and I'm just here kind of learning as well and I've been an oncology nurse for 36 years.

Jean Ridgeway: Okay.

Q14: I'm not as impressive as (Attendee). My name is (Attendee) and I am also a clinical nurse educator for Novartis. I've been an oncology nurse for 11 years and I did primarily chemotherapy infusions in Dallas. So, thank you all for letting me be here and listen to all of your stories.

Jean Ridgeway: Well, great. Eleven fifteen. So, this is just a set of slides, but they're more for talking points than anything else.

MDS doesn't just happen in the United States. It happens internationally and so there are actually are international specialists all over the world and joining our physician colleagues are the nurses at the bedside or in the clinic and so many years ago some of us recognized that what we need to do improve even the care of the patient is to improve the education of the nurse and so there's a number of us that endeavored to do that to help people really get up to speed and stay at the state

of the science with all the new things that are coming out. So, there's quite a host of people who are involved in that.

So, there is an evaluation, correct, Audrey? Did you hand it out or you want them to fill it out online or…?

Audrey Hassan: (inaudible 31:17)

Jean Ridgeway: It's painless.

So, we talked a bit about Myelodysplastic Syndrome and so when to start treatment. So, there are a… when I hear your stories around the table when do you start treatment. Sometimes the bigger issue is how do I get diagnosed? So, we've alluded to that a lot of people with Myelodysplastic Syndrome have anemia, a majority of people do and oftentimes it's the symptoms from the anemia that drive people to go to the doctor. I'm really tired. I'm short of breath. You can have low platelets and in that case people may have bleeding. They may have a tooth extraction and the bleeding never stops or perhaps even if their white cells are low they can have infections and so the journey to get to the diagnosis is often kind of arduous, complicated, takes a long time and many people say what your comment was that they go to the door and it says hematology/oncology and they swear they're in the wrong place or they get in the car and they call and say am I supposed to be here because most people don't know that those two subspecialties are conjoined together and that sometimes anemia may be benign, not cancerous, iron deficiency or B12 deficiency, but sometimes it can be a subtle sign of malignancy. So, that's how people start.

So, when to start treatment with MDS? So, how many people in the room have had a bone marrow? (Attendee), you said you've had a bone marrow. (Attendee)'s had one over here. So part of getting diagnosed with Myelodysplastic Syndrome we can look at your blood and they can do some sophisticated tests with your blood. It's common to look for iron deficiency, for vitamin deficiencies perhaps for viruses, your thyroid level, but ultimately people need a bone marrow evaluation to truly make the diagnosis and so they look at the hematopathologist, the experts, take a look at that and with a lot of other testing it it's what does it look like under the microscope and our physician… the first component talked about what does it really look like under the microscope and then there are specialized testings. They're genetic testing where they actually look at the DNA and they look for abnormalities. So, unlike when you hear people yelling at each other on the TV about like who's the baby's daddy, we're not doing that. That's constitutional DNA and that identifies us and you can get that by brushing your cheek, but the DNA is actually from the bone marrow because you want to look at the malignant cells and so that's where it comes from and sometimes people have like you the abnormality with the fifth chromosome, the 5Q- where the Q piece of the chromosome is missing and that becomes why is that important? Because chromosomes hold all of our genetic information. They basically tell all of the different functioning parts of us what to do. So when you're missing a large component of

a chromosome, we only have 26… we only have 23 chromosomes it's kind of like going out to your car and missing the front quarter panel. It's not exactly what you want to drive out of the parking lot because it's just not going to function that well. So, it's the same type of situation. So, oftentimes after that's done…

Q15: Are you born with that 5Q-?

Jean Ridgeway: Are you born with it.

Q16: Or does (inaudible 35:10) into it?

Jean Ridgeway: So, most people will say that you're not born with the 5Q- because all during your life up until whatever age and we don't know what the triggers are to cause that abnormality. So, there are some people who do genetic testing and look at some familial abnormalities but 5Q- is not one of them. There's a gene out there called RUNX1 that people may have more of a propensity for it but usually not. You're born with normal chromosomes and something… we don't know what the vulnerabilities are. You can say that you live alongside your brothers and sisters. You basically have the same diet, the same exposure. I get it, he doesn't. What's the difference? Nobody really knows. We know that age is a factor. In (Attendee)'s case who has a therapy related MDS, his prior exposure to chemotherapy is being pointed at, but we don't know that for sure.

