Speakers:
Jamile Shammo, MD, FASCP, FACP
Jean Ridgeway, MSN, APN, NP-C, AOCN

Q1: (inaudible 0:00) treatment (inaudible 0:01) and we are really happy with the doctors and the nurses and everything there. So, we're okay.

Jean Ridgeway: Good.

Q2: I'm *(Attendee)* and I was diagnosed in 2011 (inaudible 0:20) with the refractory anemia and ring sideroblastosis and I have told in the conference I'm Vidaza resistant, Revlimid resistant. I'm on Exjade for chelation. I'm in my 130 or 20. I lost count of my blood transfusion and they evaluated me for bone marrow and did not… They won't do it. So, I agree with the first gentleman who was talking about spiritual. My spirituality is the one that I hang on. I do yoga and meditation and he's my best caregiver I think after (inaudible 1:12) retiring from my (inaudible 1:15) clinic. I am his first dog pet. He takes care of me more than I take care of myself.

Jean Ridgeway: That's great.

Q2: Thank you. Thank you.

Jean Ridgeway: Well thank you for coming. Who's next?

Q3: My name is *(Attendee)* and my mom was diagnosed in 2010. She was taking Vidaza and she stopped responding to it and now she started Dacogen and the reason I'm here is because I want to know what are the treatment alternatives if Dacogen doesn't work what do people suggest as an alternative for possible… maybe not cures, but treatment that could work long term.

Jean Ridgeway: Good for you for coming. Who'd you bring with?

Q3: I brought my fiancée *(Attendee).*

Jean Ridgeway: Wow. A fiancée. That's good husband material, right ladies? Welcome *(Attendee).*

Q4: I'm *(Attendee)*. I'm here with my husband *(Attendee)* and he's the one who has MDS and I like to reiterate that just like several other ladies have said that the positive attitude, I think, has a lot to do with how you feel and how progressive the disease and he seems to be pretty positive all the time or most of the time about it which is a hard thing to be positive with.

Jean Ridgeway: Hi, *(Attendee)*.

Q5: I'm *(Attendee)*. I've had some… they started searching for something 10 years ago around after 18 months they found out what it was and right now all I'm really on besides your regular stuff that they load you up on a bunch of pills is testosterone which replaced Aranesp because my body quit responding to it. So down the road, I'm going to have to go to something else because testosterone eventually my body will get used to it and it'll lose its effectiveness. So, I'm here to just watch… One thing I have noticed though ever since I've been going to these and ever since started how much really the treatment of MDS has changed and like a few years ago she would have never showed all those medicines because for a while there I was down to two. Now, it's back up…

Jean Ridgeway: Welcome back. I have been involved with the MDS Foundation for a number of years and so I've seen *(Attendee)* before. I think I've seen you. You were at Rush last year and of course a celebrity, but you know… Alright. Who's next?

Q6: I'm *(Attendee)* and I was diagnosed just 18 months ago and right now I'm on the watching and waiting and maybe starting Aranesp. I don't know, but I like his testosterone story better. That might be better than Aranesp.

Jean Ridgeway: Ask the doctor.

Q7: I'm *(Attendee)* and I'm his wife.

Jean Ridgeway: *(Attendee)* has a broken wing. Go ahead. Who's next?

Q8: Yes. My name is *(Attendee)*. I've been diagnosed with the MDS CMML for less than a year. I've been six months of Vidaza and it failed. So, I'm looking for other options and one of the hardest part is I'm just by myself. So, I don't have like person to drive me or just to look after me. So, that's becoming a harder part with the transplant as an option. So, I'm also looking for clinical trials. So, just in between change now trying to evaluate what is good and bad there's hope. So, that's where I'm at.

Q9: I'm *(Attendee)* and I was diagnosed in the fall of 2011 with RARS and I'm on weekly shots of Aranesp and periodic transfusions.

Jean Ridgeway: So, let's see. I'll tell you a little bit about myself. I'm a Chicago resident. I live up on the far northwest side and I started being interested in MDS and hematological malignancies when I was first starting out as a nurse many decades ago and MDS was really an unknown kind of entity. Some folks has referred to it as preleukemia. I must have slept through the leukemia lectures as well because I didn't remember that either, but found myself on a combined at a big academic hospital, leukemia and solid tumor unit over at the University of Illinois and became exquisitely interested in it because lo and behold one of my parent's best

friends who had just been the stellar picture of health showed up on our unit one day and that really started my journey and learning about it and one of the bonuses of working at an academic institution is exposure to clinical trials. So as a bedside nurse, we started doing a study. It was called the CALGB9710 study, not CALGB stands for what used to be a large cooperative group which is now called Alliance, but it was called the Cancer and Leukemia Group B. 9710 meant that it went to the FDA for approval in 1997 and it was the licensing trial that brought Vidaza to the FDA and allowed us to gain license in 2004. So in 1997 when we were doing that study, we had some patients on it and so I'm going to tell you a little secret. The patients were given the medicine and they did their shot at home. Now, the drug comes as a powderized agent in a small little vial and it had to be drawn up and then you had to insert the sterile water and so patients had to like learn how to mix it and learn how to draw it up and give themselves injections because in the study it was given every day for seven days and we just found it easier as people came back and forth who wants to come the clinic every day? Of course, absolutely no one. So, people learned how to inject at home and they did. So, but then when the drug got approval there was a lot of concern from our lovely government that said how could we do that? People do it with insulin and they do it with a lot of other things, but I guess they won't allow us to do it and so you have to come to the clinic to have it done. So, we started looking at that and started watching people have really good results. Now, one thing… I don't know how much you read about these clinical trials, but when that study was done it was called a crossover design and when people responded… When they lacked response they could crossover. So if they were randomized to supportive care, the flip of the coin says you get drug, you get supportive care. Well, if her counts start dropping then we can switch her over to the side that gets agent, but after people had the drug and they had a response, we stopped and so predictably as those folks who were followed for what happens to you after a clinical trial what we noticed was that people fell back into an old pattern. The disease reared its head again and people relapsed. So as studies went forward, it was found out that how long do you treat somebody with it? You treat them long enough to evaluate if they can have a response usually after four cycles and then you can keep them on as long as they continue to benefit and that's very variable as we've heard around the table. Some people don't respond at all. Some people have terrific responses. We have a gentleman who has CMMOL and he's had 48 cycles of that agent. So, he continues to do well and sometimes people take a little holiday, tired of coming to the clinic want to get free for a while and so there's off label recommendations of what people can do and rechallenged again.

So, that's how I started getting interested in it and then got involved with the MDS Foundation. So this foundation if you don't know much about it historically grew out of a group of patients and families whose loved ones had this disorder and they wanted to see things get better and so that's where this all started. It's considered a grass roots organization because patients and family members really are the pushing force behind it with the goals that educating not only patients, but educating providers worldwide about what's the standard of care. So if I live in England, I live in China, if I live in the US, hopefully, I can get the same healthcare because these are the recommendations. There's some limitations as you can imagine just with nationalized health insurance across the world and our own insurances - private versus public,

the VA, whatever. So, there's a lot of variability with it, but the goal is to educate providers to find new sources of treatment for patients and to get good information to patents and families.

