

Speakers

Larry Cripe, MD

Jean Ridgeway, MSN, APN, NP-C, AOCN

Larry Cripe, MD: I apologize I'm late. Like most people anymore, I always assume I'll have a quick unimpeded trip to where I'm going and I did not anticipate that there would be a walk that closed down the street I needed to go down. So if you don't mind, I'll introduce myself a little bit and tell you who I am and why I'm here sitting in front of you. I do not have a formal presentation. One, I don't like formal presentations because I think that feels like then I'm just sitting yacking at a bunch of people and I'm not a big yacker. So, I will make some opening remarks and I hope those remarks will 1) confirm that I'm not a yacker and 2) will encourage you to ask the questions that you're here to talk about because what's important to me is we cover what you want covered, not what I want covered. Fair enough so far?

So, my name is Larry Cripe. I'm a hematologist. I practice at Indiana University Simon Cancer Centers somewhere in this area. I have been practicing as a hematologist now for almost 20 years, 20-some years, yeah, 26 years. I knew on my third year of medical school that this is what I want to do with my life from the moment I met my first person with a blood disease I loved it and I have loved it to this moment. So, this is what I do. I take care of people who have various reasons for their bone marrow to fail and I do that on several levels. One, I have a very busy clinical practice. So probably, my responses to your questions will be just as if we were sitting together in a room talking about this. So if it's not scholarly enough, you can let me know and I'll try to take it up a notch. Secondly, what I love about this is it's a lot about communication. It's a lot about understanding what the future is likely to bring because as probably most of you know in this room even more vividly than I do there are often are not solutions for when the bone marrow fails that easy, straightforward and so it's a lot about communication. So, I love talking about these diseases with people. I love talking about the future, what might happen and most importantly how we can best care for somebody because I'm a strong believer that I only know the best answer once I know what that person thinks the best answer is. So, it's rare that I can come to somebody and say, "You need to do A, B and C and D, E, F will happen." Usually, what I have to do is say, "You know, I think there's A, B or C and can you tell me which one works the best for you?" So, let me stop there. Other than to say I'm pleased to be here and look forward to the next 35 – 40 minutes of questions. So, what intrepid soul is going to ask the first question? Yes, ma'am.

Q1: Do, I need to talk into this? Am I doing it right? Can you hear me? First of all I want to commend you, doctor, for coming here and wanting to communicate with us and it sounds like you do a very good job with your own patients. I personally have had a bad experience with a hematologist and I'm on my second hematologist because of that very factor. He told me I ask too many questions and if I wanted... He printed a page out of a textbook, handed it to me and said, "If you want to know what you have, go look it up." So, thank you.

Larry Cripe, MD: Let me just... because I'm sure... First of all, let me say thank you for your comment. Let me also be honest. I'm sure there have people who have walked out and said that guy needs to go back to basic communication. So, maybe we can just... you can elaborate a little bit on that? What could the physician have done differently, one or two things, and maybe we

can reflect on that because that's sort of selfishly because I really like hearing this because then I can understand and reflect upon what I do. So, is that fair to just sort of spend a few moments on that just talk about from your perspective what could we do better as physicians and nurse practitioners and people who really are dedicated to helping you? So, do you mind just one or two things?

Q1: Anything in particular because I could go on for your...

Larry Cripe, MD: Well, I don't want you to go on. I definitely want you to go on, but so let's list two things. Just what could he have done?

Q1: He could have answered my questions. I could have went explained things a little more so I and my family would understand them. He told me I had 2 to 4 years to live and I have had a second opinion and found a great hematologist since then. No one else has said that. He was giving me injections at \$5,000 a pop that I feel that I didn't need and the second opinion doctor felt that I didn't need. So, is that enough?

Larry Cripe, MD: Good. I think that's great. Thank you. So, let me just affirm one more thing and then we'll open it up further is I would absolutely agree with you. If someone said to me, "I don't want your questions," I would say, "Well, this is not going to be a good relationship," and in fact I occasionally reverse that... turn that table around and say to the person I'm caring for, "If you're not going to ask me questions, I'm not really going to be able to help you very much because I really need to know what you need to know." So, I applaud you for asking those questions. I would only say 1 thing and it sounds like you may have done this. If you are a question asker, bring it in a list if you can and the minute the doctor walks in the room to say here are the questions I'm really interested in covering, but give them some slack and if they say I can't cover 6,732 questions. Can we do the first 2,000? You know what I mean?

