Speakers
(Selina Luger, MD)
(Emmanuel C. Besa, MD)
Sandy Kurtin, RN, MS, AOCN, ANP-C

Sandy Kurtin: If you have specific questions about things, we can try to guide you to where you might find that in your booklets. Also really just like to hear you all share some of your struggles, fears, successes with each other because I think we can sit up here and do wah, wah, wah, wah, wah, wah. Right? But you're the ones really living this and I think it's sometimes helpful just to have an exchange of thoughts and ideas and things that maybe you can share with others. So, any… what were you all chatting about at lunch? Probably the noise. The construction. We heard a few things. It's going one way, I heard a few people, but anything come up over lunch that was surprising to you or… Yeah?

Q1: Okay. I only have low red blood cell count, but I keep getting all these bruises. Does that have to do with the MDS itself?

Sandy Kurtin: It may. I mean, you can bruise because your platelets are low, but you can also bruise if you're on aspirin or any other kind of blood thinners. As we get older, the fatty layer in your arms, in particular, goes away and it doesn't take much of anything to get a bruise there.

Q1: And usually you don't have to do with the blood, nothing?

Sandy Kurtin: No. No, because if your platelets are normal, that shouldn't… it should be related to the MDS and red blood cells don't really do anything for clotting the blood. Yes?

Q2: How critical is nutrition in this?

Sandy Kurtin: Very. You know, we try… because all cells need protein and calories to be produced and to survive including blood cells and so it is important to try to get a good diet and actually we have that video. Oh, here you are. (inaudible 2:16). That's a scary thought. Okay. This is the "Healthy Body Healthy Mind." So, I'm glad you asked that question because I would have forgotten. Kevin probably would have reminded me eventually. I don't know how long this is. Does it give you minutes on…?

Video:
It can rob its victims of virtually all of their energy.

It's just being worn out and I feel tired.

The Myelodysplastic Syndrome are a group of little known conditions where the bone marrow does not produce enough normal blood cells for the body to function properly. This can result in the crushing fatigue that is characteristic of anemia. Although a diagnosis of MDS can be devastating, there are new therapies available. They're improving outcomes especially for older patients who may not be good candidates for intensive treatments.

So, we are actually treating many more patients at higher ages with drugs that try to increase the lifespan of those patients in a sensible and relevant way.

I'm Dr. Scott McFarland. Today, we'll dispel some of the most common myths about MDS. We'll see that each MDS patient is an individual and needs individualized treatment and even though with low risk MDS of a serious disease plus experts will highlight the fact that there're now disease modifying strategies that even elderly patients can tolerate. That's coming up next on "Healthy Body Healthy Mind."

Sandy Kurtin: I'm going to let you guys go to the website and look at this and because it's… I think it's a fairly video and I want a chance to talk, but just so you know that that's there and they do talk a little bit about diet and exercise and those kinds of things. So, it's… So, what I tell patients is it's fine… you can… eating healthy is important. I also am a firm believer that it shouldn't be a lot of work because if you create this strict diet to the point where you have to think about every little thing you eat, that's just too stressful and stress at that… you don't need that. So, the real key, to me, is just balance and I always say everything in moderation, some things in excess some of the time because you have to have some fun. Right? Right? So, don't make it so hard for yourself that you… but you need some proteins and you need calories and you really need to stay hydrated. Very, very important. Water is really important for everybody and most people don't drink enough water and that will help you and then the exercise we talked about and then getting… trying to get some good rest. Yes?

Q3: How do you approach your illness if you have other conditions that are being treated as well like psoriasis, (inaudible 5:27). We have multiple conditions and multiple medications.

Sandy Kurtin: And that's a really good question. I mean, most of us as we get older end up with more than one thing going on and with that comes drugs because us providers work… we're really pill pushers, right, and so you end up taking many medications and you do have to balance all that and so we have to really treat the whole you and sometimes treating one problem causes problems with the other problem and I think that's, to me, where it's so important to get your plan together because you would love to think that all these people were talking about you and what they're doing to you, but the reality is is… I have a theory about global warming. There is a layer of faxes up at that atmosphere and never got to where they were supposed to go and it's creating this not an ozone layer, it's a fax layer because you can… we do everything digitally now. Everybody has electronic records because that's what we have to do. It's called meaningful use and in order for Medicare to continue to pay you and be contracted, you have to… there's all these criteria and one of the criteria is an electronic medical record and so when we do a note, we click Fax. Poof. Off it goes. Same way we do prescriptions now. We don't write them by hand hardly at all. They're all electronic and the bad thing is is you never really know if anybody got them and you don't have time to call everybody and so I say to patients take charge, be in charge of your own self and your own journey and your own care. Get your records so that if you're going to see the guy for arthritis or there's a guy for psoriasis or the cardiologist, you can say, "You know, I just had this. Did you get this?" No, no, no, no and I know I've been in some peoples' offices where they have stacks of paper and you know it's in there, but did they read it? Probably not. So being informed about yourself and staying organized and keeping that material together can really help overcome that because you'll have your list of medicines and then if