Q17: I firmly believe that the Avanex that she was on to treat the MS is what triggered this and of course the doctors say we can't… (Inaudible 36:25) coming out showing that this Avanex might be a causing factor in blood disorders.

Jean Ridgeway: In blood disorders. Yeah. So, it's hard to say why one person would be vulnerable whereas many other people aren't. In some of the science in medicine nowadays is really trying to identify why some people are more vulnerable to abnormalities.

So when do people usually start treatment? In general after you go to the hematologist and they do the testing for some people it's watching and waiting. How are you feeling? Do you need transfusions? Because in the world of MDS you can divide it into two big categories. One is called low risk MDS and the other is called high risk MDS and when you think about people who have low risk disease there are some nomenclature looking at their genetics that we can examine, but basically it says that the disease may not really progress very quickly. It may be just kind of we're going to watch and wait. We'll have you come back in a month. We'll see what your blood counts are. If the cytogenetics are normal or they don't have some… there are some bad character actors and in the cytogenetics. If you don't have them and they put you into a category of low risk then what they want to do is just watch your blood counts and they want to make you feel better. That's what we do in low risk and we want to see if we can improve hematopoiesis or the formation of blood. So sometimes with that it's those Epogen shots to help

boost up the red blood cells, but then when we look at folks who have the other subtype, we look at how can we help these people survive longer because we know that the disease tends to be more aggressive and the natural history left unchecked for MDS is that it can evolve to acute leukemia. So the difference when the pathologist tell us they look at someone's slide and we get the report back from them they give us a very nicely written out report and they'll say that this person has MDS RAEB2, refractory anemia with excess blast type 2, or this person has acute leukemia. Oftentimes the fine line is just how many blasts you have in the bone marrow. So, he showed a slide of how blood is formed and as normal stem cells become mature cells they are blasts but then they grow up. When they get stuck in immaturity those are the blast cells and if you have five percent in your bone marrow or greater then you most likely have a disease going on unless you're getting Neupogen or the white blood cell shots. So, if you have less than 20 percent blasts then you still have MDS, but if you cross the threshold over 20 you have acute leukemia. So if you think about the low risk people and you think about the high risk people in MDS, the low risk people have lower numbers of blasts. The high risk people are, in general, going to have higher numbers of blasts maybe, 16, 18 percent. They may be more cytopenic. So, we want to help them survive and what we want to do, too, is begin to change the character of their disease and can we modify that through some medications and the answer is many times yes, but not always and it's choice. So, your father-in-law is 90. He was told he has MDS. Correct? Is that (Attendee) back there? How's my eyesight? Not so good.

Q18: (inaudible 40:11) more detail (inaudible).

Jean Ridgeway: Well, you know? I'll tell you. If you go to the MDS website. First of all a lot of this stuff's in the book and you can get this book as a PDF file online. So, you can just kind of like pull it off and they also have a lot of other information. So, a lot of the things that I'll talk to you about are readily available on the website. They have educational webinars and if you want to be a total geek you could go to Google Images and put in MDS and you could see all type of great little pictures that are purple and dots and whatever, but there's a lot of information out there and the MDS Foundation has quite a bit of it.

Q18: This information is on my father-in-law's… what he's doing. So, I'll (inaudible 40:59) I'll just tell you (inaudible)

Jean Ridgeway: Oh, you were going to give us the answers.

Q18: So, he was recommended (inaudible 41:03)

Jean Ridgeway: Azacitidine.

Q18: Yes, as a chemo and his IPSS-R is intermediate to high and he had leukemia type cells of the number six on a scale of one to 20.

Jean Ridgeway: Maybe six percent?

Q18: Six percent. And he takes Aranesp injections every two weeks.

Jean Ridgeway: Aranesp. So, that's that red cell. There's a long acting one and a short acting one.

Q18: So, that sounds alright?

Jean Ridgeway: That sounds good and Azacitidine can be given either as a shot like an insulin shot or it also can be given intravenously. So, either or.