So, that's what we see and so there's a group of us nurses because it's interesting. I think anybody in this room has had a blood transfusion knows that you spend some time with the nurses and so nurses really need to know what's going on and just like you mentioned you didn't know about this in nursing school because it's a rare disorder. So unless you have a personal interest for whatever reason, you're not going to learn about it until you put some effort into it and so as a group a number of us try to help each other and help patients to learn a little bit more. So, that's what this is all about. There's a whole group of us. You can tell we're from all over the world. We've done some great events together and tried to put together some learning materials as well. So, we represent across the globe and these discussion groups are held across the globe. So, it's very interesting and patients have no matter if you live in Greece, Argentina or the US, people have the same concerns. Families have the same concerns.

So, these are some of the things we'll try to cover. I really am very serious about being respectful of your time. It's a holiday weekend for goodness sakes. It's gorgeous outside, but I got to tell you this room is fabulous. What a great looking room we are in. So, it's kind of fun to be down here and I hope you enjoy your surroundings as well. Anyway, we'll go through some of these. If we don't get through all of them that's okay because there's a book, the binder, goes through all of this as well. So, but it's your chance to maybe hear it in a different forum and to ask some questions. So if you have a question, help me by just pressing the button so I can hear you. That'd be great.

We just really want to look at Understanding Your Disease and Dr. Shammo talked a lot about that. I think she's a great physician and she works with MDS patients and does a great job and she talks just like a physician which may be a little bit at a level that's not quite understandable to you. So, I'm hopeful that the reinforcement you'll hear from me will say, "Oh, yeah. I heard that before and I understand that a little better." So hopefully, that'll happen in our time together and really helping both you and your family members to become a partner. If your mom or dad or your spouse has this disorder and you need a partner. That's very helpful is to have somebody who is understanding about what's going on with you, what's normal, what's abnormal, what to expect, etc.

So, what I didn't tell you is that I work in the outpatient arena now and I work probably half of my time with stem cell transplants patients. I work with adults. So if you're older than 18 to 19 that kind of falls into my domain. If you're younger than that, we have our colleagues in Pediatrics that treat, but I work with primarily adults and all of them have hematological malignancies. Question.

Q10: Which university or hospital are you…?

Jean Ridgeway: Chicago. University of Chicago, 5741 South Maryland. We built a great new hospital. Probably seen the news flashes. People are very unhappy with us lately because we don't have a trauma center and so we don't have a trauma center. They lost their licensing for that and for whatever reasons I'm not super familiar with health policy, but I know that it's not in the plan of the University to reestablish a trauma center there. Keep your eyes open. You'll be seeing something real soon. Trust me.

So, what is MDS? We talked about this. What is it? It's Myelodysplastic Syndrome. So, it's a syndrome of disorders. It's a group of bone marrow cancers and it's clonal. Clone means that one thing look like another. So Dolly, the sheep, remember her? So, why did they call her Dolly? Because she was named after Dolly Parton. She was cloned out of a mammalian cell, a breast cell. She was a clone. Big trouble. So in this case, all the cells look like each other. So when the pathologist look at your material underneath the microscope, to them the trained eye, one cell looks like another looks like another of the malignant clone and it's a hematological malignancy. It means it's a blood cancer. It originates from the stem cell. We know that the error has occurred someplace in the stem cell lineages and so when we talk about blood development the mother cell is a stem cell. So, you have to be a little bit careful when you hear about stem cell because sometimes in the media you hear references to embryonic stem cell. That's not at all what we're talking about. We're talking about the originating cell that makes all of your blood lineages. So, that's called a hematological stem cell and it's not one disease, but it's a group and it originates in the bone marrow, but it looks very different. It can behave very differently. It's got lots of different names. So, people call that heterogeneity. So, it's very different. So, just like in this room your case is very different from your case. Although you share a lot of common issues and problems, things are not identical.

What happens? So, the cells are abnormal in shape and size. They're called dysplastic cells. So, cells that don't have normal shape cannot function normally. So if you went outside and someone swapped all your car tires for triangles or squares, you would have wheels on your car, but it would be a bumpy ride. Just wouldn't be the same. So, dysplastic cells do the same thing. They just are not able to function like they should. So, if you have platelets that are… you may have 100,000 platelets, which is still not a normal platelet count, but if someone wants to do surgery on you or put in a portacath, some type of venous access device, you're probably going to have a lot of difficulty with bleeding because the platelets you have don't function normally and the other thing with MDS is that cells that don't work well lead to ineffective hematopoiesis and then the result is something called cytopenias. That means your blood counts are low. So when your red counts are low, you're anemic. Correct? When the white cells are low you're neutropenic and when the platelets are low, you're thrombocytopenic, but if all of them are low, I heard you reference before that you have pancytopenia. That means that all the blood counts are under the normal level. There is a risk, about a 30 percent risk, of folks developing acute leukemia. So the natural history for some people if they have a more aggressive disease, people can evolve to acute leukemia, but not everyone, but in general as the disease goes on the bone

marrow function can decline. You might need more transfusions. You may need a different therapy, but things can be stabilized at a number of different junctures with different ages.

So, here's a little cartoon that comes from the National Institute of Health and so here's the healthy bone marrow and what we're saying is this is the hemopoietic stem cell, the mother cell, and when it decides to become a blood cell it makes a very big decision. It becomes one of two main families. The upper ones are called lymphoid cells and those are B cells and T cells and MDS is not directly involved with lymphoid cells. It's involved with myeloid cells and that's the M in MDS. So, myeloid cells if they were normal and functioning in your bone marrow, they should be all these ones over to the far right, neutrophils and that's what they look like. The acidophils, red cells and then platelets. So, that's what a normal functioning bone marrow that's what it looks like and that's what should happen.

Now, if things begin to get abnormal what happens? We're not quite sure what the triggers are for what causes and allows some people to develop MDS. It could be prior therapies with chemotherapy, maybe it's immunosuppression due to some other type of illness. Maybe exposure to radiation or if you had radiation in combination with some other therapy, but what's going to happen that instead of developing normal cells, you have these abnormal cells and they're very immature and so immature myeloid cells are called blast cells. They don't grow up and become healthy, productive cells in your bloodstream. They just get stuck in immaturity like you'd get stuck in adolescence. It's not a good thing and so they also have the unique ability to continue to replicate themselves without dying and that's called immortality, but when you have malignant cells that immortalized it's never a good thing because they just keep reproducing. So, one becomes two and two becomes four, but then four becomes 16 and 16 becomes 64 and so on. So instead of having a slow progression, you can have quite an acceleration of malignant cells that are in your bone marrow and what happens is those malignant cells, the bad cells, they crowd out the good cells. So when I go on vacation and I leave my garden unattended, which I do every year. When I come back, what's there? Are the good cells there and the good plants? Yeah, they're kind of there, but what really benefitted while I was away?

Q11: The weeds.