somebody wants to give you one that doesn't go along with the rest of those, there's some kind of interaction. It's going to be a lot easier to see that than if there… you're hoping that they have all the information. It's just… The reality is is it just gets really busy and it's hard to keep up with everything for every patient and it's… and when you have an informed patient that's taking control of their own care, they keep you on task. They'll say, "No. Let me just show you that." I was telling Dr. Luger and Dr. Besa that usually you guys can find it a whole lot quicker than we can when you have your booklet because it's organized, you know where it is, you put it there and we're going to dig around in our computer system which is a monstrosity and we won't find it. So, that's probably the best thing is to get all that together and create your own little binder. Yes?

Q4: I found over the years is you talk to people and they're talking about different medications they get. I question and I ask them why… why did the doctor give you this? They look at me with a blank stare. They have no idea. It's just that he told me that's what I'm going to do and I do it. Well, I've learned just the opposite. I question everything and I gotten to the point now where I've gotten a reputation in both Florida and up here that when I go in and sit and get my treatments with the nurses, I keep them on their toes. They say, "Here comes Rick," and I question everything that they do. In fact, I've corrected them when they were doing things wrong because I know what the procedure is and they were varying from the procedure and I tell them, "Well, about this? Why aren't you doing this?" and whip them in line. So, I say your own best advocate and if you don't stick up for yourself nobody will.

Sandy Kurtin: No. You know, it's really… it's very true to… and if people have issues with you asking questions then that's not your problem. That's their problem and we should be willing to explain what we're doing and why we're doing it and I think that's fair. There's a page in here that talks about preparing for your visit and you don't want to ask the same question every time you come 15 times. We get a little perturbed as my grandmother would say, but it's very okay to ask questions and come organized and just say, "You know, there's a few things I'd like to go over," and write them down. So, think about it before you go and then it's going to be more meaningful to you. So as you're reading through it something or you watch a video or you talk to somebody and you have a thought, write it down, take it to the appointment and say, "I have a question about this."

Q4: I really shook them up in Florida. One day, I had a PA for the doctor that met with me and I told him what the thing should be and he went in and he typed everything into the computer and then I went in for my treatment and as they bring the stuff out, I'd ask them what's that, what's that and they were trying to give me something and I told them, "No," and I got furious about it. Boy, they acted quickly. They got the doctor. They pulled him in the line and they got the PA and we went in and we sat down and I talked to him. I said, "I sat here and told that man what he had to do. He told me it was going to be done that way and I get into the treatment room and it isn't," and he says… he apologized. It never happened again.

Sandy Kurtin: Yeah. No, it's good to stick up for yourself and have your information organized. Okay. What else? What else did you talk about at lunch?

Q5: Transfusions. How many transfusions are too much? Is there any kind of criteria? For example, we talk about iron buildup, chelating agents (inaudible 11:54).

Sandy Kurtin: There is no such thing as too many. It's what you need. There are risks. So, every unit of blood has 250 mg. of iron in it. Our body is incredibly efficient at reutilizing iron and most of us will never be iron deficient. It's rare. You have to either be losing blood somewhere or have one of a very few abnormalities in absorbing iron in your gut. So if you gastric bypass surgery and they took out that part of your stomach, it's… you don't absorb iron very well. So, people that have had gastric bypass have trouble with iron deficiency. There's a few genetic abnormalities. So, the only way really to lose iron is to bleed which we don't recommend, but so when people who have like iron overload because of a genetic disorder, hemochromatosis, we phlebotomize them. We take off blood because the reason is we do that is because it takes iron with it. So after you've had about 20 units of blood, generally we think somewhere between 20 and 40, every person's a little different, but generally after 20 units of blood you're going to end up with too much iron. Too much iron can bind up… It creates oxygen free radicals, the substances that can damage tissue and it binds up in things like the liver and the heart and the brain and the adrenal glands and the thyroid and it can cause harm. So, transfusion dependence, meaning needing blood, 2 units of blood once a month at least for a period of time, is usually a reason for us to start thinking about treating you in a different way.