Q18: But you think at 90 that that would be beneficial at this point or he just wanted to do the other. He's just doing transfusions.

Jean Ridgeway: You know what? I'm going to be naughty and just say you really got to talk to the oncologist and the oncologist needs to talk to the patient and he needs to weigh it out because I don't know if your father-in-law spends his days running marathons or if he spends his day in bed. So, like what's his lifestyle and what's going on with him. Physicians are not in the business to make bad recommendations. So, it's data driven. They want to look at the numbers and when we look at people who have high risk MDS we know that, yes, most likely as their bone marrow starts it's also called a bone marrow failure disorder and what that means is the bone marrow just can't do its job and so the only job our bone marrow has is to make our blood cells which is really big job. I mean it's much more sophisticated than that, but when you think about if that organ fails what's going to happen is the blood counts fail, the red cells go down. Even the white cells and some other components of our immune system are going to go down also. So, there's the chance for more infections and then so but Azacitidine is… it was the first therapy approved. So, he's a high risk guy, but it's also a personal choice. What does he really want to do and I'm going to make an assumption that he'll go back to the doctor and he'll have another appointment and he'll have another discussion and we change our minds. We do something different and so… but I think probably the best thing that you could bring back to him is just more information and help him make his own.

Q19: My kind of observation was now chemotherapy didn't think of the hair loss on that. Anytime that they're going to do some kind of alternation to the body medically it is considered a chemotherapy. So, chemotherapy gets a bad rap because they think the hair loss and the radiation. Anytime they try to alter your stuff with medicine it is a chemotherapy.

Q20: And I did low dose for a year.

Jean Ridgeway: Low dose Azacitidine?

Q20: Dacogen.

Jean Ridgeway: Oh, Dacogen. Okay. So, Decitabine. They're sister medicines.

Q20: And I didn't lose anything. It was three days in a row once a month all year. It didn't change anything for me, but it wasn't scary. It wasn't something to worry about.

Jean Ridgeway: That's good to… I mean you can hear it from me, but it's way better to hear from a person who's lived it. And even traditional chemotherapy. Right, (Attendee) You probably got like chop for your lymphoma, but that's not a walk in the park, but it's incredible how resilient we can be and you kind of step up for the challenge.

Other things. So, we talked about an allogeneic transplant. Now you know that that means you get the stem cells from somebody else. If you're fortunate enough to have a sibling, you have a one in four chance of matching with them and you said you have two full matches, but it's a high risk procedure with lots of its own very unique side effects that… so it can be… and 90 is too old for a transplant. Our oldest transplant is 75 year old gentlemen who had MDS. So, he's doing quite well. He's about a year and a half out of his transplant. He's doing okay, but I will tell you that the centers across the country although it's being looked at as an alternative, most centers… we screen people well. Where I work we do a very intensive half day. It's called a multidisciplinary conference and we have physical therapy, occupational therapy. We have a geriatric oncologist. We have our transplanters. We have social work. Everybody comes in and spends a half an hour with the patient and the primary caregiver because you need a caregiver and then we get together and we discuss things and make some recommendations and sometimes people are really not well enough to go through transplant. Even if they're 55 sometimes… it's not the magic bullet. So although it's out there and people hear it sometimes people get a little disappointed if they're too old. They think oh, I missed the train. This could have done it, but not necessarily. So and age alone really shouldn't be an exclusion for treatment. It's a complicated question and the other thing about MDS therapies are that the way that they work it's not like taking penicillin or amoxicillin if you have a sinus infection. Ten days and you're done, earache's gone, it's gone forever. That's not how things work with Myelodysplastic Syndrome. You have to be on these therapies for a good four to six months. Most of these therapies like Azacitidine is anywhere from seven consecutive days or five consecutive days every 28 days. So once a month for four to six months and then people get their blood counts evaluated. Oftentimes there's another bone marrow evaluation to see if it works or not. We've had people at our clinic on Azacitidine for years and there's much more literature out there about how long do you stay on therapy. For some people if it continues to work and they tolerate it pretty well they stay on it. Sometimes people want to take a little break and so… but we know that inherently it's a stem cell disorder. So, we're not giving you new stem cells and we're not really correcting the error in the stem cell. So, we need to lok at some options that as patients continue to live with a chronic disorder. So, you'll be followed for life with a chronic disorder, but you can do that. Right, (Attendee)?

