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Sandy Kurtin: … have on Wednesday of this past week was International MDS Awareness Day and so we're just… that's why this program was scheduled around that date. So, she's passing around a flyer and to tell you a little bit more about how we are collaborating with the MDS Alliance which is all of the organizations around the world working with patients who have MDS and their caregivers trying to really bring all of the best information forward for everyone. So, my name is Sandy Kurtin and I'm a nurse practitioner and I work at the University of Arizona Cancer Center in Tucson, Arizona and I'm going to spend a little time going through the *Building Blocks of Hope* which you all should have a copy of in your packets and so we're going to just talk about that briefly while you're finishing up your lunch and then hopefully we can take a good amount of time to just really go through questions that you have. You heard a lot of very detailed information this morning, some of it complicated and so if there's things I can help you do to understand some of those things, we'll take our time to go through all of that.

So, the *Building Blocks of Hope* is something that we have (inaudible 1:34) MDS Foundation and I'm on the executive committee also, the Board of Directors and Chair of the Nurse Leadership Board which is an international group of nurses and we collectively created the *Building Blocks of Hope* and as I say you have a copy. It's this binder here that has several booklets in it and the idea was really to provide you with a resource that goes through the information that you… some of what you just heard this morning. We're in the process of updating this now and so be looking for that coming forward soon. This is our list of members. So, it references the people all over the world. So, we're very excited about that.

So, part of what you heard today was some of the issue of who should be treated and maybe not… or not be treated and so when we talk about MDS and we understand all of the information that you heard from the physicians this morning in terms of things that when I talk to patients I always say there's things that are in the worry bucket, this bucket over here where I say you know what? That means we're probably have to do something sooner than later and then there's things over here that are in the we're okay bucket and when that balance is changing is when we really have to look at doing things that are going to modify all of the things that you just heard about. So, we can give transfusions. We can give growth factors. We can help you treat infections, but none of those things change any of that blue print underneath that is the reason that MDS is happening. So, we talk about disease modifying therapy. So things like Azacitidine, Decitabine and Lenalidomide now otherwise known as Revlimid, Vidaza and Dacogen are disease modifying therapies. Growth factors, things like Procrit or Neupogen are supportive care. We know that to start disease modifying therapy there are what we call these treatment triggers and they include if you become transfusion dependent because what that's telling us is that your factory, your bone marrow, is not producing red blood cells

appropriately and roughly 90 percent of all pateints with MDS over the course of their disease at some point will become transfusion dependent. So, it's the most common thing that we see.

You might also develop what we call progressive or symptomatic cytopenia. So, a cytopenia is a low blood count and that can be red blood cells, anemia, white blood cells, neutropenia or platelets which is thrombocytopenia. So, if any of those cell lines they call come from the same factory start to go down and that's continuing that tells us what if the factory is not working well. We need to start changing the underlying disease. If the blast count goes up, blasts are immature myeloid cells. They should never be in the peripheral blood and they should be less than five percent in your bone marrow and so if we start to see blasts in the peripheral blood, when you go and get your blood counts frequently, that's worrisome to us. That means that in this MDS to AML trajectory, here's MDS over here and here's AML and you're moving over here toward the AML side and that's where we worry a little bit more or if you have high risk disease. So, there are some… somebody asked the question earlier about starting therapy before you become transfusion dependent. There are certain signatures, if you will. So, your molecular profile that are considered high risk where we know that in a matter of months or even less than that that disease is going to change just by virtue of that blueprint and in those instances we will start disease modifying therapy before you become transfusion dependent. So, transfusion dependent is not the only trigger. There are different things we look at. Then we're going to look at you as an individual and so you heard a little bit, kind of scary, actually. I was sitting in the back of the room going whoa! So, I've been doing this for 32 years. I've been working with MDS for 32 years and this is in a very, very, very exciting time. We've not had a new drug for 10 years. We are way overdue and there's a lot of really good and exciting science happening right now. So, you should be hopeful and we're going to talk about the trick is to be well. So, we'll talk about that later, but we're going to look at you as an individual and we're going to look at are you fit or are you frail and so this has nothing really to do with chronological age. We try to get people away from oh, you're 80. Well, you know what? I have a lot of patients who are 80 that can outdo people that I see that are 40 or 50 and can outdo me and I won't tell you my age, but you already know I've been doing this for 32 years, so you start doing the math and I'm getting up there, but so we want to know are you fit or frail and that's going to help us understand how much can we really push because anything we do has some side effects.