Q5: Two units of blood in a month?

Sandy Kurtin: Yes

Q5: In a month.

Sandy Kurtin: On a regular basis. So, if that… then you're transfusion dependant and if we… and we know that unless we fix the factory, that's going to continue and you're going to continue to be exposed to this excess iron. There are other things you can get from transfusions. Viral transmissions, allergic reactions, rare but serious complications in the lungs or the heart and so it isn't something to take lightly. It has its own set of side effects. Yes?

Q6: My husband was diagnosed with MDS about 8 years ago, low platelets. They've been keeping an eye on him in the 8 years. Gradually, it is… the platelets are going down. He's down to 60 or something like that.

Q6-2: Fifty-seven.

Q6: Fifty-seven and still but nobody has recommended a bone marrow biopsy. What would that show that… since he's okay at this point that he's okay. Leave him alone.

Sandy Kurtin: You can't really diagnose MDS completely without a bone marrow biopsy because you need to have that… It's like a tissue biopsy. It's just like you wouldn't treat someone for breast cancer without doing a breast biopsy. You wouldn't treat someone with colon cancer without getting a piece of the colon. It's the diagnostic piece to say this is what it really is and so we would… What it would do for you whether you decided to act on it or not is at least

give you some idea is it still low risk? Is it becoming more high risk? What can I expect? So, it isn't something that all of a sudden that just happens, but it gives you at least a clue of where you're at because over eight years a lot can change and so we would do one just so we had an idea of what… is there something evolving or not? Do we need to act on this or not?

Q6: Well, we were told if it gets down to 40 then he would start.

Sandy Kurtin: Because then you don't have much room to move. Then if you do start treatment, we need… it's going to get worse before it gets better. We need a little room to work. It's going to make it safer for you. That's what… That's the way I would approach it. Not that I want everybody to go out and have bone marrow biopsies, but I've heard from a couple people already they're not very fun and they don't have to be terrible. You just need someone who is good at it.

Q6: So, it's possible that it's not that. It's something else.

Sandy Kurtin: It could be. That would be the other question. Is there a second process going on that could be treated in a different way? So, yes. That's the only way to know. Yes?

Q7: Could you elaborate on the chromosome part of the talk? For instance, what are the qualifications for getting chromosomes tested or how's that work?

Sandy Kurtin: So, what we know about any disease… So chromosomes, we all get our chromosomes from our parents. So, we have these 2 sets, 1 from the mom, 1 from the dad and so we have these pairs and they are the blueprint. They're basically the instruction sheet and they say you become a lung cell, become a brain cell, become whatever, become a red blood cell. They're the blueprint. It's an information sheet. In most diseases in the hematological or the blood cancers in particular, there are certain chromosomes that we know are particularly naughty, bad players. They make cells do bad things and behave badly and so we know in MDS that chromosome abnormalities are fairly common, roughly 50 percent. There are a lot of people who have normal chromosomes who still have MDS. It's still cancer, but there are certain chromosome abnormalities that we worry about because they tend to behave particularly badly and more commonly turn into leukemia and then there are other chromosomes like –Y, for instance. –Y is very common just as a part of aging. It doesn't really mean anything. It's nothing to worry about. If you have deletion 5Q then that's good to know because you could do very well on Revlimid. It's information for us to fully diagnose the disease and put it in a risk category, so we know how best to treat it. That's why it's important.

Q7: If you go to the… if you have a doctor (inaudible 18:46) care, at what point does he say, "I think you should have a chromosome test?" or does he do that in the beginning?

Sandy Kurtin: No, it's… the only way, unfortunately, today the only way and there are people working on doing it in different ways but right now the only way you can get chromosomes is through a bone marrow biopsy.

Q7: Through what?

Sandy Kurtin: A bone marrow biopsy. We take the liquid part of marrow and we send it out for cytogenetics, what's called cytogenetics. That's a chromosome analysis. Did you have that done?

Q7: I had a bone marrow test done recently.

Sandy Kurtin: Well hopefully, the sent it out for chromosomes. You should ask them. They should have done that while they're in there because we just take one little extra bit and we send it out. That's the only way you can really effectively diagnose the MDS.

Q7: I see. Thank you.

Sandy Kurtin: Other things, questions, things to share, fears? Yes.