Jean Ridgeway: The weeds. You betcha and so plenty of weeds in the garden. So, plenty of bad cells in the bone marrow are like plenty of weeds in the garden. The normal cells are still there, but they're struggling. Do they have a survival advantage over the weeds? (Disagreement sound) I don't know why, but every year those doggone weeds come back. I never plant them. I don't know why they're there, but they're there and they cause havoc and it's the same thing with these MDS cells. We don't know why they're there. We don't know how they got there, but we know they're there and they crowd out the good cells.

So, how is it diagnosed? So, it sounds like everybody in this room has been diagnosed. There's no one in the process of get diagnosed, but you get there almost serendipitously. You don't feel

good. You're kind of tired. Maybe you've had some infections, but it can be a number of weeks or sometimes months or years for some people to get diagnosed, but to actually make the diagnosis of MDS you do need a bone marrow biopsy. They look at your peripheral blood and we check lots of things, but you do need a bone marrow biopsy and aspiration and then we check. She showed you a nice picture of the cytogenetics. So, that was one cell and since it's a clonal disorder then the chromosomes are going to look… the chromosome from one cell is going to look just like the chromosome from the other usually. So, that's why if you look at one, you can pretty much predict what they're all going to look like. So, that's cytogenetics. We look at how much iron do you have to start with and then additional tests.

So, she mentioned too about sometimes people can have a missed diagnosis of MDS because some things masquerade like B12 deficiency. So, people who have B12 deficiency can have GI problems. Maybe they've had a big colon surgery and are missing a big part of their colon. These folks who are having these big banded… the people who are rather obese and then they have their stomachs stapled or they have their intestines rerouted. They just don't absorb nutrition like they used to and they can have some problems. Folks who drink their lunch and breakfast and dinner instead of eating can have a B12 deficiency. So, alcoholism and you have to check a TSH level and then a testosterone level can be helpful as well and then you also want to look at how well are the kidneys and the liver working. So, all those things were checked for you as you went into it.

And then she talked a bit about this but when MDS first began to be more commonly recognized there was a process of what are we all talking about. Correct? So, people wanted to call MDS the same disease in every language and prior to 1972 that really was not happening. So not so very long ago the very first classification system came up and they call it the FAB and that stands for French, American and British and those were the three groups of hematopathologist that got together and defined what they were looking at and if you see the categories, there's five of them: RA, RARS… I've heard you guys like with these terms, CMMOL, CML, RAEB, but you can see that four of the five are based with the RA and that's called refractory anemia and it really points to the truth that about 80 percent or eight out of 10 MDS patients have trouble with anemia. So, it's very common. So, you can have refractory anemia. You can have excess blasts. How many is enough? If you have five percent… When we do a bone marrow biopsy and the pathologist read it for us, up to five percent is normal, but if you cross the invisible line of more than five percent of blasts in the bone marrow that's abnormal. So, that's excess blasts and they used to talk about RAEB1 and 2, how many blasts make it still MDS and that's changed a little bit. The WHO stands for the World Health Organization and this first classification came out in about 1997 and a lot of things began to change. So in '97, more people had computers. Correct? And that meant hospitals, too, and so what used to be confined to the academic centers was now out in the community and so cytogenetics which was a more specific specialized test has also moved out in the community and they began to recognize that all these different chromosomal abnormalities played a significant part and really needed to be identified a certain disorder. So instead of someone just having RA or refractory anemia, they could have RA but with a 5Q-. So

that meant on the fifth chromosome, on the Q arm part of it was gone and in 2008 that was updated and it's actually in the process of being updated again. So, she talked about the point mutations a little bit towards the end of her presentation. As the new classifications come out, we'll also begin to see more references to point mutations. So, further definition of how very specific the diagnosis can be. Question.

Q12: What does 7 chromosome Q deletion mean?

Jean Ridgeway: What does…?

Q12: Is that more severe?

Jean Ridgeway: So, it means… 7Q deletion. So, chromosomes have… If you remember the picture that she showed you of the chromosomes they look like these long skinny worms. If you remember really hard, in the middle there's a pinch. It's called a centromere. So, there's actually arms above and arms below and if you're above the pinch, you're a P arm, if you're below the pinch, you're a Q arm. So when they talk about 7Q- if it's a true 7Q- that means if I'm the seventh chromosome and here's like half of me and here's the other half then my Q arm on the bottom is going to be missing. So, what's difficult to grasp if you're not familiar with genetics is how much information is carried on that group of genes within the chromosome and so it would be similar to going out to your car again with the square wheels. Now, you've lopped off the front quarter panel. So, a lot of your car is missing and it may not work so well and so it's the same thing 7Q-. So in MDS, 7Q- is considered an intermediate risk. So, it can pretend a more aggressive disorder.

Q12: So, my second question to that is what is a typical life expectancy with someone with the 7Q deletion?

Jean Ridgeway: Lots of…

Q12: Is there a typical?

Jean Ridgeway: No, there's not typical and most people will say just like at the end she was talking about people talk about survival or prognosis. There's so many factors like how old is the person? Are they 25 or are they 95?

Q12: They're 76.

Jean Ridgeway: It's a very complicated question because you can't look at it in isolation. It's one determinant, but it's not the only determinant.

Q13: So, what does this gene…? I have gene 7 monosomy.

Jean Ridgeway: So you have a monosomy 7. So monosomy 7 you should have two pairs. So, if one pair is missing then you only have one of those chromosomes.

Q13: So, what is that translating to in terms of…? What is a 7 gene function? What does it do? Like there's so many genes on there. Each one has got a different function?

Jean Ridgeway: So if you have monosomy 7, it means you have one chromosome 7. On chromosomes are genes and then genes are the computer language basically that tell how to have our bodies function. So, there's actually a website that you could go to. You could look up chromosomes and the different genes that are on them, but whenever you're missing a significant piece of information within your chromosomes, it's not a good thing. So… and again, we don't know all the functionality of every gene on that seventh chromosome, but what we do know is that when you're missing pieces of chromosome it usually means that your disease is going to be more stubborn. It may be less effective… less… you may have less benefit from treatment, but it's not the only thing. It's not the only thing and the other thing is that when they look at your chromosomes, they usually count 20 of them. That would be the standard to count 20 and when you read the chromosome report, it may say three out of 20 or it may say 20 out of 20 that all 20 cells that they looked at and there's variability in there. It can be… It has to be at least three to be counted as clonal. So it depends on how many of those cells carry that abnormality as well, but again not in isolation. You have to look at a lot of different disease factors to get the information.