What other comorbidities? Do you have diabetes? Is it well controlled? Do you have arthritis? Is that well controlled? Do you have COPD? Is that well controlled? So, that matters and certainly if you're considering a transplant comorbidities are a big deal. There's something called a comorbidity index and we're going to look to see are your lungs good, is your heart good, is your liver good and can you actually endure that intensity of treatment. Then we're going to look at your risk profile. So, you saw the survival curves. Obviously, being lower risk is better than being higher risk although people can with treatment can do well in each scenario if we do it in the right way. We're going to look at that cytogenetic status. So, you heard a lot about those. So, cytogenetics is what we say when we talk about chromosomes. Chromosomes are your blueprint. Your blue print tells your cells to grow up and be a lung cell, a liver cell, a bone marrow cell and if you have a bad blueprint you're not going to make normal cells and there are certain parts of that blueprint that we worry more about than others. So, the 5Q- is just one of those chromosome abnormalities.

What is your lifestyle? So, I live in Arizona, Tucson. We have a lot of winter visitors. Many of them come to play golf and they have said, "You know what, Sandy, you can do whatever you want to me on Monday, Wednesday or Friday, but on Tuesdays and Thursdays I play golf." So, we try to say what is your lifestyle? Do you live two places like many people do based on weather? What are your wishes and so we really need to talk about all of that so we can individualize the therapy specifically to you.

So, you heard a little bit about allogeneic bone marrow transplantation. So, this is really today the only potential cure for this disease. Allogeneic means you have to get somebody else's bone marrow. In MDS and other myeloid malignancies like AML you cannot get your own bone marrow. So, that's an autologous transplant. Autologous transplants are much easier than an allogeneic stem cell transplant. So, the first trick is to get a donor. So, we heard somebody has a perfect match. That's awesome, but often that's difficult to find and so there are other strategies that are being used, but you have to be otherwise healthy. So, you have to be fit. You have to have your comorbidities under control. We talk… I emphasize all the time when I'm talking to people that age, chronological age alone should never exclude treatment. So, the average age of onset of MDS today is 73. At 73 if you look at the actuarial tables the average life expectancy is roughly 16 years. So, my contention is is if you have a disease that needs treatment and you are fit enough to receive it, we should treat you and I've started people on therapy who are 86 and they've done and they've continued on treatment for a period of time. So, try not to say oop, you're 85. So, very, very important.

The other really, really critical thing to remember and this is important for you as patients or as caregivers is that any of the thigs that we do to treat you they have to get in there, they have to reprogram that bone marrow, all that stuff that you hard about this morning that might go wrong, it takes a while to overcome that. So the way that these drugs work is very, very different than what you might see used to treat a lymphoma or a breast cancer or a lung cancer and it might take up to four or six months before we really know if it's working. So once we say, okay, you know what? You got MDS. You have the triggers. We need to treat you. We say, you know, we have to commit to at least four months of therapy. We need some time to let these drugs work. In the meantime, the most common side effect for all of the treatments that we use is low blood counts and your blood actually might get worse before it gets better. So, that gets a little scary and you might be getting a transfusion every two and a half weeks and now during your initial treatment maybe you need it in 10 days and you're thinking you know what? This is making it worse, not better, but that's expected. We expect those cytopenias up front, those low counts up front and we need to just help get you through that initial three and four months of therapy so that you actually have the potential for a response. So, it takes a partnership working as a team to try to get through that. Unfortunately, we still see a lot all over the world actually people start therapy and then when these low counts start there's panic and they stop prematurely and then we're really not done justice in terms of allowing you to potentially have a response.

So, this is a cartoon that sort of demonstrates that. So, before treatment begins you have this marrow. It's kind of crowded with these abnormal cells that are housed in the bone marrow. We then initiate treatment and we're going to see this big jump. So, I call it the ravine. This is in the first few months of therapy. Then we give it a little bit more time and we get to the other side of that ravine and those

numbers are getting better, but they may not ever be completely normal again and that's okay. If you have lower than normal blood counts but you're not symptomatic that's okay. We are happy with that. If you're now not needing transfusions and you're not getting infections and you don't have any bleeding which are the things we look for from these cytopenias, we're okay with that. So, your blood might not get back to normal and I know people who follow their counts say hey, but I'm not normal. Well, I'm not normal either, but that's okay. It's okay as long as you don't feel bad and then basically it'll sort of reset itself and this is kind of the new normal. So, what we need to do is manage those early toxicities, get you through those first few months of treatment and hopefully get you to the other side where we can sustain that for as long as possible. So, this takes working together, managing those side effects, having you really be a part of that and committing to those first several months of therapy.