Q21: You can do that. Yes. You can do that and, but my curiosity is if the IPSS is part of the thing driving it, I was 51 when I was when I was diagnosed and I certainly would rather be fixed and hope to go through a good portion of life because everything that I've gone through medically every single medication… we're having to watch the liver, the kidney, the spleen, the… you name it, we're having to watch everything closely because every medication can cause damage to the organs. How many medications have I been on because my doctor in Houston goes, "Oh, don't worry. I always have another one up my sleeve," and I'm like…

Jean Ridgeway: I'm going to that doctor. That's where I'm going.

Q21: I am all for that, but at the same time I'm so nervous about my organs and I'm the one being proactive with the local oncology staff going, "Okay. Is it time to do a CMP versus a CBC because I need to know that you're looking at my organ levels and seeing how things are." I would have rather have had the stem cell transplant if I had known if that's something I could have pushed and said is that something you can do?

Jean Ridgeway: Not to be the devil's advocate, but the best hope for long term survival after transplant is having your disease in control before you go to transplant.

Q21: And that's a good point.

Jean Ridgeway: But that wasn't really happening then your physicians at least it sounds like they've, obviously, done the right thing.

Q21: Yeah. I'm under control.

Jean Ridgeway: You're under control without a transplant. Life is not bad without a transplant if you don't really need one.

Q21: I did ask the question and the idea in Houston is the stem cell transplant would be the last option.

Q22: That's what I was told.

Q21: Okay.

Jean Ridgeway: It's so individual. We said at the beginning that around the table are going to be a lot of different scenarios and any one… it's not one size fits all.

Q23: My question to you then is if the best result in transplant is being disease controlled at transplant why is it a last option?

Jean Ridgeway: Well…

Q23: That's kind of where I went with it.

Jean Ridgeway: What the literature says is like when is it best to transplant. There's been a number of studies done and the literature really does support that. People who are low risk MDS they get the benefit when they lose response and do begin to accelerate. People who have a higher grade MDS we know that you need to get them into control before you transplant. So again, it goes back to low risk versus high risk and what the data is really saying. If you're truly low risk and you're getting EPO or maybe you're getting Azacitidine and your disease is under control then the data tells us there really is no benefit to do lower risk versus higher risk later.

Q23: Once you've had a transplant, do you eventually get off all the medications if it goes well or do you still stay on medications?

Jean Ridgeway: Well, that's a loaded question. So, first are you saying to me…? First of all I guess what I want to ask you is…

Q23: To me from everything I'm getting from what you're saying if you're very young and all these other medications can cause so much damage like she was talking about to your other organs, why not have the transplant rather than damage the other organs if you're controlled.

Jean Ridgeway: Yeah. There's a lot of damage that goes on with transplant and the other thing is that although transplants are best hope for long term disease control people relapse.

Q23: Oh, okay. So, you generally don't get off the medications.

Jean Ridgeway: Well, you take some medications if you're a transplant recipient in that to control infection and to decrease the rate of rejection. So, there's a period of time that you do have to be on all of those medicines anywhere from three – six months to a year. They're one of the unique side effects from stem cell transplant is something called graph versus host disease and that means that your body and the donor cells they kind of de-identify one another. Your body says I don't like those cells and so the T cells go ahead and they create an inflammatory response and it can be… sometimes it's easy controlled. Sometimes it's not easy control. People can succumb to graph versus host disease. So, the complications that are involved in allogeneic transplant are… they're pretty significant. It's not a panacea honestly. We kind of breeze through this and say oh, transplants like the answer, but that is… that's a very lightly said statement with a lot of information behind it. So, don't get the wrong impression of a transplant. If you've met with a transplant physician they basically throw all the numbers out at you and they say…

Q24: One of the things like my doctor says is that because the risk still of transplant of death is so very high and he said that would be like one of the last things because what we're doing is working. I'm very fortunate that the doctor that I see goes to a lot of conferences and he talks to a lot of Harvard Business School of Medicine doctors and what have you and so he takes my case and they kind of talk about it. He says it's like getting other opinions without having to pay for them. Which I like.