Q8: Question. The autoimmune system. Put that in one category. Now, we go to the category of your (inaudible 19:54). Does the blood circulating throughout the body affect the autoimmune system how?

Sandy Kurtin: So, your immune system is comprised of certain kinds of blood cells that also originate in the bone marrow and then they grow up and leave home early like in their teens and they go out to lymph nodes and the spleen and other organs. So, most of your immune cells are lymphocytes and those lymphocytes don't mature in the marrow. They start in marrow and then they go out to other tissues. Many autoimmune disorders, so rheumatoid arthritis, lupus, psoriasis, any of those disorders are usually these immune cells becoming a little too active and taking it out on your own body. So, there's sort of that autoimmune. That's autoimmune. When you have an autoimmune disorder you're more prone to developing certain kinds of cancer. Lymphomas, for instance, MDS also in some peoples' minds because there's this chronic inflammatory process going on. Then you have the other piece of the bone marrow or the factory which are these myeloid cells. So, those are red blood cells. The other kind of white blood cells called granulocytes and platelets. So, you start with a stem cell. It goes to… I actually have a slide. Where'd I put the clicker? It goes to… It's faster to go to… Can you push Home? You'll never look at that building in the same way. So, here's the hematopoietic what we call the hematopoietic tree. Right? So, here's your bone marrow. You have stem cell. When we do a bone marrow transplant, all we're really doing is giving very high doses of chemotherapy, sometimes radiation and then we reinfuse these cells and they create this whole other factory. So, here's the lymphoid system. So, this starts here. It comes to this mutlipotent stem cell and at that point it has to commit to either becoming a lymphoid cell or a myeloid cell. Myelodysplasia is this little piece of the factory. Lymphoma, lymphoid, lymphomas, CLL, myelomas come from this part here. These are your immune cells. So, they all come from the same place, originate in the same place, but… So if you're manipulating one part, you can theoretically manipulate the other part and disorders in this area like I said can create so much stress on the factory over time that it creates second abnormalities. Does that answer your question?

Q8: Yes.

Sandy Kurtin: Okay. Yes?

Q9: I was just wondering. Like you were saying arthritis and lupus are also a factor in this, but when you say they're affected do they cause MDS or do they…?

Sandy Kurtin: They can create exposure to different kinds of cancer because of the chronic stress on the system over time. So, people without immune disorders are much more at risk for lymphoma. We know that for sure and we… and there's some suspicion about some of the other hematological malignancies for the same reason because it's just putting a strain on this system.

Q9: And how about treatment of MDS if you have these conditions?

Sandy Kurtin: We… Again, you have to just treat the whole person and you have to consider when you're using certain drugs. So for instance, Revlimid, you were talking to me about that over lunch, is an immunomodulatory agent and it may be that you have underlying symptoms that are part of your other disease that are being more… you're more sensitive to the affects, I guess I would say, of those… of that medicine because of those preexisting conditions and sometimes that means we have to adjust the dose. We might have to schedule it in a slightly different way. We may need to treat the other problem more aggressively at the same time. You got to treat the whole you. That's always a challenge. You can't say, "Well, you know what? Go see your cardiologist, go see your…" We get to divvying people out on so many doctors and you need someone to treat the whole you and that's always a trick, too, which is, again, why you get organized and you figure out who's keeping of track of the whole me. Is there one person that knows all the stuff that's going on with me that can try to keep this in balance because you'll… We have the primary (inaudible 24:59) physicians will say, "Come back when you're done with your cancer." Right? That's not going to happen. This is a long term process. So, we need people to be a team and communicate and sometimes the system doesn't work very well. So, if you empower yourself you're going to have people be better aware of what's going on.

Q9: And when you say (inaudible 25:23), do you mean that you have to really dictate to the doctor that is treating you for the MDS that he has to do more with the whole body rather than just the MDS?

Sandy Kurtin: Well, good luck with that. I think it's really just being aware. Like if I have people that come and say, "You know, I was just at the cardiologist and he just switched me from Coumadin to Plavix." That's important for me to know because I'm going to be looking at your platelet count and if that platelet count gets down below 50, you got to stop those drugs and if the cardiologist doesn't want you to stop the drug because you have a valve then we need to argue about who gets to decide about your Plavix and Coumadin because I can tell you this happens all the time. Cardiologists will say, "No, I want them on it," and I'll say, "No. You can't. He's below 50," and we have to have a conversation about what else can we do so that the valve doesn't clot off. We need to work as a team and I wish it was that the system allowed us for us to that every day effectively, but it doesn't, honestly, and if you've got people in 3 different buildings even in the same system, chances are they never even see each other at work. Right? Because it's big. Like you think the people in this building see the people in that building?