And I'm going to share a couple… these are patients that I've personally taken care of and share a couple of examples. So, this is a younger patient that I had who was in her late thirties which is unusual for MDS, but it does happen and she had her second child and was very, very tired and everybody thought she had postpartum depression, but in fact she had MDS and so the pink line is the hemoglobin, the goldenrod line is the platelets and then the purplish blue color is white blood cells. So, you can see early on she started in this case Azacitidine. There's an early drop. Things actually got worse. She needed transfusion support. So, that's this. These are each transfusions. Her platelets actually got worse and here's cycle one, cycle two, cycle three, cycle four, up they go and all of the cell lines got better, but not until cycle four. So, it just illustrates to you you got to really commit to continuing treatment even in the presence of low blood counts and just be very, very vigilant and aggressive about managing those side effects so that hopefully the drugs can work for you. This young lady went on to have a stem cell transplant because she had a sister who was a perfect match.

This is a patient that I followed that probably was on Revlimid longer than anybody in the world and so we did the original Revlimid trials at the University of Arizona, Dr. Alan List and myself and research nurses and clinical trial staff and this is a gentleman who started… had been on several prior therapies, but again you can see this very quick drop in blood counts early on got worse then got better and he actually was on Revlimid a little over 12 years, transfusion independent. He did die a year and a half ago with heart disease, not of MDS and so… but had we bailed out because the drug was causing low counts, he never would have had 12 ½ years of an extended life and the other really important thing here and you guys may not, obviously, don't expect you to know that, but the normal platelet count is somewhere been 150,000 and 300,000. This is 150,000 right here. He had two normal platelet counts in 12 ½ years. So, the platelets ran 65,000 – 70,000, not bleeding, no problems, okay. It's a different… it's a reset. So, we have to try to look at things in a little bit different way and if you're trying to follow your counts and say you know what? But I'm not normal. It's okay as long as you're not feeling bad and you're not dropping. The same thing here. His white blood cell count remained below normal, never was hospitalized until he had issues with his heart. He had seasonal episodes of sinus infections. That's these little bumps here where we give him a little bit of Neupogen and an antibiotic and then we kept going. So, it really takes having a provider that is familiar with this and also a level of comfort on your part to understand that even though the counts are below normal, if they're asymptomatic they're okay.

So, what's the trick? Well, we want you to stay healthy because staying… even though you have MDS, being health is really important to being able to take treatment, being considered for clinical trials which are coming which are very, very exciting and also if you are eligible for a stem cell transplant that's a requirement. You have to be fit and you have to have your comorbidities, these other illnesses, under control. So, a balanced diet, being active as much as you can. It doesn't mean you have to go crazy and working out at the gym. Just walking, do some strengthening exercises. Very simple things, avoiding infection and bleeding. So, being practical. Avoiding people who are obviously ill, getting your flu shot, getting your pneumonia vaccine. Try to live. Enjoy life as much as you can. That's the whole point. I tell patients all the time we're really wonderful people. My goal is not to have you spend all my time… all your time with me. We want you… the whole idea is to do… give you the time to be with your loved ones and doing the things you like. So, balancing rest and activity, taking advantage of available resources. We're going to talk a little bit more about *Building Blocks of Hope*, asking for help and then really taking an active role in being part of this journey, if you will. So, being here today is a big first step for that.

So, one of the things that we did with the *Building Blocks of Hope* is we tried to start the booklet off, if you take a minute to grab it with the first booklet, Book One which talks about understanding MDS and this is going to be updated. It does have the IPSS and the IPSS-R in it, but it'll go through that in some level of detail. This is also online. You can get to it on the MDS Foundation website. There are embedded videos and slide shows that you can access and listen to where some people learn better from hearing it verbally versus just reading it or doing both, obviously. So, we also then talk about seeking treatment and about those disease modifying agents that we have so far and stem cell transplant and then the third book is on Quick Tips. So, this is going through the common signs and symptoms that we see or side effects that we see from treatment or from the disease itself and just a very quick overview of things that you can do to manage some of those common toxicities. There's a booklet on iron overload. So, those of you that may have had a lot of transfusions and have accumulated excess iron. That's covered in that booklet and then Book Five is a really a tool to help you begin to track you information. It also has a segment in here about being well and advocating for yourself. We've now created an app based on this book which I've just finished a pilot testing of with a small group of MDS patients and their caregivers and this app will be launched at ASH in December and then available for use in January. So, it's really an electronic version of being able to track your counts and access resources on your smart phone and/or an iPad, for instance. So, be looking for that and then the last booklet is really about the MDS Foundation, the Centers of Excellence and some of the other resources there.