So we looked at this a bit before. It's the IPSS scoring system and we know that CMMOL is not a disease that you can use it for and the other important thing to know is that this is done with initial diagnosis. So if you've had treatment for a year or 10 years or 15 years, the IPSS scoring system is not used. It's done at the beginning to understand how the disease is going to behave. So, it's a static measurement and on the MDS Foundation website, there's an IPSS calculator. It's also you can find it in Google. So, and it will spell out for you if you enter the data that they're looking for, the number will come out as well and, again, remember we talked about that it's blast percentages, the cytogenetics and then the cytopenias and then the IPPSR or the revised IPSS scoring system came out in 2012 and it looked at the effect of transfusions on someone who has MDS as well and then it further categorized out the significance of cytogenetics. So if you want to be inquisitive, you can go to the website and *Blood* is a magazine that hematologists read. That sounds very appropriate, doesn't it? So, it has public access and if you want to read the entire article, there's the website for you. You can go in and get it and read the whole article and then here's the IPSS-R.com. There's also an iPhone app for you as well. So if you're interested in any or all or none, it's all out there. So, it's out there in the public domain. So if you don't get the information from your practitioner, it's your health information. Remember that you can ask for your health information and you can get it because it belongs to you. So, you can go ahead and get that and plug those in.

So, what do we know about MDS? Average age is 73. It's more common in men than women. It remains an incurable but treatable malignancy and we know that transplant, allotransplant, is the "only cure," but the leading cause of death for groups of folks is really the disease itself and we look at risk stratified treatment strategies to help people understand what treatment is best and what does that mean? Risk stratified means that if you're low risk you're going to be treated… options will be presented in one set of categories, but if you're a high risk person those treatment options are going to look a lot different. So, that's what risk stratified means.

When do you get treated? So somebody over here is on watch and wait. (Attendee), you're on watch and wait. So, that's kind of an uncomfortable place to be. So, the doctor says, "Okay. You have this and we'll see you in a month and check your blood counts." Six months. Okay. Whatever the duration is, it's kind of an uneasy feeling to say that okay like what on earth is going to happen to me, but watchful waiting for some folks is appropriate. You get the diagnosis if you have a low risk disease. We know because of lots of other folks that gone before you what to expect, but if you're uncomfortable with that, you know, you can say well, I'd really like to come back in three months because six months seems like an eternity to me to wait. So, could we come back a little earlier? And that's okay, too, but watchful waiting… So, it's all based on how things ar going with you. Transfusion dependence can be a trigger for treatment. I'll tell you I have a lady who has refractory anemia and she refuses treatment and she's been getting transfusions, I think, not nine years now and she's on Exjade for chelation, but she's like, "I don't want to do treatment," and so she continues to get transfusions only an that's worked well with her. She went to Florida for the winter. She got transfused at Moffet. She's doing good. So for her… and it's all about choice. What you want to do and what you don't want to do.

If you start having progressive or symptomatic cytopenias, if your blast percentage… There was a gentleman earlier talking about like blasts. Some people do have blasts in their blood, but again it's the tempo of it. How many are there, how often do they replicate, etc. and then if it's a higher risk disease that definitely needs a different look at as opposed to a low risk disease because things behave very differently for folks who have a higher risk disorder.

Then we look at individual treatment selection. Performance status means are you up and walking around? There's a couple actual different scales that health professionals use. If you're up getting dressed every day then you're 100 percent. If you're a little tired and taking a nap here and there you may be 90 percent. If you're zero, you're pushing up the daisies. So, that's how bad. If you're 50 percent means that probably half of your time may be spent in bed. There are people who that fits, but that's what performance status is. So when folks look at what treatment would be appropriate, certainly disease status is part of it, but how are you physically and how active are you plays a large part of that as well and then comorbidities and that's a fancy word of saying like what other health problems do you have? Do you have diabetes? Do you have congestive heart failure? Do you have peripheral vascular disease, cardiovascular? There's lots of things that can go out there and if the average age is 70, chances are that have one or two. You may have high blood pressure. You may have insulin dependent diabetes. So, that's a very

important consideration when your practitioner looks at what are you going to get treated with and then you look at the risk categories and then we talked about already primary versus secondary MDS. So, secondary is treatment related either chemotherapy, immunosuppressive therapies like Remicade for some folks who have Crohn's disease or radiation. Some folks who have rheumatoid arthritis. They get oral chemotherapy agents called methotrexate. Sometimes those folks develop some blood issues as well. Will look at the cytogenetics and then look at lifestyle. What do people really want? Like my patient who's like, "I'm not doing treatment." Just not doing it. She's probably 75 now, maybe 77.

So, we talked about all these already. FDA approved agents are limited but as (Attendee) was saying before, 2004 was the year of licensing for 5-Azacitidine. So after the study was completed, very interesting nobody wanted to pick up that drug because they said it's a very small population of patients and it took a very long time for anybody to pick that drug up and start manufacturing and having the rights to it. So, after the study closed we used to be able to get the drug for patients through the National Institute of Health after a very long process. It was ridiculous, but controlled… it's a substance that's not approved. So, they did have some and we were able to get it for some people.

Talked about that and then here's another slide under what's out there as far as clinical trials. So if you're a web savvy person, there is some terrific websites to look at for clinical trials. So, someone shopping treatment, clinical trials. So, you go to nci.gov. So, that's the National Cancer Institute.gov. So when you go to that page, you can put in MDS and all the trials that are available all over the country are going to come up. It's a very, very busy page and things about clinical trials that you may or may not be aware of is that they may only be "open" at certain sites. So just because something's available at Rush, doesn't mean U of C is going to have it and there's quite a process that has to occur from an institution's perspective in order to be able to hold that clinical trial. The other thing is that you have to match what they're looking for. So, some studies like Dr. Shammo was talking about were folks who failed hypomethylators. That means that you've had either Vidaza or Decitabine or Dacogen and you haven't had any response for them and so if you don't meet their criteria then you can't try to get on that Onconova trial. So, every study is very unique. It doesn't matter your age usually although I think if you're over 100 they may exclude you, but usually they're not… it's not age related, but has everything to do with how healthy you are because they want to make sure that when they're testing these agents they're looking at the right group of people and they want to compare apples to apples. So, they can be a bit restrictive. In some studies are only offered in faraway places. MD Anderson has a terrific clinical trials program. MD Anderson is in Houston, Texas. The Mayo Clinic also has a very robust program. Here in the Chicagoland area, you're looking at five major medical centers. So, you've got Northwestern up the street, you got UC in the Southside. You've got Rush on the near West Side, you've got U of I. You've got Loyola and between the five of us there are quite a few clinical trials. So the other thing you can do to look for a clinical trial is you go to an academic page. So, a home page for the University of Chicago, the

University of Illinois. If you live in Kansas, go to the University of Kansas and you look up clinical trials.

Q14: There's a Mayo Clinic here. Is it in Chicago?

Jean Ridgeway: So, there are some satellites of Mayo Clinic and I think they've been trying to open one up in the western suburbs. I don't know if anybody has any more information than that, but a lot of these big… medicine is business and so a lot of these centers are trying to open ancillary sites. So sometimes if the headquarters of the hospital, say, is in Rochester, Minnesota for Mayo Clinic. The clinical trial may or may not be able to be open here in the Chicago area even if they have a satellite because of the restrictions that are forced upon the institution to have the clinical trial. There's a flood of paperwork and when you're dealing with drugs then they have to have an investigational pharmacy and accountability, etc. So, it all depends.

Q14: Is that a consulting group at least for the Mayo…

Jean Ridgeway: Say that one more time.