Q1: Yes.

Larry Cripe, MD: But I think most physicians welcome the idea that you have taken the time to organize what's important to you because so often I believe our inability to communicate well is we think, "Oh, my gosh. There's so much I could say at this visit." Does that make... So, I applaud you and I would encourage other people if you're a question asker, go for it, but bring it in a list and let the doctor know right away that that's really what you're going to be... and then make sure you understand there is a prioritization. Often we can't spend as much time as we'd like to in any one visit and finally, which I do reluctantly because I know how hard it is to get the doctors and how long people wait, but sometimes it's about scheduling a visit just for questions to say I don't want to talk about medicine, symptoms, I just want to talk about what I need to know at this point. So, that's sometimes very useful. Sir, I think you were...

Q2: I had a similar experience. The doctor, the hematologist, that I first saw that couldn't find out what the problem was for a long time and then we... I insisted on a bone biopsy literally and so I said, "We need to find an answer," and so we did and that came out MSDRCND and he says, "Well, what we'll do if you feel tired, you just come in. I'll give you a blood transfusion," and that triggered a... I said, "Wait a minute," and I called the MDS Foundation and I says,

“Where are the specialists in this area?” and it was the Simon Center and we saw Dr. Sayer and confirmed, but he says, “That’s not where you start,” and so I think it’s important... the second opinion, I think, is not a bad thing to do and as a result, I have a different hematologist. I’m from Fort Wayne, Indiana. Because of that he may be a great oncologist, but when it came to MDS, I knew that he didn’t know because every time he had to go look it up the next time to visit he changed his story, see, and so that’s why we came to IU.

Larry Cripe, MD: Thank you for that story. Yeah. It makes sense to me. I’m always interested in how few times we all ask for second opinions, but I think, once again, I’ll give my colleagues the benefit of the doubt and maybe not everybody, but I do think that we do like to think of this as a partnership and that I think the pushing back while maybe on a bad day is annoying, on most days I think the physician likes to understand where you are because there are many times that I see people with clearly evidence of bone marrow not working well. I’m aware that the bone marrow biopsy and ask for it often doesn’t give us an answer and so I say, “Well, maybe we should wait until we really need to make decision.” It sounds like you were more of the mindset, “No, I really would like to know as much as possible right now.” So, it is a dialog. I guess, that’s the thing I just keep coming back to. It is a dialog. It’s about saying to somebody, “You know, I had these expectations,” and that’s where it’s also always good to bring somebody with because then they know your expectations and they can look at you and we often, myself included, we say okay, whatever I got I’m grateful for, but your friend or family member may say, “Wait a minute. That’s not really what we... We really had a more specific goal in mind.” So, yeah. Great for you and Dr. Sayer is an awesome individual. I love working (inaudible 10:50). What else? Are there communication, disease, pathophysiology, treatments?

Q3: I have a question.

Larry Cripe, MD: Yes, ma’am.

Q3: My husband has MDS, who is sitting right here, and we’re just kind of the opposite. Our doctor has been very upfront and very open with us and does not know that he sent us on to Dr. Nelson and then Dr. Nelson, he discussed with you and the bone marrow transplant, he’s not a candidate for. So from that, we’re just kind of biding our time because there’s not... The question that’s come up as far as Neupogen and as far as blood transfusions when that actually starts or when... I mean, is that something that Dr. Tamer and he are going to have work that out and it’s all these questions that come and everybody wants an answer and there’s not necessarily any clear answers or quick answers, but he’s also fighting with a terrible ear problem and now we can’t seem to get that... because his counts are so low, we can’t get that cleared up enough to have the doctor that deals with that want to do surgery and so we’re just kind of running into... I don’t know where we go. I’m not sure, but other than we’re here to see you because you’re the guru of MDS and there’s big signs on this all the way from South Bend telling me that.

?: No pressure.

Larry Cripe, MD: Well, I’m glad I made it. Here’s how and I’m happy to try to approach it more specifically, but I think generically I ask a question what are the goals. So at any point in time what is our or are our goals? So, do you mind if I talk about this more specific then?

Q3: Yes, I am.