So, that's this. This is My MDS Manager. So, this is the app. Let me see if I have… this is an actually just finished at my PhD courses and I'm testing this app for dissertation. So, I'll pass it around. You guys can have a look. This is how it looks and so the pilot group has been very instrumental in giving us feedback on the how easy it is to read and how easy it is to enter information. It will have a download and print function. It has the capability if you register through a Google account to push out to you if a clinical trial becomes available in your area or anywhere near you based on your IPSS-R score the app will push like a text message to your app to alert you to say, hey, this might be an option for you and here's how you find out more about that. So, we're pretty

excited about that. It allows you to track your symptoms in real time. So, wherever you are and if you're having certain problems, let's say nausea and vomiting it'll send out to you the information from the *Building Blocks of Hope* specifically for that problem. So, we're excited about that. We had a lot of good feedback from the pilot group.

We also have the MDS patient outreach and advocacy program. So, the (inaudible 24:03) if you haven't met her and signing in as our patient liaison who does a really great job we think in really linking people to other people and to resources. So, if you ever have a question whatever it is clinical, personal, whatever. If you reach out she'll connect you to whatever the appropriate resource is. She does a great job with that.

So, that's all I'm going to say and I think would help me and I think we'll finish early because then you guys can get back to having your Saturday is if I could just have you guys go around… Did you do this this morning talk about… okay. Because I came from the airport. So, I was a little bit late. I'm going to ask you just to go around the room and tell us who you are and what your story is briefly. So, I'll start with you and can you talk into the mics because then people can hear you.

Q1: My name is (Attendee). I'm MDS patient on Vidaza, fifth month. Red blood dependent, transfusion. Was diagnosed a little over two years ago, actually three years ago and we had let it just simmer until my blasts started to increase above five. That's my story. I also have heart problems and COPD and a lot of other challenges.

Sandy Kurtin: You look pretty good.

Q1: Thank you.

Sandy Kurtin: As long as those things are under control that's a good thing. It's awesome.

Q2: I'm (Attendee), the caregiver.

Sandy Kurtin: So, she says I'm the caregiver, but you know what we cannot do this without caregivers. I have great passion for caregivers because we spend very little time with people in our clinics and then we say blah, blah, blah, blah, bye! Good luck! We'll see you in a couple weeks. And we expect you all to just do that and I always say you get married and you have your marriage certificate and it says in sickness and in health and then in fine print down there it says including but not limited to… Right? Injections, how do you know all this stuff that we expect you to do and you haven't really had any training. So, it's definitely a team and caregivers are critical. So, thank you for that. Yes?

Q3: Hi. I'm (Attendee) and I'm here with my sister who has been diagnosed with MDS and I'm here as part of her support team.

Sandy Kurtin: Wonderful.

Q4: And my name is (Attendee). I'm from Grand Junction and I was diagnosed, let's see, probably January of 2015 was when… and my red blood cell counts are low, but the other two factors, the white and the platelet counts are good, but I'm on Vidaza. I've been on it for… I did four treatments so far and got another one coming up in November. It seems to be working, but looking at bone marrow transplant possibly the first part of the year of 2017 which isn't too far away. So, yeah. It's been very informative… This seminar has been very informative.

Sandy Kurtin: Excellent.

Q5: Hi. I'm (Attendee)'s sister, (Attendee), and I'm also here as a support. We were tested and I was told I was a perfect match for my sister. So, we're looking at possibilities to where to go with that.

Sandy Kurtin: Great. Okay.

Q6: I'm (Attendee) and I'm a sister also and we just really wanted to get some more information about this because the more information we got from the doctor the more questions we had about what the cure is for it is which seems to be the transplant would probably cure, but then what are the things in between to help you live with it.

Sandy Kurtin: So, there is a lot of grey.

Q6: Grey. We're all lot.

Sandy Kurtin: So, good. It's good that you're here to learn about that.

Q6: So, very informative.

Sandy Kurtin: Good. Yes?

Q7: I'm here to support (Attendee) and…

Sandy Kurtin: (Attendee)'s got quite a team here.

Q7: She does. I married one of the (Attendee) sisters and they didn't trust the four (Attendee) sisters in Denver alone, so I came to chaperone.

Sandy Kurtin: It sounds like they might need a chaperone. So, it's probably a really good thing that you're here, but that's awesome that you guys are all here to support her.