Q9: No.

Sandy Kurtin: Probably not unless they're doing round in the hospital at the same time. So, really, it's sad but true having yourself be organized and being aware of what's going on with you and just simply communicating that is important. I think the other thing I try to get specialists to understand is if you broke it you own it. So, that's hard for them to accept because everybody's busy. So if we're giving you a drug that causes blood pressure to go sky high, we're partially in charge of that fixing it because we made it worse. So, we just have to… It's not perfect, but I think being well informed yourself and having all your materials together is huge because it's going to make it easier for people to help you and then it doesn't take them as much time and then they're much more willing to do it. Yeah.

Q10: I do have that issue. I've been treated with thyroid all of my life, had many surgeries and I think my thyroid has a lot to do with the way I adapt to medications and treatments. So, my doctor is here and she corresponds with Dr. Luger especially on my future blood tests now because there's a different way they have to test me.

Sandy Kurtin: Yes and particularly on Revlimid because Revlimid affects thyroid functions. So, very important. So, that's good. I mean, it's always best if someone can pick up a phone and have a quick conversation, but it doesn't happen every day.

Q10: They met each other in a parking lot one night and discussed me.

Sandy Kurtin: That's it.

Q10: How are you going to treat my patient?

Sandy Kurtin: So, good for them because that's the best case scenario. You're absolutely right.

Q10: Because I'm very sensitive to everything, everything and that helps my factory. So, I also know it's going to dictate my treatment for Revlimid. I know that now.

Sandy Kurtin: Well, I'm glad they met in the parking lot.

Q10: I told them. You got to talk to each other.

Sandy Kurtin: Yeah and you know sometimes it's just a matter of that could you give so and so a call? Making that suggestion and…

Q10: No, I told them because I know it deals with the thyroid. It's terrible. Terrible.

Sandy Kurtin: Okay. What else? Anybody have other concerns, questions, anything?

Q11: General question.

Sandy Kurtin: General.

Q11: You have the CBC and there must be a dozen or 15 different things on there and I personally when I look at it, I look for platelets. I see that number okay put the paper away. Alright. Well, I'm okay. Now, should there be supporting or negative parts of that CBC that will tell me more than that one number?

Sandy Kurtin: Not for platelets. So platelets, the platelets come from a cell called the megakaryocyte which is here. This big thing right here is a megakaryocyte and megakaryocytes produce all of your platelets and that's these little things here. You can only measure megakaryocytes in the bone marrow. So, you can't see them on a peripheral blood smear. So when we have someone with a platelet problem over time, the question that we have is do you have a factory for platelets? Do you have megakaryocytes? Yes or no and/or are you getting… destroying them too quickly once they get made and sent out which is what a bone marrow would tell you is do you have these little platelet factory cells in your bone marrow. So, the only way to really measure platelets is with a platelet count on a CBC, differential and platelet that you get on your blood work. When you look at the blood work what we look at is we're going to look at the… That's MDS pushing it out of the way. Back up the bus. Let's try that again. Pushed the wrong button. So when we look… we're going to measure… so when we did a CBC, you're going to total white blood count and it's going to tell you cumulatively about all of these and then we're going to look at these neutrophils. You may hear people talk about an ANC, absolute neutrophil count. This is actually in your book under Quick Tips. It'll tell you about neutropenia in MDS, thrombocytopenia in MDS. It's in the very first few pages and it'll tell you how to calculate an ANC, but when those neutrophils are low that's when you're more at risk for infection. So, we look at the total white blood count, we look at the neutrophils. We look at the hemoglobin and hematocrit. Everybody wants to know about their RBCs. I don't really ever pay attention to that number. It's not important to me. It doesn't mean anything in the day to day what we do. So, I never follow that number ever. Just it's not meaningful in looking at this to me. It's important in other diseases, but not so much in MDS and then we're going to look at red blood cells. That's so hemoglobin and hematocrit measures red blood cells. The platelet count gives you the platelets and then the white blood cell count and the neutrophil, percents of neutrophils, are basically telling you what this looks like from here to here. That's what we follow. Yes?

Q12: The relationship between hematocrit and hemoglobin. I've been told that rule of thumb hemoglobin three times is hematocrit. If they're not, what is that indicating?