Larry Cripe, MD: So, if there is a... let me just say... let's say there's something wrong with somebody's knee for which there's a surgical procedure that needs to be done and the surgeon says, "If you did not have MDS, I would do surgery." So then it's a dialog between me and the surgeon to understand what it is about the blood counts right now that make you not want to do to the surgery. Is it that the surgery will be less effective or is it the surgery will be more risky? You may want to write this down, by the way, that our... somebody may want to write it...

Q3: I have, but I don't know what I did with it.

Larry Cripe, MD: Because my plan is for you to specifically go to your surgeon and your oncologist and ask these questions. So, if the surgeon said, "Well, you know, this surgery in the best of circumstances is not very successful and now the risks are too high," then I would just put it off the table and I would say, "What is our next option?" because our goal is to still make the knee work better or get rid of knee pains. Does that make sense so far?

Q3: Yes.

Larry Cripe, MD: So, it's always risk versus benefit. Well, let's take the other side and let's say the procedure itself is likely to be of benefit, but he's worried about the risk. So then, it's a hematologist's job to try to minimize those risks. So, if the risk is related to infection then Neupogen to try to see if you can't increase the neutrophil count may be the appropriate thing to do around the time of the operation. I will say that in general if somebody is not yet showing signs of infections that are spontaneous and severe, usually that tells us that the neutrophils they're making are adequate, but you could always... the surgeon may say, "I want some added benefit," so then you would do some Neupogen around the procedure. So, that's then trying to say can we minimize the risk or can we decrease the risk? So, that's one around procedures. So, what is a procedure, what is a likely benefit? If it's truly going to be a benefit and this is where goals because sometimes we'll say to somebody, "Well, we don't think the knee pain is severe enough to put you through a procedure." It's your prospective needs to be given, you may need to say, "Wait a minute. In this case, that knee is debilitating me and if I don't..." So then you say, "Well, okay. The benefit now is there." So, you're always trying to maximizing your sense of benefit, minimize your risk. The other question you asked is really how do we navigate toward the future and so I think it's a reasonable question to ask given my disease and given that the goal of curing my disease with the bone marrow transplant is not feasible that that can't be done for whatever reason, what is likely to happen in the next 12 – 18 months or whatever time period you want to use and how will we know that? So, let's just take red cell transfusions because that's fairly easy to talk about. So then you would say, "Well, how will I know when I need red cell transfusions?" and the doctor would say, "Well, when you develop symptoms such as being tired, short of breath, things like that or when we see a hemoglobin value hit a certain level," and these aren't cast in stone, but the doctor almost always has a sense of what he or she is going to do and then you'll say, "Well, how will I know once we start that that's the right thing to do?" and then you should... what the doctor will probably do or the nurse practitioner or nurse will say, "Well, we'll give you a transfusion and then we'll see how you feel," and so let's say that a

person is relatively healthy and their hemoglobin is 8.1 and you give that person a transfusion. Most of the time they won't feel substantially better because their body has learned to adapt to that. On the other hand, they may say, "I feel 20 years younger," in which case you in collaboration with your doctor and nurses would want to say, "Let's keep an eye on my symptoms. I now know how much better I can feel and I now know where I was feeling and my levels and that's when we'll decide on transfusions." Does that make sense?

Q3: Yes.

Larry Cripe, MD: So, it's really about... So, there's a concept that I love called Sentinel Events. So, it's we as physicians and nurses have a sense of what the future might look like for every... any one individual and I think asking for those sort of things. So, you might say to me, "Dr. Cripe, when will you be worried? When do you think...? When will you look...? What will you see that will make you concerned?" or I might say to you, "You know, I'd really like to talk about how we're going to do this once you're on transfusions." So, I think it's worthwhile speculating a little bit about the future because I guarantee you your doctor knows... What we don't like to get and I'm going to use you as an example. What we don't like to get to is where we're forced to or we flippantly start saying, "Well, you're going to die in two to four years," or... because then that gives a time that's not fair. What you're really saying is let's see. I anticipate this could happen and once this happens this is how we'll respond and evaluate. Does that help? Alright. Thank you. That was a great question.

Q4: How fast does this progress? How fast can this progress?