Q8: I'm (Attendee). My caregiver is here. My brother. I've had MDS for nine and a half years. I've been through the supportive therapies of Procrit and Aranesp. They no longer work. I've been through two courses of Vidaza, didn't really work. I am now transfusion dependent and my hematologist oncologist is looking for new things.

Sandy Kurtin: Good. So, there are a lot of really, really good trials that are coming really soon that we have a lady that honestly they didn't expect her to live more than two or three months and she is in complete remission. So, there's some really, really good compounds coming forward. So, definitely look into that.

Q9: (inaudible 29:36)

Sandy Kurtin: They just have letters and numbers, but she has a particular marker called IDH2 and so there are a subgroup of patients, one of those you saw those bubbles that he showed you. In one of those bubbles there's something called IDH2 and there are IDH2 inhibitors out there and this is what she's responding to, but there are also other drugs, the Venetoclax that you heard about looks very promising. So, stay well and…

Q8: That's my goal.

Sandy Kurtin: Have somebody who can advocate and look for you and check into the MDS Foundation.

Q8: I'm already four years past my original expiration date.

Sandy Kurtin: I have several of those patients. They come in and they go through (inaudible 30:25) unannounced like a carton of milk. I'm now three and a half years past… right? Because you look at those curves and you have to understand that it is just purely based on the science of the disease and it tells us something about risk, but not about you as an individual. So, it really takes knowing all that other stuff and staying well is a really big part of this. So, thank you and you're the caregiver. So, what is your name?

Q9: (Attendee).

Q10: What am I supposed to say?

Q11: Tell them who you are and what you have.

Q10: What?

Q11: Who you are and what disease you have.

Q10: I am (Attendee). I have iron overload and MDS.

Sandy Kurtin: Hi, (Attendee). Nice to meet you.

Q10: That's all. Anyway, I think I have another doctor that will check (inaudible 31:18). Thank you.

Sandy Kurtin: Good.

Q11: I'm (Attendee) and I'm trying to be her caregiver, but she doesn't think she needs one.

Q10: She is wonderful to me.

Sandy Kurtin: So, (Attendee)'s a little determined.

Q12: Hi. I'm (Attendee) and my son, (Attendee), was diagnosed in September and he's looking to have a transplant come up and I'll be his primary caregiver.

Sandy Kurtin: Okay. Great.

Q13: I'm her husband, his father and I've got to try to survive alone while she's the caregiver up here in Denver and we're just…

Sandy Kurtin: You guys are going…

Q12: Someplace else (inaudible 32:00)

Q13: Well, he's from Gillette… He and his wife are from Gillette, Wyoming and we live in Colorado Springs.

Q12: And I'll be moving up to Denver with him to do his transplant.

Sandy Kurtin: So, you're coming to Denver. Okay.

Q14: I'm (Attendee). I'm his sister (inaudible 32:18).

Sandy Kurtin: We've got another big team going here. This is good.

Q15: I'm (Attendee). I'm 37 and I was diagnosed last month. So, hoping to get a transplant soon.

Sandy Kurtin: MPN and (inaudible 32:34) crossover something that we're really learning a lot more about now and understanding better and transplant's definitely the right choice for you. So, that's good that you're on that track.

Q16: I'm (Attendee). I'm his wife. I will be the caregiver giving her a break, but we have two daughters. So, I believe I'd be taking care of them as well.

Sandy Kurtin: It gets tricky. So, it's good that you have a team. That's awesome. Very good.

Q17: Hi. I'm (Attendee). I was diagnosed five months ago right the day before my 60th birthday, asymptomatic MDS. I'm on watch and wait and trying to be… trying to learn as much as I can. That's my wife, (Attendee). She's the caregiver.

Q18: Hi. I'm (Attendee). I was diagnosed probably five years ago, I don't know, but my symptoms are stable. So, I see Dr. Pollyea once a year. If there's anything I need as far as what's on the cutting edge in the future, I look to him for my health.

Sandy Kurtin: Good. Wonderful.

Q18: This is my caretaker, (Attendee).

Q19: And, yeah, caretaker and caregiver, but I take more than I give.

Sandy Kurtin: Okay. It's good that you're honest about that.

Q20: Hi. I'm (Attendee). I was diagnosed about a year and a half ago with MDS and multiple myeloma and I have not had any treatments. I'm doing alternative treatments right now like acupuncture and herbal supplements and tai chi and all that kind of stuff. I'm just hoping that that will work.

Sandy Kurtin: Alright.

Q21: I'm (Attendee). I have a brother who is suffering from this. He lives 3,000 miles away and I was just trying to get a background of information so I can understand what he's going through.