Q14: Is there like a physician consulting group for the MDS for Mayo Clinic here or…

Jean Ridgeway: I don't know. I don't know the answer. I mean, one of the things that the MDS Foundation offers is that they have a directory of MDS Centers of Excellence. So, physicians that they know who really are thought leaders in the country about MDS. So, Dr. Shammo is over at Rush. I work with a couple physicians who have been involved with MDS for many, many years. Richard Larson is one of the physicians that I work with. Lucy Godly is one of our younger, brilliant physician scientists, but there's quite a few people in the Chicago area. The other thing I would say about when you go for an opinion or a second opinion or a third opinion is if you don't like your doctor then go find a new one. There's plenty of them out there and we're all different. Some people like to be treated by men, some people like to be treated by women, but medicine is consumer driven and you want to go to somebody reliable, but don't be afraid to get a second opinion. Search for someone that's a good fit with your personality and feel free to do that. Don't be intimidated by it.

So, these are just some of the things that are under investigation and it talks about what some of the side effects are. This is the Onconova study, Panobinostat. Some of these are oral. Some of them are injectable but the take home point is that there's a lot of them. There did not used to be and looking at combinations of different agents is also becoming more common as well. I got to point this at the right direction. There's no monitor here. That's why I keep looking backwards.

Key principles of therapy. So, we talked about the allotransplant. Allotransplant means that instead… I don't know if any of you have ever had friends who have multiple myeloma. Multiple myeloma is a lymphoid malignancy and they do something called atalogous transplant

where their own stem cells are created and harvested and they do their own stem cells, but that's not effective and it's been tried already in MDS. So, we know it doesn't work. So, it's an allogeneic. That means you got to get your cells from somebody else. So since we get half of our information from our mother and our father, chances are that maybe our brother or sister will be match. There's a one in four chance. Now if you have more siblings, the statistics go up a little bit, but not as good as you would hope. Like if you had nine siblings, you're for sure going to have like a couple matches. That just doesn't work, but if you have a sibling you could potentially be a half of match and that's called a haplo and there are plenty of centers around the country that do something called a haplo transplant where someone's a half match. We talked about age a little bit and our center has done patients into their 70s, but it is a very rigorous therapy. Receiving the chemotherapy and getting the cells back that's not so bad per se, but the side effects and the after effects… You were asking before about side effects and she showed a couple of the slides about like survival. There's like a 30 percent survival curve after… that means three out of 10 people live a year. That's a big risk and your body and your organ systems really have to be able to withstand that because people can become very ill. So, there's usually a pretty rigorous screening that goes on. First, we want your disease in the best remission possible, but otherwise your kidneys and your heart and your liver, and your lungs need to be working pretty well in order to go under through the therapy. So, the older we get, it gets a little bit more difficult.

Q14: I have a question. This is about the… for the bone marrow transplant. The level of matching.

Jean Ridgeway: The level of matching.

Q14: Yeah with a donor. You mentioned about low match or something. What is a match?

Jean Ridgeway: So, what does a match mean?

Q14: Qualification like minimum requirement for match is like 50 percent match is that a good (inaudible 47:07).

Jean Ridgeway: So what we do is we check on the six chromosome… something called the HLA. That's found on your sixth chromosome. So, it's HLA typing. So, they used to test out to six to eight. Now, we go all the way out to 10 different genes and areas on the sixth chromosome that we're looking at and that's because the better the match the less potential you have for something called graft versus host disease. That's a big complication for folks who have a transplant where they receive someone else's cells because we have something in our bodies called T cells and their job is to recognize self versus none self. So if I go home today and I start having this terrible sore throat, my T cells are going to rev up and say, "Wow. We really don't like that bacteria," and they're going to go after it and their job is to recognize that that bacteria is bad. It's not self. So, it's self versus non self and their job is to get rid of it. When you have a

transplant, we have to do something called T cell depletion in the patient and that's because you're now going to give me somebody else's blood system. So, what's my immune system going to do? It's going to say that is not me and what the natural response is is it's going to create an immune type of response and reject the cells and destroy the cells. So now if we've given high doses of chemotherapy and you reject the cells then you don't have any cells at all. So, the better the match the less likely you can have graft versus host disease. So, most centers now are doing 10 out of 10 HLA matches and that's pretty much the standard in transplant.

Q14: The doctors say before they do this transplant they wipe out your bone marrow with a high dose of chemo. That mean your whole immune system is gone and you… Immune system is gone or just the blood is gone or what is the difference between the blood and the immune system? Are they the same? Are we talking the same or these apples and oranges?

Jean Ridgeway: They're a little bit different. Our immune system is a very complicated system. So, our blood system gives us some of our immune capabilities, but we have another component to our immune system as well. When somebody gets a stem cell transplant, we have to give them enough chemotherapy so that the stem cells are destroyed, but not so much that we kill the bone marrow. So, when I give my lovely garden that enjoys a brief vacation every July, too much fertilizer, what happens to my entire garden? It dies. So if I went to replant my garden and I had over fertilized it is anything going to grow? No, it's not going to grow. So, the fine science is to get rid of enough of the person's disease without destroying their bone marrow. So, leaving enough healthy tissue so that the new stem cells will come in and seed and then repopulate. Now in so doing, you do affect the immune system in a lot of different ways. So, people become immune compromised and that's part of the T cells because I now don't want… Now, I still have T cells in the rest of my body. I have T cells in my skin, in my GI system and I don't want the T cells to become active and begin to reject all these other cells otherwise you develop this syndrome called graft versus host disease and it's very complicated. So, they're a little different.

Q14: And I was also told that they give this chemotherapy and it doesn't distinguish between the good ones and the bad ones and it can kill both. So, how do you segregate or separate the good cells from the bad cells and have the chemo go after just the bad ones and destroy the bad guys in town?

Jean Ridgeway: So how traditional chemotherapy works is that normal cells go through a cycle where they divide and replicate, but they always balance off. So, normal dividing cells have a balance. Now with malignant cells, we talked about how they live forever. So, they're constantly multiplying. So any cells that are normally dividing do get affected by chemotherapy and through the years we've been able to discover how much chemotherapy is able to not only get rid of the diseases, but cause minimal side effects, but many of the side effects that we see with traditional chemotherapy are related to the cells that are multiplying on a regular basis and the first cell that you think about are the blood cells. So when you give someone chemotherapy to get rid of a malignancy, you also cause them to have low blood cells, but then those blood cells

will come back. You'll lose your hair because your hair is replicating. About 85 percent of the hair on our heads at any given day, those of who still have some, is growing. So when people get chemo, there are certain drugs, not all drugs that cause people to lose their hair, but not all of it. It's subsequent cycles and people will lose hair. Anyplace you have hair growth, you have hair loss. So the men enjoy not having to shave, the women enjoy not having to shave their legs, but the face is… it grows lot faster and you lose it on your head as well. Cells in our GI system. So, that's from your mouth all the way down to your rectum have a certain type of cell that can be affected by chemotherapy and so people can get mouth soreness. They can get diarrhea that is more related to… The mouth kind of becomes the mirror of the GI system. So when we look at people's mouths when we go around and see people, if people's mouths are very red and dry and sore they're having nausea, vomiting and diarrhea that's because of the rest of their GI system is red and sore. So, it becomes that. So, those are the side effects and it's been through experience and time of how much chemo do you give to destroy the bone marrow, but not too much to make it incapable of being able to accept the new cells.