Larry Cripe, MD: Those are two profoundly different questions. So, let me... I always hate saying things that probably most of you know, but let me just say it in case I can say it in a way that makes sense. So, when I meet with a person with MDS, once again, I'm thinking about what are the goals from my standpoint. I'm interested in what are the goals from their standpoint. I'm trying to find out where... what options for treatment overlap. In medicine, we or at least this physician was trained to really think about the risk and benefits and so what we like to do in blood cancers like MDS is say, "If I don't intervene, what's likely to happen and is that better or worse than if I do intervene?" I'm going to get to your question, honest to goodness. So, we do something called risk stratify. So, we try to say what are the outcomes we worry about? We worry about people dying from infections or bleeding. We worry about people having a poor quality of life. We worry about... and then we say, "Well, how likely is that to happen?" and if somebody's likely to die soon, we say that person has high risk and therefore it may make more sense to use a treatment that is also higher risk because we're really trying to do something. In terms of how... It's not that this progresses fast as much as in my opinion the future becomes more clear earlier for some people. So, some people we say, "Well, your neutrophil count is low, but you're okay until you get infections," and that one person may go three, four years before there's an infection and then other person is in your office a month later with an infection and you look at that person and you think, "This is not going to go as well as we want it to go." It's not that the... So, I try to fight against this concept that the disease is really marching along at a certain rate. It's really time allows us to understand how significant the bone marrow failure is for somebody. So, when I meet somebody, I explain and when you go to the MDS website and get their booklets, you'll see the risk stratification. Now, I'm a lumpner, so I tend to put people

into larger groups. Some people like to split like oh, you have not quite so good, but not quite so bad, but sort of in the middle. I like to sort of just lump it because I think it's easier for me to explain and understand. So, I would say to somebody, "You know, I think this..." So if somebody who has the highest risk, I would say, "You know, I really think we just need to make a treatment decision." Somebody who has a lower risk, I would say, "You know, let's see how the next two to three months, four months, six months go. We may not need to make a treatment decision for years maybe," and as somebody in the middle, I'd say, "Well, you're in the middle. Right? So, I don't want to finalize the treatment decision right now with you, but I would like to see you every other week for a couple times and let's get a sense of it whether you're going... which way you're going to split off." So, it goes similar to that discussion we were just having is... I think a great question to ask, now your doctor may not like this, but and it's a bit of a gruesome question. So, I apologize if this offends anybody, but there is empirical evidence that if you ask physicians and their patients, now this is not with MDS, but with things like chronic heart disease, would you be surprised if I died in six months and they say the patient has asked that question. The physician and patient groupings that they both agree on, the answer to that question, everyone does much better. So, you may say to somebody, "Would you be surprised if I have an infection in the next three months? Would you be surprised if I'm going to be hospitalized? Would you be surprised if I needed transfusions?" and they say, "Oh, my God. Yes. I don't think this is going to happen for years," that gives you a better sense. On the other hand if they pause and like squirm, you're dealing with a different animal. Great question. Thank you so much. Yes, sir.

Q4: Is there an age limit for anybody to have a bone marrow transplant?

Larry Cripe, MD: I am not a bone marrow transplant physician for a reason because I don't think that's the right technology in many situations. So, this is a completely, let me just say, biased answer. So, I think practically we are extending the age at which we'll do bone marrow transplants way too high. I think we're presenting it to people who are not likely to do well. On the other hand, there are people who are vigorously healthy well into their, whatever age you want to say. I think they deserve an option and an opportunity to have that discussion. So, what I say to people who are older and I won't tell you what threshold that is, but every year it gets higher. I will say, "I worry that what's going to happen is that the final months to year of your life is going to be miserable," and I worry more about that risk. So if you're more risk adverse, you may want to take my advice. On the other hand if you're more risk be damned, I want to try to benefit from what medical technology has to offer then at our site we practice that almost everybody sees a bone marrow transplant physician at some point just to have that discussion. So if I had to work back, I'm not aware of anyone who's really doing them in people at 80 and above, but that grey zone now is sort of 67 to 75 and I think if you're in that age group and you say, "You know, I think I'm willing to accept the risk," then I would find a transplant center that would talk to you about it because they're extending the age because they're getting awful clever about how they do them, but the challenge, once again when they go bad, it's really miserable to watch. So, I never push somebody in that direction. I hopefully just sort of guide them in that way. Does that...?

Q4: Yeah. The reason I ask you they told my wife and this is my wife that she was too old for a transplant, so just forget it.