Sandy Kurtin: Good. Awesome. Alright. Well, welcome, everyone. So, I'm just going to open it up to questions. Does anybody have questions about what they heard… if you could just pan and we'll try to take turns? Yes?

Q22: I just have a question. In terms of prevented the pneumococcal vaccine they recommend. There're two variations – active and inactive for MDS. Do you go with the inactive or the active?

Sandy Kurtin: You don't want any kind of live virus. So, no shingles vaccine because you can get really, really sick and there is a specific sequence for people who are immunocompromised. So, they give… so if you just tell them it's the one that includes the Prevnar they'll do that in the appropriate way. So, a very good question and so even if your counts are low what the CDC says, the Center of Disease Control, is treat the herd because all it takes is one sick person to infect the rest of the herd. So, when your counts are a little low, those immunizations may not work quite as well, but they can help some. So, it's better to do that than to do nothing. So, good question. Yes.

Q23: Yes. Thank you. The chart that showed that had the ravine in it, is that after treatment?

Sandy Kurtin: Yes. So, it goes from having the marrow be too crowded and then taking the big dip because you got to clean it out and then it takes a little time for that factory…

Q23: So, that's preparation.

Sandy Kurtin: … and then it comes back up and it may not every really return back to normal, but that's okay if you have what I call moderate asymptomatic cytopenias meaning their counts are below normal, but you're not having symptoms.

Q23: So, there's no stem cell transplant in that…

Sandy Kurtin: No. That was not a… but a stem cell transplant would be the same. Often though after a stem cell transplant because you get a new bone marrow basically the numbers will usually revert to normal eventually because you have new cells.

Q23: Okay and you mentioned you're golfer and whatever. How long until after a stem cell transplant in the case of (Attendee) here, how long until a person returns to their pre-disease strength?

Sandy Kurtin: It all really… did you guys all hear that question? So, the question is is after a stem cell transplant how long does it take for someone to get back to their pre-stem cell transplant strength and it really depends. It depends on how well you are going into it, how you do with the treatment itself and that's variable and then how much you worked at it when you're out and it takes work. It's hard. There's some really hard days, but they… that's why you have to have a caregiver 24/7 or you can't have one of these because you need somebody with you, but you got to… We make our people… Well, we don't make them, but we encourage them to walk. One of the docs that I work with has a whistle. They bought him a whistle because he's always in there going, "How many laps did you do today?" in the transplant unit. So, you got to move, move, move as hard as it is it makes a huge difference in how well you recover and we know that from statistics and from doing research on this. So, being active during the transplant, before the transplant, kind of going into training mode, if you will, doesn't mean you have to run a marathon but you got to walk. You got to keep the lungs working, you got to keep your quad strong, but realistically we tell people give it a year, realistically, and it's not like one day you're down and the next day woo hoo, I'm all better. It's a gradual process. Some of that will depend on whether or not there's graph versus host disease and that really is determined by how well… what kind of a match you have and do you have a donor?

Q23: Probably (inaudible 38:39)

Sandy Kurtin: Okay. So, it'll depend on the type of transplant and what… So, there's a lot of variables there, but what you can do now is to really… I know you think I'm crazy saying this because you probably are really tired, but stay active and walk and your job as a team is to help him do that, even nag a little because it's hard, but you got to do it. It makes a big, big difference. Same over here with (Attendee)'s team. You got to get her moving. You look pretty good.

Q24: (inaudible 39:14)

Sandy Kurtin: Well, cord blood if you think about it babies have chromosomes from both parents and umbilical cord is the exchange of all of these very nutrient rich programmed cells that generate

this human being and so you can basically get these very rich stem cells from cord and so they do collect these stem cells and after a baby's been born and then they harvest them, if you will, and they treat them and save them just like you…

Q24: (inaudible 40:03) so we wondered if that's something that gets others still might want to consider to save them.

Sandy Kurtin: Yeah and so the current thinking is no because they're not good indefinitely. After about 8 or 10 years, the viability of the cells is in question. We don't really know are they going to be normal or not. It's very expensive to store them and it's not covered by insurance. It's an out of pocket expense and at the rate of scientific discovery there's so many things happening where over time that may not be something that you need to do and then meanwhile you spent all that money and you aren't really sure about the viability of them and if it's eight or nine years later. So, we don't really recommend that people have a baby for that reason or do that. If it's somebody that is… So, you get your chromosomes from your mom and your dad or whoever those people are that donate their cells and so once you start getting to cousin, aunt, there's different parents involved. So, the chances of them being a perfect match even though they're related to you go down considerably. So, our first choice is all of the sibling even if it's a haplo. So, there's… he mentioned haplo. That means half. So, even if it's a half match. There's some data that haplos can actually be better than like an eight out of 10 match. So, there's a lot of different things we look at in terms of who could be a donor.