Sandy Kurtin: You're probably either dehydrated or over hydrated. So, we don't follow hematocrit as often because it's a percent in solution. So, it's basically a concentration and if you're dehydrated… So if you've ever been hospitalized and they give you a bunch of fluid, your hemoglobin… your hematocrit goes down and then you get out and it corrects itself because it's delutional. So when there's a big drop when you're in the hospital because you're on all this fluid it's delutional. So, we tend to follow hemoglobin and that's why that is the criteria in the IPSS scoring system is hemoglobin because it's basically measuring the molecule itself which has to be carried. We like to think of them… There's an ICU physician that I worked with for years that talks about box cars. Like you got to have the box cars to carry the oxygen molecules. The red cells are the box cars. If you don't have any box cars, you can't carry them.

Right? So, your oxygen level's going to go down because that's what red cells do. They carry oxygen. So hemoglobin is what gives you that number. Does answer it?

Q12: (Agreement sound).

Sandy Kurtin: Okay. Yeah. Other questions, concerns, things you want to share?

Q13: I saw something about avoiding aspirin.

Sandy Kurtin: Yes. If your platelets are low.

Q13: Are they talking about the baby aspirin, the 81 mgs?

Sandy Kurtin: If your platelets are below 50,000, we prefer not to have any kind of blood thinning… You know, platelets… Aspirin works by inhibiting prostaglandin which basically help to make platelets sticky. So, this is why they use it in cardiovascular disease because you have plaque or whatever going on and there's inflammation in the internal lumen of the vessel and that inflammation brings all these cells together and the platelets rush in there and try to plug it up thus forming a clot. So, they give you aspirin so your platelets aren't sticky, but when your platelets are low that can also predispose you to bleeding. So when you're below 50,000, we have to reassess all blood thinners. Above 50,000 it's okay to take it, but we don't want you on high doses and we need to keep an eye on it.

Q13: If you're taking it because the cardiologist (inaudible 35:11) says it's okay and the hematologist says…

Sandy Kurtin: Says no, no, no. Then they have to get on the phone.

Q13: The hematologist said take baby aspirin every other day. Check with your cardiologist (inaudible 35:24) that be okay because they want to start no (inaudible 35:27).

Sandy Kurtin: Only when the platelets are low and one dose of aspirin can affect platelets for seven days. So sometimes the every other day is a happy medium and so yeah. So, that's what we do. But yes, this is very common when you're arguing with the cardiologist and so I'll tell you when I worked in the hospitals that I don't go anymore. I'm in the clinic all the time, but I would always say to the ICU physicians and the cardiovascular people, "You know, the heart would have nothing to do without the blood." That didn't go over too well. They think they're top dog. I'm like, "No, no, no. You have nothing to do without the blood." Right? Yes.

Q14: I was taking Naproxen for my back and my doctor told me don't take it, that or aspirin.

Sandy Kurtin: Naproxen is not as bad on platelets as aspirin is. You can use it with caution. It is hard on the kidneys. Any nonsteroidal. So, Ibuprofen, Naproxen are hard on kidneys and as we get older that becomes an issue anyway. So, you have to be cautious about that. Drink lots and lots of fluids, but it's… not sure it's likely to cause platelet disorder. What it can do is irritate the gut and make you more prone to a GI bleed. So if you're on those chronically for pain, you

should be taking a proton pump inhibitor, something to block the acidity in the gut and then usually it's okay to take it, but we, again, we have to keep an eye on the platelets.

Q14: What's a proton…

Sandy Kurtin: Proton… PPIs. Things like Aciphex, Protonix, Pepcid, Prilosec, acid blockers. Sorry, I'm speaking in lingo. Yes.

Q15: While attending one of these forums in New York some years back, there was a young lady there that was on blood transfusions. She was in the red blood cells and she had… she was young. She had children in elementary school and she found out that she would go and get a blood transfusion on a Monday. She'd come out and wonderful. By Thursday, she's right back feeling lousy again and she couldn't understand this and to make a long story short, she boiled it down to the fact that the blood that she was receiving on those poor days was almost ready to expire and therefore the lifespan of the red blood cells that already darn near expired, she wasn't getting the quality of blood. She was getting quantity. Somebody in an auto accident gets quantity that are interested in and needing, not quality. So, she started trying and she used the expression at the blood bank, 'schmoozing' them to get them to use the younger blood rather than the older blood and she convinced them that that was the thing to do. So, she got blood that was only donated yesterday or today or whatever