Jean Ridgeway: You're a lucky girl.

Q24: Yeah which I like and so he says he talks about my case with them and they all said if what we're doing is working then why would you do anything else. And to answer your questions, (Attendee) when you talk about the stuff of other things that other organs that it's affecting and what have you. I can't even… when you read the stuff about what medicine does… I can't even look at that. I get that thing in the mail. I take my medicine and I shred that stuff. I've already read that and I don't want to know anymore because if you read that it's…

Q23: So much (inaudible 54:53).

Q24: It does. It scares the crap out of you. You wouldn't even take if you actually sat down and you read it and you're like oh, my God. I'm going to start taking this. Are you kidding me? I don't even read it anymore. It's like yeah, yeah I know that. They give you that survey every month and you're like yeah, yeah, okay. I can't.

Jean Ridgeway: People who are on Revlimid or Lenalidomide since it's an analog of Thalidomide, the FDA has some pretty stringent rules where you have to take a survey every month and say I'm not going to share my medicine and all that kind of stuff. Okay. Yeah. Fine because they won't dispense the drug without it.

Q23: The pharmacist has the whole survey they may have to fill out with you.

Jean Ridgeway: It's the world we live in. What can we say?

Alright. So back to like for therapies for Azacitidine or even Lenalidomide the therapies take time to work because what we're trying to do is change… we're trying to change the natural history and trying to change the bone marrow itself. So, it takes a while to work. So, sometimes if there are people here who have a family member that hasn't started treatment or they're about to start treatment good to know that you need to just give it time. So, give it time and blood counts can get worse before they get better and the other thing is if you are on treatment to be in good contact with your healthcare provider. I don't know with physicians we have a lot of nurse practitioners and physician assistants, but you should have a number where you can contact people and earlier is better than later. So, if you start having diarrhea, common things occur

commonly, but if it's not better in, say, 48 hours or you have a fever you need to give a call if you're on treatment. So, that's that.

So, this is just a little carton and what we're looking at is why is time required? So, you saw some actual slides of MDS before and so this little cartoon shows that in the bone marrow itself the red disks are the red cells and then the yellow ones are the bad cells and you can see that there's quite a bit of activity in there, but as far as with the MDS what happens is things begin to get very crowded in the bone marrow itself and there can be the ability then to produce normal cells. So, you begin to see a decrease in blood counts and that's what we talked about. It drives people to the doctor. Some people get really sick and then they show up in the emergency room. It's not uncommon that it usually happens on Friday at five o'clock when I want to sign my pager out that I get a call from the ED that we need an emergency bone marrow. I'm like, dude, an emergency bone marrow just like doesn't exist. So, but if you get profoundly anemic and it kind of you're living with it, but then say you go out on the golf course and you want to golf the stress is going to tax your organs like your heart. So, people go to the emergency room with chest pain and they can be found to be profoundly anemic. So, the MDS is decreasing the body's ability to do that and so as you start to go through treatment then what happens is that the malignant cells begin to get cleared out of the bone marrow. So, one of the things that's interesting in hematology is that even though we can have a malignant clone that's creating these blood cells it is creating some blood cells and then when you go and you get rid of it you have a bit of emptiness. So when I go on vacation in July and I leave my garden untended when I come back the weeds have overgrown and so I go in there and I start plucking out all the weeds and my little garden, my good guys are kind of like hanging on by a thread and so it's the same thing in your marrow. You got rid of the disease and the healthy cells are few and far between and they need some time and space to regenerate. So, we begin to see more decreases in values before things improve and get better and they can actually grow healthy. So, what we're hoping for is that the bone marrow then begins to respond and people create good blood cells and they repopulate the bone marrow because some medication has been able to create a new garden basically and then what happens is your counts recover and you get weaned off of what we call supportive care. Supportive care is getting transfusions, maybe getting growth factors as the bone marrow begins now to produce normal cells that give us all the things that we need to function. So, that's kind of a simplistic way to look at it and the graph just shows that and ANC stands for an absolutely neutrophil cont. So when the hematologist looks at your blood counts, your CBC they kin in on a lot of things but the big three are they look at your white blood cell, your WBC and the subtitle under that is the absolute neutrophil count or the ANC and that's something that helps us understand how vulnerable you may be to bacterial infection. So, sometimes when people's ANCs are very low you get an antibiotic and they say take this as protection, prophylactic, and so you can see at the beginning that people's white blood cell counts can dip pretty dramatically. We pick a number of 1,500, 1.5, for an absolute neutrophil count. We'd like to see all of our patients live there with that. That helps us feel better and hopefully will help people get through without infections.