Yes?

Q25: I was wondering as a caregiver (inaudible 41:55) whether I should have the (inaudible).

Sandy Kurtin: The biggest thing is just the flu shot and the Pneumovax if you've not had a pneumonia vaccine. Shingles is a live vaccine. So even if you have it, you don't want to get it. You can't be exposed to kids or other people who are immune compromised for a period of time. So, it's not something you would want to do like right before this or during this. So, if it's something you're considering I would really talk to your primary care provider to discuss the pros and the cons of that vaccine, but that's it and then stay well yourself and that's challenging sometimes being a caregiver. We put a lot of responsibility on your shoulders. So, it's a good thing that you can tag team a little bit and really… This is a time to call in the troops and get people in there to help you out and say I need you to pick up… I use this example and I think, you know what? I don't have dry cleaning because I hate to take stuff to the dry cleaner, but if you had to pick up clothes at the dry cleaner, let's say, or whatever it is, go I need you to go get this on Tuesday at 2:00. Give them specific tasks. If people offer help, say yes, thank you. I could use X. Make a list as a family and say here's what could really help me now today is somebody picking up something or dropping something off on Wednesday. Be specific. Ask for help. It really is important.

Q26: (inaudible 43:33 – 43:41)

Sandy Kurtin: No, no. I mean, it's not that. You, obviously, are going then have to really limit direct contact and be cautious about that, but we have caregivers who get sick. I mean, that happens. It's an intense process. So… and there's bugs going around that everybody gets and so you just have to wash your hands, wash your hands, wash your hands, wash your hands. Take the hand sanitizer with you wherever you go and be sensible. Other questions?

Q27: How about the health of a donor? What are they doing (inaudible 44:20)?

Sandy Kurtin: Donors. So, we do like I did yesterday I saw a donor and donor eval and we just have to make sure that you're not… they're not sick themselves and/or they don't have some underlying disease that might be transmitted to you by virtue of their own bone marrow because that's their genes. So, we do a complete history and physical, do EKGs and things to… chest x-rays and things to make sure that they're not harboring any disease and that they are willing without coercion to do this that they feel comfortable with the process of being a donor.

Q28: What about (inaudible 45:09 – 45:21)?

Sandy Kurtin: So, I personally think that eating should not be work and all of these extremes… I mean, I practiced (inaudible 45:34) for 32 years. So, I remember when beta carotenes were all the rage and literally people were orange from eating so many carrots and drinking so much carrot juice. Literally, they came and their hands… it was this color like this little orange swath in the rug here and then we learned through science it didn't make a difference and so excess to me is not ever the key. The other thing that I think I've learned over time and we have a very robust cancer prevention program at the University of Arizona. You think about all the people that they (inaudible 46:08) and then they were… and none of those fads ever… none of it ever panned out. None of it made a difference.

Q28: (inaudible 46:16)

Sandy Kurtin: Dr. Weil is still there and so he's a big part of that program, but even he will tell you that moderation is the key, be sensible, eat a balanced diet, get your nutrients from food, not processed food. So, it doesn't mean that you have to go all organic, but some people adhere to that. It means that we are not intended to get our nutrients in pills. We're intended to get them in food and many of the things that are claimed have no science. So, I subscribe to something called the Natural Medicines Database and it's a very good resource and they study everything from cats claw to creosote to red clover to whatever it is that people might want to take and so if somebody comes to me and say I want to take whatever the current rage is, I'd say okay, well, bring what you have. These compounds that are supposed to magically improve your immune system for instance and if I don't find any data in there there's no information I saw don't take it. We don't know. There's no data. If there are some things that people like turmeric. People actually have studied. There's been a lot of work out of India for years, centuries and there's actually some data there, but there's a lot of stuff that has no data where certainly if you're on treatment we are concerned that it might interfere with your therapy because there's no information. Either make it too toxic or make it not work. So, balance is the key in my opinion. I don't have people follow any really strict diet. I have them try to

avoid processed foods, excess sugar. That means they can't have any sugar, but excess sugar which is something we know causes diabetes and heart disease and high fat diet causing heart disease. So, really thinking about you as a whole being well not just specifically the MDS.

Other questions that people have? Yes.

Q29: Is anyone from (inaudible 48:33)?