Q14: How good is the chemotherapy effective in distinguishing like the good ones from the bad ones?

Jean Ridgeway: So, it doesn't. It doesn't. Any cell that's rapidly multiplying gets affected by chemotherapy. That's why if it could spare your hair or spare your GI system it would, but traditional chemotherapy, chemotherapy like Cytoxan, methotrexate, 5FU doesn't do that. We have some… Now, the new drugs that we're beginning to see… There's a drug called Rituxan that people who have lymphoma that's a targeted therapy for a target that's just present on the lymphoma cells. In some of these newer cells… I mean, these newer drugs target things that are only very malignant cells.

Q14: I have this gene 7 monosomy.

Jean Ridgeway: Right. You have monosomy 7.

Q14: So, is this treatment trying to fix that chromosome and make it like a pair and then my disease will go away or what is this abnormal DNA destroying and… If it destroys the bad cells then I will have empty gene 7 pair kind of chromosome?

Jean Ridgeway: So the goal when we treat people with doses of chemotherapy or even more sophisticated drugs like 5-Azacytodine or Decitabine is that you restore the normal stem cells. So, you get rid of the bad ones and only the good ones are left and they begin to allow you to have normal cell growth, but it's very, very… That's a very simplistic explanation, but the goal is to get rid of the malignant clone and have the healthy ones survive to repopulate and sometimes that can be done with some of the therapies we have for MDS, but sometimes it requires more aggressive therapy and we're yet to really find out the perfect drug for MDS that can target exactly what's wrong because if we could then we'd read about it in the newspaper. It

would be everywhere, but we're just not there yet. We've come a long way in the past 15 years and in the next 15 years I'm sure what we'll do a lot more as we try to develop drugs that target molecular abnormalities, we're just not there yet.

Q15: You mentioned up there that blood counts often get worse before they get better.

Jean Ridgeway: That's true.

Q15: For what period of time on an average would they get worse before you start seeing it get better?

Jean Ridgeway: So, usually within the first month. So if you think back to my garden when I come back and I pull out all the weeds, at first things don't look well at all, but things will begin to come back, but many times when people have MDS and they're just beginning treatment oftentimes we know the malignant stem cell drives hematopoiesis. That's a fancy way of saying that somehow the malignant clone is generating blood and when you start to remove the malignant clone then you have less blood production. So, we usually see folks have the most difficult with treatment and the most cytopenias and infections and hospitalizations that first month or two. Predominately the first month.

Q16: I want to answer (Attendee)'s question. You can correct me if I'm wrong. (Attendee), if you going to have a comparison of garden. Unless she takes some chemical go all the way to the root, all the way down and pull it out that's the only way the weed is killed. Right now you are asking genetic manipulation. We are not there yet. The genetic manipulation to bring back your monosomy, we don't know yet. So, that is not… You are a little bit outside still. You are on the little bit surface, but not all the way deep to the roots and somehow we mutate. As we age, we mutate. That's why it is not a genetic disease except a few hereditary. It is our own mutation as we come. So, you are a mutant. We are all mutants now. Alright? To bring back… I'm putting it very simplistic way because my son asked my oncologist the first question. Now my mom has it. Do I get it? He said it is your own. She's not giving you this one.

Jean Ridgeway: It's not heritable.

Q16: Right. It is very assuring to know that. Coming back to treatment and chromosomes, these are like DNA chromosomes. So, we are manipulating the protein. We are manipulating the (inaudible 58:38) level. That's all we are trying to do, but it also a temporary just like Dr. Shammo put it it is diabetes controlled, not cured unless we go to the further into the pancreatic cell. So, read and have knowledge, but don't go bonkers in your reading either. We have to caution ourselves. If not, we go really there is so much. Other day my son calls me, "Mom, there is this measles that's…"

Jean Ridgeway: That is out of Mayo Clinic.

Q16: … out of Mayo Clinic. What do you think? Wipe out myeloma. You are myelo. I said, "Wait a minute. I am myelodysplastic. It is still up in the air." Our example (inaudible 59:28) I have big qualm with it. This Vidaza is up outside in the market. Are you from the company, sir?

Jean Ridgeway: No. He works in a specialty pharmacy.

Q16: Four years ago, it is in a (inaudible 59:42). Why can't we get it here? Is it the company? Because you can get a $1,500 for each treatment or is cheaper as to go home and stop going to the day and getting the IV. That is I don't know who are the proactive people here to fight against that kind of…

Jean Ridgeway: Ridiculous.

Q16: Four years. If by chance we are born in France or somewhere else in Europe, we would have treated it by mouth. Figure it out.

Jean Ridgeway: Well to speak to your point about being active and contacting people, the folks who are on Epogen or Darbepoetin, a few years ago, I can't remember how many, less than 10, Epogen was being very, very widely used in the oncology community because it helps with people who have anemia. So, a lot of people have anemia. If you're going through breast cancer treatment you have repetitive cycles on a monthly basis and your hemoglobin would go down and people would get treated with Epogen and their bone marrow is a lot different than folks who have MDS. So unfortunately, there are a couple people who had head and neck cancer and they died and the government and the FDA attributed their deaths, they were directly related to Epogen and so since the government through CMS is the largest payer of medications like Epogen, the government came down and said we are now going to restrict the use of this agent and you have to meet a very certain set of criteria. So, there was a big contingent of patients from the MDS Foundation who went and spoke before Congress and said do not take this medicine away from us because we get it on an every other week basis or an every month basis and it allows us to maintain our hemoglobins, it allows to function and feel well and because of the petitioning of the patients as their own advocates the government said okay, we're going to exclude MDS as the diagnosis when they look at restrictions for people who can get Epogen. So, you can thank a group of folks who picked up the telephone and hopped on a plane or drove on over to Washington. So, I think healthcare policy workers are listening. They just need to hear from us. I don't think it's an election year, but you know it's always an election year in Cook County.

Q17: I actually have a question for and this is off subject a little bit but still within the frame. For anyone who has been or is on Vidaza, are you getting it subcu or IV and if you are or have received it subcu what kind of side effects have you received because like I said, round three for dad… round one IV, two subcu, no issues this time around subcu and…

Jean Ridgeway: Big welts?

Q17: Oh, my gosh and he's far more exhausted than ever, but his numbers are better than they have been. So, I'm just… I didn't know if there's…

Jean Ridgeway: Who wants to speak to that for the Vidaza people? Reactions? What did you get, a subcu or IV?

Q18: (inaudible 1:03:21)

Jean Ridgeway: You're on coumadin. So, coumadin is a blood thinner.

Q18: (inaudible 1:03:30)

Jean Ridgeway: Who else is a Vidaza person who can speak to that? Anybody else?