Q25: (inaudible 1:00:45)

Jean Ridgeway: So, the absolute neutrophil count. So, what we like to see are patients to have an absolute neutrophil count of 1,500 or greater. Now if you just look at the WBC, the white blood cell count, there's a formula to calculate it. In our day and age, fortunately, there's usually it's calculated for us underneath. There's something called a differential. What kind of white cells are within that WBC and so if you see an… sometimes they call it an absolute granulocyte count, but it's an ANC. So, that helps us for bacterial infections. The other thing that you can do is that get a flu shot. That does nothing to do with your ANC, but if you want to talk about keeping healthy, that and good hand washing. So, I'm a big proponent of when you enter the store to wipe off the cart, the handle on the cart so to keep yourself as healthy as you can.

Q26: You said 1.5?

Jean Ridgeway: 1.5 is if you like… if you do… or 1,500. So, that's what we say; 1.5 would be the absolute neutrophil count. So and sometimes during that low dip point then that's when people start having side effects and it's not uncommon for some people who start with Decitabine or Azacitidine sometimes with Lenalidomide as well that they have some side effects and sometimes they may get fevers or end up in the hospital during that first or second cycle because their counts can really plummet as the bone marrow is getting healthier. So, fever is just something that needs to be respected. So if you get a fever you're really not feeling, you got to call somebody because we need to take care of it and probably have to see you. So sometimes it means that you come into the hospital for a couple of days. Hopefully not, but if that's what it takes to keep you healthy in the long run then that's what happens.

So, there are lots of things that can be done, but again so a minimum of four to six months. Things get worse before they get better and sometimes with the blood counts trending down it may take blood counts a longer period of time to get better or back to a good level. Sometimes the dose of the drug has changed or sometimes people wait for an additional week to start the next cycle of treatment.

So when people start if you're brand new to Lenalidomide or Revlimid you usually come in every week for a good eight weeks and we're going to see what your CBC does because if you go too low and a lot of people do at the beginning then the dose has to be changed and that's not uncommon. In the clinical trial about 80 percent of people who started on that drug needed a change in their dose.

Q27: I started on 10 (inaudible 1:03:40)

Jean Ridgeway: Because your counts went down.

Q27: And I thought (inaudible 1:03:47)

Jean Ridgeway: So, what would you recommend?

Q27: I recommend sometimes you just have to take a deep breath and you just got to go with it. I didn't know really what to expect. I was going to my doctor every week, but my daughter was also playing volleyball, it was her senior year in high school. She's on Varsity. I didn't want to miss a game.

Jean Ridgeway: But you know what? We all live life to live.

Q27: The only thing is I didn't want things to change and that was my biggest thing in my mind I wasn't going to let it define me or change me. I thought I (inaudible 1:04:46) but you have to (inaudible) it goes down. You got to deal with it.

Jean Ridgeway: People feel pretty tired.

Q27: Oh, I was tired.

Jean Ridgeway: And you have to rest but the other piece is that being active is also very helpful in keeping… it sounds counterintuitive, but you almost have to be active to feel better. You can't just slide into the PJs and live in them. It's better to get dressed, get your make up on, shave and get out.

Q27: (inaudible 1:05:19) this too shall pass is what I have to tell myself. (inaudible) The calm (inaudible)

Jean Ridgeway: Exactly. I think sometimes it's hard not knowing anybody else who's ever had this disorder. You don't really have an advocate to bounce it off. I will tell you that the Leukemia and Lymphoma Society, so LLS.org is another really good organization that helps people with blood cancers. They actually have a patient program where patient survivors become trained counselors and patients who are newly diagnosed with a blood cancer can call the local chapter and ask to be in contact with another patient. So, I usually recommend that. I only give my perspective. I don't give the lived experience. So, it can be really helpful to just meet up with somebody.