Sandy Kurtin: So, there's a lot of people that argue about this because theoretically that's true. So if the… Regulation for red blood cells is 42 days. Platelets are only 4. So, you can… so a donated unit of blood can be there for 42 days before it expires and the lifespan of a red blood cell is 120 days, but part of what… So, some people say if the unit's about to expire, those cells aren't going to be as fresh or last as long or give you the same oomph. There are people that are… The American Association of Blood Banks that will argue, no, no, no. That's not true because once transfused, red blood cells are temporary. They're not your own. They function differently. It's not the same as making your own. They're borrowed. So, borrowed units of blood give you a little bump, but at the end of the day you got to replenish them. What does happen over time is people stop getting the benefit from transfusion. So as you have more and more and more units of blood and if the disease is really the problem, people are saying, "I don't feel any better anymore when I get blood," and it isn't really the age of the blood, it's the disease and that's another clue that it's probably time to think about doing something to the underlying process because you're basically developing antibodies. Every time you get a unit of blood, you're having like a mini transplant because you're getting somebody else's cells and you're exposed to those cells and your body and your immune system are saying these are not my own and it does some stuff. So over time that can actually then create a separate problem even beyond iron overload, but it's true. There are people that say or they say, "Wow. It must have been a football player," because they felt so good after that unit of blood and want to track that guy down and lock him up. Not that I'm encouraging that or anything. Okay. What else? Questions.

Q16: Just another share. (inaudible 41:02) doctors collaborating. Dr. Hexler's, a gorgeous doctor from here, and when the dentist had recommended a gum (inaudible 41:12) and those kinds of things, she said no. She actually got on the phone with the dentist and they had a discussion about what type of treatment should be used. So, accolades to her.

Sandy Kurtin: That's good. Yes, I mean, the dentist is always a big question. Can I go to the dentist? Can I have a cleaning? Good luck to you.

Q16: (inaudible 41:31).

Sandy Kurtin: Try it again. There you go. Alright. Bye, bye. But yeah, that's… I mean you can go to the dentist as long your neutrophils are good and your platelets are okay, it's fine to go to the dentist, but if those numbers are low then we should chat and if your platelets are low and you need surgery, we have people coordinate it because what we do in our centers, we'll have them come, get platelets, drive over and see the dentist for the extraction or come get platelet transfusions and have whatever it is, the colonoscopy or whatever else it is that they need to do. So, collaboration is very important and you just got… that's why it's important to get organized and keep everybody clued in.

Q17: So, think of your dentist do you need to worry about normal routine?

Sandy Kurtin: Not usually. If the neutrophils are good then you should… and your platelets are good because gums tend to bleed, you should be okay. It's not the same as if you have an artificial valve or a knee replacement or a hip replacement. In those cases, you need to have antibiotics before and after, but otherwise you should be able to go to the dentist. Yeah.

Q18: It brings up a question you were talking about exercise earlier with… I had two knee replacements. Would that be a problem?

Sandy Kurtin: To go to the dentist? Yeah.

Q18: No. Using the exercise with the knee replacement.

Sandy Kurtin: No. Not… I mean, unless they are painful you should be able to exercise. They'd have you do that in rehab. Didn't they do that in rehab?

Q18: For the knees years ago, 15 years ago, yeah, but I didn't have MDS then that I knew about anyway.

Sandy Kurtin: I mean, you're pretty mobile anyway. So, you can probably do other things, but if it hurts or whatnot you need to get it checked out. Don't just keep doing it on your own.

Q18: Okay. Thank you.

Q19: I have a one question. Nobody's ever told me… Well, I'll ask here, but I don't want any (inaudible 43:41). Does alcohol have anything to do with MDS or is (inaudible 43:47)?

Sandy Kurtin: So as far… We do know that tobacco use is a cause, can cause any kind of cancer, MDS including, because it contains benzene as the primary component in tobacco. So, heavy smokers are more at risk for any kind of cancer, but MDS, certainly and/or secondary smoke

exposure over time. So, that can definitely predispose you and that's been now published probably in the last couple of years. There isn't really data yet at this point to say that alcohol causes MDS. We know that it increases the risk in certain kinds of cancer, breast cancer, certainly. What it can do though is affect platelets and so if you have more than a little bit at any one time, it can drop your platelets very suddenly by 50 percent, so we… and if you're on medications it can change the way those medications are absorbed and/or make them too strong or not strong enough and so we try to tell people to take it easy. Again, moderation is the key. Some things in excess some of the time, right, but really want people to be cautious. Yes. Anybody else? One thing we didn't talk about, Dee, is there the questionnaire in here? No. I don't see it in here. There is a patient questionnaire that is… Oh, it is in here.