Q19: Yeah. I can speak for that.

Jean Ridgeway: Did you get it as a shot or did you get it in intravenous?

Q19: I got it as an injection and…

Jean Ridgeway: Which means really you got two or three injections every day. Right?

Q19: No, I got one injection every day and that goes on for seven business days and after that three weeks of just monitoring and just start our monthly cycle again, but I didn't seem to have much difficulty with it. I took some anti-nausea medicine, but then I kind of gave it up because I didn't feel any different. Sometimes I had some loss of appetite and they give some Megestrol.

Jean Ridgeway: (inaudible 1:05:39)

Q19: Yeah. Megestrol and I think I picked up on that one, but the only main thing I saw is they put it in the tummy. So, I get some red rash like (inaudible 1:05:55) but it's kind of little bit sore sometime and but that's all I got. I survived through, but it didn't work for me.

Jean Ridgeway: And so I'll tell you what I've seen. I've seen people having absolutely nothing subcutaneous and some people having terrific either hematomas. That means like a little bruising, but other people can get these very large welts where the injection is that are painless, but then some people can get and they're very painful and they get kind of hot and itchy and usually depending on the size of the person because the medicine is dosed on how big you are, you get sometimes one, two or three shots every day. Now when they did the study, the study

was done every day for seven days, but some clinics aren't open seven days and so some people get five days, they get the weekend off and then they get the next two days and people have looked at is that a good thing? Does it really work? There's a lot of literature out there and then the company looked at how about doing it intravenously since a lot of people said I hate these shots. Can we just start an IV or if I have portacath do it intravenously and how well it worked was proven equivalent. I'll tell you from my experience is that people who get it intravenously have far more nausea than the people who get it subcutaneously. Almost everybody universally gets some nausea from this medicine and you know in life women have more nausea than men, younger women have more than older women and if you're a drinker, ie. drinking your lunch instead of eating it, you probably don't have any nausea at all and we know that has something to do with your chemo receptors but so… but that's very true and you're very right that Zofran or Odansetron it's biggest side effects is cause constipation. So, it becomes take this pill to get rid of this and take this pill to get rid of that.

Q20: Right and in fact my younger nephews are all physicians. They said why don't you smoke pot? And I said…

Jean Ridgeway: You got to move to Colorado or Washington to do that. You could eat it.

Q20: I said wait a minute. I said wait a minute being a physician smoking it this won't be looking good. (inaudible 1:08:07) and you know how it is. Get the Dronabinol There is a drug Dronabinol if nausea becomes.

Jean Ridgeway: That's called Marinol. So, Marinol is… Dronabinol is the THC which is the active ingredient in marijuana that's been proven to help people with more refractory nausea. Some people don't really like to take it. It gets into your fat cells and so it can last for a long time.

Q20: I can give you those spices that I use. There are (inaudible 1:08:44). That is like… I have to show you. I will show you on my Internet.

Q21: (inaudible 1:08:53)

Jean Ridgeway: No, but you can go ahead and ask questions.

Q21: (inaudible 1:08:57)

Jean Ridgeway: Oh, you want to get through it. I'm looking at time. We got 20 minutes. So, we'll go through this. Almost.

So how much time is required? This kind of looks at what happens in the bone marrow. So before your treatment begins if you look at your bone marrow looking like this and those cells

that are kind of yellow and crablike, those represent more disease and so the blood counts can begin to drop as normal cells are crowded out by the abnormal cells and the center one is so you've had some treatment and things begin to clear out. So, you begin to see less of the abnormal cells and just normal cells. Somebody asked when do you begin to see the most side effects? Usually within the four to six week. So, this graph on the top there is weeks in treatment on the very bottom. So, you can see that ANC, that's the absolute neutrophil count, those are the healthy white blood cells. They start high and then they drop and then they begin to pick up and level off and this is all based on data. It's not just an artist's rendition of what can happen.

Q22: (inaudible 1:10:03)

Jean Ridgeway: If your ANC is already down, then you're going to go down further. That's what's going to happen. So, that's predictable and usually caregivers, the provider, will say they'll warn you against the neutropenic fever. Sometimes people get put on what's called prophylactic antibiotics to protect you from the risk of infection. That might be an antibiotic and antifungal and an antiviral. So, it may be something like Levaquin, Diflucan and Acyclovir. So sometimes during a very profound period, that's done. What we know about MDS patients is that many of them before they arrive and get the diagnosis have been cytopenic for a long time and they're not infected and so we kind of shy away from just prophylacting somebody with antibiotics.

Q23: What if someone's on (inaudible 1:10:55)

Jean Ridgeway: Then they stay on until their blood counts recover. If you're no longer neutropenic once you get above 1,000 then usually they get taken off.

Q24: I have a question. I was on this Vidaza for six months and it didn't work so while in my thought bag is why couldn't they tell this in the first two couple of months it is not working and just save four months of some other thing rather than sticking around with this and finding it's not working. After five months my transfusion went from two to one weeks. So, that is…

Jean Ridgeway: So, we don't know and the data tells us in the clinical trials that to really get the best look and especially for people that are questionable whether it's working or not you have to go at least four if not six. So, the true recommendation in the oncology community is to continue on to at least six before you make a decision to change therapy. That's why because it's… and it's well supported in the literature. So and then this goes on. If the bone marrow begins to recover then you begin to have much more normal blood cells and so things look a lot different in the third panel than they do in the first panel and then really back to normal in that last panel. So and then hopefully as a robust response is as people begin to respond, for some people who have… who respond they do great. My gentleman who's been on this drug for… I mean, he happens to be someone who's derived a great benefit. He's not had a transfusion in years. So, he's been fortunate and has a really good response.

We talked about when do toxicities happen or side effects. They happen usually early. Does it exclude you from having them later? (Disagreement sound) No, it does not and a lot of times if people have been having difficulty, we talked about the road to getting diagnosed. Some people get diagnosed because they've had infections. They've had a pneumonia. They've had a skin infection. They've had an ear infection and in primary care one of the things that isn't done on a regular basis is looking at somebody's CBC not until you've had a lot of infections. Then they'll look at it and say that, "Wow. You don't have a lot of neutrophils," and they may begin to look at something quite differently, but remember common things occur commonly and so when people are first getting diagnosed, a lot of other things are excluded before something as rare as MDS is thought about and, again, it looks different for every patient.

Time is required for the best responses, a minimum of four to six months. So, there's your answer. Cytopenias get worse before they get better and then during the initial cycles of therapy oftentimes people will have to have dose modifications. That means the dose or the timing has changed. Sometimes if people get sick and they end up in the hospital for a week or two then you don't start to treat them Monday after they've been discharged on Friday if they're really not recovered. So, sometimes there's a delay in therapy and that's to allow people to recover.