Q28: They call (Attendee) at oncology their forever patient because she's been going there for so long and people go for different chemos they're there for a short period and they're done and so it's like she's like the regular face there.

Q29: I told my doctor happy anniversary in January.

Jean Ridgeway: That's good. That's good.

These are some slides from one of my colleagues, Sandy Curtin, who works in Arizona and so these are looking at a patient's blood counts and just to help you maybe get a little bit of a sense of how patients' blood counts can be. So, the pink squares are hemoglobin. That's what carries the oxygen. The yellow triangles are platelets and then the blue ones are white blood cell count. So, what you see starting over to my right is that the white count was kind of low. The hemoglobin was pretty high, but his counts kind of went up and down and up and down and he went through four cycles, but if you look at the yellow boxes the platelets go up and up and up all throughout, but look how long it took him. It took about till the third cycle to see a change in the platelet count and his hemoglobin looks like it followed almost a predictable cycle where it would drop and then recover and then drop again with the initiation of therapy, but here at the beginning he starts treatments with some lower blood counts or we say cytopenias and if you think of your bone marrow as the factory that makes your cells these medications are trying to fix the factory and then he actually had more transfusions needed before he got better and then this is a gentleman who did get a transplant and so then he gets somebody else's cells on the other side of that rectangular box and counts are better. So, it's just a cartoon to give you a… Now somebody was saying how long am I going to be on this? This is a patient who's been on Lenalidomide for 10 years and in this old slide. So, it[s a couple years longer, but what you see is the same thing. Hemoglobin, platelets and white count and so you see when this person started way back in 2002 he must have been on the clinical trial, the hemoglobin he was like nine and eight and then lo behold maybe about many months into it you see a gradual increase in his hemoglobin all the way across. So, he lives now his new normal is 11 or 12, but still not "normal" for a man, but very much improved and I would think he has a good quality of life. The same thing with the platelet count. Over time, again, how long can you be on it? We don't really know how long people can be on it because these therapies only came to be in the 2000s, the early 2000s. So, here this is all the way over to 2011. So, people do stay on therapy for a long time. In the world of oncology there's different meetings that we attend, the American Society of Hematology, and we look at long term follow up. What happens to patients? Somebody asked the questions about secondary malignancies and Lenalidomide and there is reports of some secondary malignancies in the literature. They're not zero, but they're not 90 percent or the FDA would pull the medications off the market. What it speaks to is you have to be diligent about your healthcare. You still have to do that other stuff like mammogram and the colonoscopy. If things change on your scan you should be evaluated. If people have an abnormality that's a malignancy, it sets you into a category that you're just higher risk in general. Something about your DNA has allowed one malignancy or one abnormality. So, you need to pay much more attention to your healthcare. So, that's a good thing.

So, what can I do to stay healthy? There is no magic diet. Just eat a balanced diet. You can be a vegan. You can be like a carnivore and a staunch carnivore and dinner just eat balanced diet. I want some brisket before I leave by the way. Anyway. How about daily activity? Yes. Even walking. Walking is a good thing. All of us should have at least 20 minutes of dedicated intentional exercise. You can ride a bicycle, you can walk, but you can find something. There are

a lot of options. Avoid infection. So not only do you get a flu shot, everybody in your house gets a flu shot. No, they're not going to be allergic to it. They're not going to get sick from it. It's not a live virus, but they should get it. They really, really should and do the things that you like to do. There's a lot of resources. One of the most common things that folks with MDS talk about is that they can't do the things they want to do because they have fatigue and tiredness and so you need to be brave and humble at the same time and know when to ask for help. Somebody else could clean your house or they could carry down the laundry. So, finding that balance of wanting to be super person but knowing that you may need a little help and that's okay. Most people will way what can I do to help you? Give them something to do. They can clean out your gutters. Gutters are moldy, yukky things that immunocompromised patients shouldn't clean out their own gutters, (Attendee). So, find something that you can practically do and save your energy for the things that you want do.

Q30: Do you suggest pneumonia shots and shingles shots as well?

Jean Ridgeway: So, pneumonia shot is fine. The shingle injection is a live virus. So depending on people's white count, it's only approved for those people over the age of 60 and depending on where like their immune status is, yes or no, but it is a live virus. If your spouse gets the injection, the shingles shot, they are not contagious unless they develop the pox. So they get the vesicles. Otherwise they're not contagious. So, it's fine for the people around you to get it.