Sandy Kurtin: Does anybody ever recover from this disease? Well, right now we know there is no cure other than a stem cell transplant or an allogeneic bone marrow transplant. We have people living longer and longer on therapy. We have a lot of new compounds coming forward, but today the disease is not curable without a transplant. So, our goal right now is to control it for as long as we can while… and allow people to feel as well as they can during that time and in the meantime moving the research forward which is going at a very, very, very rapid pace.

Q29: What about (inaudible 49:21) the medication that… the chemo that he's on. It's no longer working and they stopped it (inaudible 49:30).

Sandy Kurtin: So, the question was what if the medicine he's on is no longer working do they just stop and he dies? Sometimes that happens. I think this is really the importance of educating yourselves and being aware of what things might be available next and asking that of your providers to say what happens if this stops working? You also want to have a plan in mind and not try to decide what that is in the midst of a crisis situation. So, we always think about you know what? What if this stops working what next and it's been a challenge until very recently and people that have failed the hypomethylating agents, Azacitidine and Decitabine because we know that when they stop working the disease can move fairly quickly, but now that's where these new trials are coming into play. So, having that game plan in mind and knowing where those trials might be available in an area near you really becomes very important and having your provider know and be able to refer you or you refer yourself is important so that you make… you have a plan.

Q30: What's the process to get in a clinical trial?

Sandy Kurtin: The process to get in a clinical trial is we… you have to have good lungs, good heart. I mean, it doesn't mean you can't have a history, but they need to be working well right now. So, even if you have COPD if your lungs are working okay that's alright. Even if you have heart disease if you pass the tests that need to be done, an EKG usually and an echocardiograph, you still will qualify for a trial. So, you have to be fit and you… and then you need to meet the eligibility criteria whatever they are. So, if that means… So, if there's a trial that specifically says you have to have high risk MDS and you have (inaudible 51:37) MDS you can't get in that trial, but you might get in a trial for low risk MDS. So, there's a lot of different criteria. That's one of the things we're trying to do with our app. I don't know where that ended up. All over here… is to get people connected to be aware of these clinical trials and what comes out and where you are and you can ask about that and see where the nearest center is running that trial.

Other questions? Does anybody have questions here?

Q31: The MDS Foundation has a really good thing on Facebook and once in a while there are people with good testimonials on there and (inaudible 52:33) a lot of (inaudible) education (inaudible) Centers of Excellence (inaudible 52:40)

Sandy Kurtin: Good. That's good to hear. I'm going to have to check out Facebook (inaudible 52:48). I didn't do that. Shame on me.

Q32: There are also patients on the MDS (inaudible 52:54) because everybody's (inaudible)

Sandy Kurtin: Absolutely. It's very… that's why we talk about it. It's individual. It's not one size fit all at all by any means. So, really that tailoring and personal choice and all of those things play in as much as the individual disease profile.

Does anybody have other questions? Things you want to share or ask? Yes?

Q33: (inaudible 53:31) shots as well. Is that something that our daughter (inaudible 53:37) she needsa flu shot, but (inaudible).

Sandy Kurtin: No, they don't. That's not indicated in children usually. How old are they?

Q33: They're five and nine.

Sandy Kurtin: So, they're a little bit older. So, they're done with all their childhood immunizations. No. No, and I would talk to the pediatrician and just let them know what's going on in case something comes up so they're aware which is a good idea. So, if there's stuff going around the school let the kids' teachers know.

Q33: (inaudible 54:13)

Sandy Kurtin: Oh. Well, there you go.

Q33: (inaudible 54:15)

Sandy Kurtin: There you go. Yeah. That's the key. Really it's all here and cover your mouth. So, anybody else have a question? Now's the time to ask it.

Audrey: Thank you, Sandy.

Sandy Kurtin: Thank you.

Audrey: And again, Sandy donated her time today. So, thank you so much.

(Applause)

Audrey: I just wanted to make a brief announcement. I had passed out the evaluation forms. If you could please fill them out, I'll collect them. We take your comments very seriously. Moving forward any recommendations on how to improve the program, what you liked, maybe what we can improve upon we would highly encourage you to write down because we do take your comments seriously. So, we'd like to implement them if you have any suggestions. Thank you so much and immediately following this program in room number five which is directly outside this door and to the left there will be a presentation on iron overload for those that want to stay and we'll end… Mallory from Novartis will be handing out the program on that. Thank you, everybody, for coming.

(Applause)

Audrey: And Dr. Pollyea already has asked me when are we coming back? He'd love to do another one. So, we will be back and if you have any questions following this program, anything regarding MDS or something that you forgot to ask please contact the Foundation and we're happy to help.