This is a patient of Dr. List's and Sandy Curtain and this is showing a couple of things. So when you look at these squiggly lines, the purple boxes, so the very top one is this gentleman's hemoglobin. The platelets are the triangles at the bottom and then the white blood cell count and so you can see that initially when the gentleman was diagnosed his hemoglobin dropped and his white blood count and his platelets were low and then these are all time marks at what looks about a week in between, but the take-home point is that this patient continued to maintain his hemoglobin and then improve as well as with his other counts. So things got better for this gentleman as he continued with treatment. One of the things that did happen is HCT stands for hemopoietic stem cell transplant. So, this gentleman did get a transplant and you can see after transplant he gets somebody's new blood system and he's done even better.

This is a patient who's been on Lenalidomide or Revlimid that oral agent that we talked about for a while and you can see at the very top again hemoglobin. So, he's starting at about nine. He drops to eight, but through the years and this is a gentleman who's been on it for over 10 years. If you look across he's maintaining hemoglobin of about 11 grams per deciliter. So, no transfusions for him and the platelet count, again, has steadily over the years, but it's been slow. This gentleman has increased his platelet count and he's stayed relatively low in his white blood cell count. So, we really don't see him. He's in the normal range, 3 ½, a few times but overall the white blood cell counts really don't respond as robustly as his other cell lineages, but to say over time things can get better and people… how long do people stay on this drug? A long time if they're continuing to benefit from it. So, he's been on it quite a long time.

This is really towards the end. So, what can I do to stay healthy? I'd say the very best thing that you can do make sure you get a seasonal influenza vaccine. People know that I say this all the time. Thirty thousand people die in the US of influenza every year. You need to get a flu shot and people who live in your house need to get one. So, get a flu shot. Do not get the Zoster shot because that's a live virus. When you see it advertised on TV about Zoster don't get that one. That's not for you. Your family members if they're over 60 are okay to get it. They won't be contagious, but you shouldn't get it if you're the patient, but do get a seasonal flu. Eat a balanced diet, stay active, exercise, avoid infection. That's a silly thing to say, but try to stay healthy. The best thing you can do on a daily basis to stay healthy is wash your hands. If you're going in someplace public, I would encourage you to use those wipes that they offer to go ahead and wipe the cart off, keep some waterless hand gel if you're someplace really public like Home Depot or wherever, but wash your hands because viruses live on inanimate surfaces for up to a week and I heard the other day that like one of the dirtiest places you can go is an airplane. So either bring some wipes with you and wipe off your armrest and wipe off your seatbelts. That's like where the crud is really growing or make sure you wash your hands after you touch that stuff. So, things that you aren't thinking about… It's like going on a school bus as an adult. You can wear a mask. You can let the airline people know like you go up to the counter and say I may need a compromise. I'm wondering if somebody starts coughing. I tell my patients do the two by two rule. Two people in front of you and two people on the side of you, two people behind you. If somebody's coughing up a lung, move. Move or get off the plane. Just say I can't be on this plane because that recirculated air is not a good place if you're neutropenic.

Take advantage of the resources. Somebody was talking about support groups. There's some area support groups. There's a couple of really good support venues here in the Chicagoland area. One of them is called Gilda's Club. They have a meeting place over on Wells Street, Wells and Grand, not too far from here. There's a wellness house in Northbrook which is about 20 miles north of here. Hinsdale has a great wellness program as well. They offer all kind of yoga and meditation and I'd say they're very underutilized. They're usually folks if anybody is interesting in being a facilitator for a support group, I think that's great. Support groups are common. They're plus/minus. It's too cold out, it's too sunny out, I got to do this, I got to do that. So, they are out there, but you got to be really active. The Leukemia and Lymphoma Society has chapters nationwide. You can contact them. They can give you a couple insides into who might have them. Some of the big academic institutions try to have them, but they don't happen very frequently. Some of them are geared towards caregivers. So you just have to look, look, look, but those are some of the other places.

The Building Blocks of Hope. If you don't have a copy, grab one. Dee's got some. Some of them are not in the binder. You got two left. I like the kind that's not in the binder because the binder is kind of bulky and that's just me being fussy. It's also online and then you can look at those videos as well. So, all that's available. You can download it as PDF as well. And ask for help when you need it. So if things are tough at home or you'd like to put flowers in your flower boxes ask for some help and don't be embarrassed by that. People are wanting to help you and be

an active participant in staying hopeful. We've heard that from a couple people. The glass is half full. Some folks are living testimonies that people live for a long time. Nobody decided… has a crystal ball. A healthy body/healthy mind. Here's a couple other interactive YouTube things that talk about ways to stay healthy and exercise. So, lots of things out there on the Internet. That's also in the booklet and then just Building Your MDS plan as well, becoming a partner in your care.

Again, I'm just referencing *The Building Blocks of Hope*. So, it's MDS-Foundation.org to get some more of those. It's online and we talked about that and then you can custom make your handbook. You can print out pages. You can enter your lab values. Kind of the sky's the limit how you want to utilize that resource, but there's a lot of really good things in there. There's a whole section about side effects. Someone was talking about side effects before. So, there is a section… If it's not in this book, it is online. It talks about how to manage like GI issues, skin issues, fatigue, etc.

So, I'm not quite sure. Dee could probably answer this. Where are they as far like the interactive patient data entry? Is that active yet for people to like put their blood counts in and stuff? Not yet. Okay. That's in the process. Somebody's creating some type of web resource. If you want to track your blood counts and your treatments, you can do that online like in an iCloud application and then pages 85 to 91 are also in there. It can be saved on your iPad or your Kindle and then here's an advocacy program. You've been involved in the advocacy program as well. Oftentimes there'll be an E-mail or something that comes out and they're looking for information just kind of asking folks what's happening geographically their area in the country. That's a good thing to do or you can give them a call toll free or E-mail Audrey as well. There's her E-mail.

Anyway this just goes through the tabs, which we don't really need to go through because we have about five minutes.

So questions, more questions, more comments? Well, I want to thank you for coming. Dee Murray has been our representative who's here from the MDS Foundation and she usually has a couple of things to hand out to you, but her box of stuff didn't come. It's going to come tomorrow after she's back in Philly. That's when it's going to come, but I'm not quite sure… You may or not as you signed in, I don't know they may… the Foundation may just send you an E-mail or something ask for some feedback. They just usually want to know what could we do differently, what would make it better, what do you want to replicate, what do you want to get rid of, that kind of stuff.

Dee: If I E-mail some questions… It's a survey (inaudible 1:23:39)

Jean Ridgeway: It's a survey. So, don't ignore the survey when you get it.

Q25: How do I get a copy of your slides today?

Jean Ridgeway: These slides? So, these slides are really in the book. This presentation…

Dee: (inaudible 1:23:55)

Jean Ridgeway: Oh, Dr…

Q25: Your slides and hers.

Jean Ridgeway: Dr. Shammo's slides…

Dee: I'll check with her on Tuesday. So, if you want one shoot me an E-mail and I'll send it to you.

Jean Ridgeway: And what's your E-mail, Dee?

Dee: It's in the book. It's (inaudible 1:24:15), but it's dmurray@mds-foundation.org.

Jean Ridgeway: She'll have to give that to you, but the information on this little presentation is really information gleaned from the book in front of you. So, that's all in… it's all in the book in front of you. It's two o'clock. You're done.

(Applause)