I told you I was going to stay on time. I have two minutes. So, a couple things I wanted to tell you also is that if you're very interested and you have a family member with MDS there's an app on the phone called the IPSS-R and so you could plug all that little information in and you can also go to the MDS Foundation website and you can play with it there. However, there is no professional interpretation, so be very careful when you do that. So, it is available, but in order to understand that remember people go to school for a really long time and it's very sophisticated. So, it is available. It's out there. I have to do it, but that's kind of my job. So, it's a little different, but it is available for you and the MDS is coming out with an app. Right, Audrey? One of my colleagues, Sandy Curtain, is working on that and so stay tuned, maybe September?

Audrey Hassan: I think so. Right now we have (inaudible 1:14:08) working so, yes in a couple months.

Jean Ridgeway: There are other apps out there. I'm not really super techy savvy, but there's symptom trackers, there's blood count trackers, there's all kind of stuff. More stuff than I definitely know about. Anyway.

So, tools and strategies. If you have a book that's great. There are extra ones here. Correct? So if you'd like to bring some for your doctor's office that would be lovely. I'm sure they would appreciate that or even for your family if they want more information and, again, you can download this on PDF form and in the book it does go through some strategies just kind of like

for living. It talks about how do you manage maybe constipation, what about nutrition. So, there's just some helpful tidbits. So, that's just kind of generic. I have one minute and this is just more about the book. Under tab five, you may want to make some extra copies and here's about the app and I guess the other thing that I would encourage you to do is that your health information belongs to you and if you're interested, not everybody wants to, but if you want a copy of your CBCs, if you're not on electronic medical records where you can get them you can request them and you can get copies of your for the interpretation of your bone marrow and that's your information and if you see another physician, if you see for a second opinion they're going to ask for probably the slides from your last bone marrow as well as the records, but I would encourage you to keep your own health records. Own that and do have copies of that for you because that can be really helpful and then there's also an advocacy and an outreach program. Were you going to speak to that at all?

Audrey Hassan: I think during the session (inaudible 1:16:07) about and I'm also available (inaudible) our heath program stays actually to create a self-sustaining support group. I know I should (inaudible) but the MDS Foundation supports a group (inaudible). We also (inaudible) to get information out on (inaudible) I can make that have to preapprove. I don't actually work with Dr. Helmer's social worker. So, after this when I go back to New Jersey I'm going to contact her and (inaudible) but either way (inaudible) and keep everybody in touch and after (inaudible) if you have any questions (inaudible) yesterday we're going to give everyone my card so they can call me. I'm happy (inaudible)

Jean Ridgeway: Because this can become a springboard if you're interested like meeting other people in the area. Now with electronic media, getting things out on Facebook is a good way. Support groups are hard. I did been quite a bit of work with them and they're never easy. We're all busy people in different stages of life, but it is nice to be able to connect with someone else or like in the caregiver role or in the patient role to do that.

Q31: (Attendee)'s been dealing with what we have for seven years and she's only met one other person with MDS in all that time and it was at an MDS seminar. It was… What's her name, Robin?

Q32: Cancer survivors… Robin Roberts.

Q31: And that's the only person, but of course she's not…

Jean Ridgeway: Well, that's kind of a big (inaudible 1:18:03) person.

Q31: She's not going to be talking to her on a regular basis. So, it is nice…

Q32: Plus she hasn't gone through what we've been going through as long term patients. So, as I told Audrey I wanted to meet people in the area who are going through regular kinds of treatments.

Jean Ridgeway: Absolutely. Alright. I'm true to my word. It's noon. It's time for lunch and then after lunch we're going to have…

Audrey Hassan: Dr. Goldberg.

Jean Ridgeway: Dr. Goldberg. Yeah. So, I think we're having lunch in this room or across the hall?

Audrey Hassan: (inaudible 1:18:34) I'll double check (inaudible).

Jean Ridgeway: So, please go around and introduce yourself if I… like Audrey said, people will be connected after the meeting, but I would encourage you to exchange names and E-mails.

Thank you.

(Applause)