Larry Cripe, MD: How many transplant centers did you go to?

Q4: No, none. That was...

Q4a: Do you know Dr. Dugan at St. Francis?

Larry Cripe, MD: Yeah.

Q4a: Well, he was my second opinion doctor and there's a group of those that are transplant doctors. He didn't even offer. I mean, he didn't offer or anything. I just wanted a second opinion. I didn't even follow through with him because I would have to see all three doctors and I'm a one doctor person.

Larry Cripe, MD: So, I would say you probably should get in front of a transplant center if you're interested in exploring.

Q4a: Well, I don't...

Q4: Not at this time.

Q4a: Yeah. I don't feel I need...

Larry Cripe, MD: No, I'm not telling you... I'm just saying that if you are... Let me depersonalize it. If you're interested in it, you should get in front of a transplant physician or maybe when you're interested in it because, once again, if you see a non-transplant physician, then you're going to get... We all have our sense of what should happen and vice versa. If the first person you're sent to for a second opinion is a transplanter and the transplanter sort of guides you towards transplant, I think you should get an opinion from somebody who's not and I think if you're... So, that would be my advice if you're... and that's once again what we strive to do is we strive to just say, "You know, the transplant physician will present it." The language is different. There's no doubt about it and my language is different and then oftentimes what I do is in service or the third voice of balancing those perspectives, but by all means if you're... it's worthwhile doing at some point. Yes, sir. You've been patiently waiting.

Q5: (inaudible 28:00), but my doctor Dr. (inaudible 28:07) MD Anderson is supposed to be one of the better ones. Anyway, I'm transfusion dependent and I'm to the point where I get transfusions about every couple days or two and sometimes (inaudible 28:25) hitting me and then the concern is the iron building up and the answer (inaudible 29:33) is Exjade and I've also talked to Dr. (inaudible 28:37) right here and essence I get two different answers. One says Exjade is the thing to do. The other says Exjade is pretty risky (inaudible 28:50). Do you want to respond to that or if you don't that's okay.

Larry Cripe, MD: I do want to respond to that. Absolutely. I think that's a fair question. So, I think there are several issues that need to just be clarified. One, it's not clear that transfusion associated iron overload for people with MDS really changes the outcomes that much. So and I was very clear that it's an area of legitimate intellectual debate and the difference is even if they exist may be minor. So, that's the benefit side of the equation in my opinion. All the data that suggests, in my opinion, I have another expert behind me. Is she making faces? Can you sit next to me? Is largely circumstantial. So, I think any enthusiasm about Exjade would need to start and say not sure. So, what about the risks? There are some people and I would include myself in that camp is that one of the risk is the expense of these medications. Right? I mean, let's face it. Very few of us retire with so much excess of income that paying some of these copays if it's not really going to help you make sense. I'm sure as all of you in the room, I work hard for my money and I don't mind spending it but I like to know that I'm really doing something. So, there's that risk. A second risk is kidney. So, there in the studies of Exjade there was an increased risk of kidney failure. Now, it wasn't high. It wasn't dramatic. It tended to be reversible, but when you sit next to somebody when you're me and I'm not sure there's benefit and you have... and you sit next to somebody whose kidney failed because of Exjade, you really feel bad about it. It doesn't matter how often it should have happened. That's happened. This third reason or the third risk on that is just an empiric risk. Even when the studies were done. So, when the physicians and research nurses and everybody was dedicated to using the drug to see if it would benefit people, a third to a half dropped out meaning they stopped taking the study drug because the side effects that they found unpleasant. So, then you're starting to say I have a very expensive drug that has uncommon, but meaningful clinical impact on kidney function that most people can't tolerate all the way from the slurry that they take to the... some people get nauseated. So, I would say I'm... When people ask me, I would say, I am not inclined to prescribe the medication. However, if you would like to let's go ahead and see what happens, but most people when I go through that discussion end up saying, "Well, you know, I'll wait." I know and I respect people like Garcia-Manero and people on the MDS Foundation who I think a couple years ago actually did say, "Well, we believe that the guidelines should be there's something called a ferritin. Right? You probably have heard of that that once it's above a certain level or you're predicting you should do that. I respect the people who said that, but I tend not to do that in my practice and mainly because the final reason is the ferritin tends to vary quite a bit. So depending on when you get the ferritin value, it may look completely different. So yeah, but on the other hand if someone said, "Oh, no. I think you should try it," then I think it's up to them to explain to you why that's worth risking the drug, the cost and the inconvenience of it. Yes, sir.