Dee: I'll send it to everyone by E-mail, so you can do it online. I sent it Tuesday.

Sandy Kurtin: It takes some time to do and I totally forgot about it, but if you have time at some point at your leisure to take that and look it over and fill it out and send it back in. It's really important for us to help us understand better how to support all of you, the MDS population, and it does take a little time to complete, so… but if you'll think about doing that that would be really helpful. Any other questions or thoughts?

Q20: Would it be a good idea if the, say, a person that has problems E-mails all the meds that they're taking and have someone at your organization look at those?

Sandy Kurtin: We can't really do that.

Q20: (inaudible 46:34) there's good bad and difference in the meds?

Sandy Kurtin: We can't really do that because we're not taking care of you, but you can send in questions.

Q20: Like rule of thumb or the…?

Sandy Kurtin: No, no. What I would do is take it to your local pharmacist. There are websites. There's a place called www.drugs.com and there's an interaction tracker and so you can plug the drugs in and it'll say these two things don't go together. This is fine or oh, my gosh, don't do that and but the pharmacists have access to that kind of information and if you go to wherever you fill your prescriptions and you take a list of medicine and you say, "Will you look at this?" they will do that for you.

?: Say that again?

Sandy Kurtin: www.drugs.com interaction tracker. Yes.

Q21: Is there a support group around the country and around like New Jersey/Pennsylvania and New York?

Sandy Kurtin: Yes. So, there is a group here in Philly I know that got started and if you will contact Audrey Hassan at the Foundation, she has a list of all of those support groups, how you can get in contact with the leader or they'll… she can send you information to them to contact you and, again, her information if you go all the way back to About the MDS Foundation, it shows you… It'll tell you who all the people are and Audrey is on on page 4 in chapter 6, but her E-mail's not on there.

Dee: Here's her E-mail. Oh, well everybody will have to write it down. It's a card. It's a business card in the back of the book. It's in the back of the book.

Sandy Kurtin: Here it is. So it's… I knew we had it in here somewhere. So, it's the card holder and this is a good idea. You can buy these individual pages and whatnot at office stores and it's just a nice way to keep it organized along with your other information with all the people. It has their fax number and phone number, so you can have the doc quickly make a copy, so they can call somebody hopefully or fax them something directly and hopefully it's not stuck up in the layer.

?: In the layer.

Sandy Kurtin: In the layer.

?: It made me think of it as a…

Sandy Kurtin: That's my version of global warming.

Q21: Mine, too. My two doctors are in the same building. They know each other.

Sandy Kurtin: That's good. Yes.

Q22: How do (inaudible 49:13) sick people come here.

Sandy Kurtin: You want to take a book?

Q22: Yeah.

Sandy Kurtin: Because we have an extra one, too,.

Q22: Thank you very much.

Sandy Kurtin: Absolutely. Yes.

Q23: I was thinking my wife needed a second opinion and that's part of our… just need to drove up here because at the campus at University, she's being going to John Hopkins. I don't even know what the hell brought her… How do we go about even looking for a second opinion? Who do we go to?

Sandy Kurtin: There's a list of centers of excellence in the book in there. It'll tell you where all the centers of excellence are for MDS. So, the MDS Foundation has a list of institutions who meet criteria to say they know something about MDS and you can look through there and see if there's something that would be a reasonable distance for you that would potentially be an option. It never hurts to do that and I mean, we have… we talk… if physician says to you or another provider says to you, "No, you can't," well then that's crazy. It's not about them. You need to do what you need to do to feel comfortable with what your decisions are and if that means hearing it from someone else and maybe they tell you exactly the same thing they just said. We just had a conversation and he said, "That's exactly what my doctor just said." So, that's always good or if they tell you something totally different and/or they may have things available there that aren't available at another place, but there's a list in there that you can refer to. It has phone numbers and contacts and the whole thing. Okay. I would take your booklet. They're going to want your site's review, but then I would take your information and be able to tell your story and say, "Here's what's happened to me and here's…" and be able to describe it in a very succinct way and that's going to make it a more meaningful meeting. Alright, you guys. Have a wonderful afternoon and thank you all (inaudible 51:13)… so much, you all.

(Applause)