Q6: If I could, I'd study probably all the abstracts I could find all over the world and what I'm wondering in Italy and Japan they did a lot of... quite a bit of work with the use of vitamin D and A. What can, we as patients, do to minimize the need for other treatments? Should we be taking vitamins to help? Is there any beneficial...? I see you're frowning.

Larry Cripe, MD: No, so that's a very...

Q6: In other words what can we do naturally with foods and vitamins to help other than... that might forestall treatment? I guess that's the question.

Larry Cripe, MD: Well, you're asking a very profound question. So, let's take a step back and say what... so basically, what happens in... so normally you have platelets, certain types of white cells and red cells and that happens through a very eloquent series of decisions a cell makes and we know at various points that vitamins will affect some of those decisions, right, and so that's why... so if you expose the limb bud of a frog, a tadpole, to vitamin D, you can change how it develops. So, we know that the biology of it is very sound. So, that's why I have a hard time being too dogmatic because what we also know is when physicians have... when we have studied this, relatively few people seem to have truly had benefit. Right? So then you're stuck with this risk benefit again. Sorry. At certain doses vitamin D is of no risk. So, you could imagine if you just do the math that there's such a low risk thing to do that even if the benefit's very low, it's still a favorable ratio. Right? Does that make sense so far? So, I think that if you were intrigued by and let me say it's very rarely vitamin D alone. Usually, there was a clue that vitamin D, for example, looked promising or vitamin A and then somebody added something different.

Q6: The K2 was added.

Larry Cripe, MD: Right. I mean, so if you see something like that and you're like saying, gosh... I would just bring it in and that's one of those question lists. I would let your physician know immediately that you'd really like to spend most of your encounter with them talking about that. What I try to do is just say can we put some reality around this? So...

Q6: Does it do harm?

Larry Cripe, MD: Well, let me just finish. Can we put some reality around it? So, if somebody is saying I want to do this because I believe it will forestall a future event, there's no way to ever assess that because you don't know, but if someone is needing transfusions and says, "I'd like to try vitamin D at this dose and this..." I would say, "Great. Let's do it, but let's assess this to see if it's really helping you as opposed to staying on it forever." Does that make sense?

Q6: Sure.

Larry Cripe, MD: So, I think it depends on... So, if you're looking to forestall a future state just make sure it's really affordable and really safe. If you're making it to change something happening then those... just make sure you can assess them. Yes, sir.

Q7: My experience I've had real good luck with these (inaudible 36:58) because the D they want to give you 50,000 (inaudible 37:09) that would help my bone (inaudible 37:09). I'd have full (inaudible 37:13) really weird. I mean, in my arms on top of this or my leg or my foot, whatever and, of course, those doctors (inaudible 37:22) finding out there's no (inaudible). So it does help, but now they've pulled me off both of them just to sort of see and I do have a question. I have gallstones and I'm from South Bend, Indiana and up there the surgeons won't operate because I have other conditions. Like I have Leiden Factor V, I have diabetes and they're just so afraid of the medicines I take and the aftereffects and the operation (inaudible 38:05). Of course (inaudible 38:07) they said well it's going to have to... you're going to have to (inaudible 38:14)

or they can't do... and then also they... but they said also if I have pain, say I got diabetes, most likely if I have pain, it will signify either a big infection (inaudible 38:28).

Larry Cripe, MD: I'm sure this won't be of much comfort, but anybody with a gallstone goes through that calculation because there's really... surgeons should not be removing gallstones that are not causing some problem.

Q7: Right, but the big worry is for my oncologist (inaudible 38:47) in Indianapolis is the fact that by the time they do it.

Larry Cripe, MD: I would just once again encourage you to think about having... helping them organize the discussion. So, to say if you removed my gallstones now what would be the benefit? What goals do we have and what risks do we have versus removing it later what goals and risks would we have? My sense is what they're saying to you is that the benefit is so small, the risk is relatively high that it doesn't make sense to do at this point and what they're going to do is they're going to wait until you have an attack, which let me assure you most people never have these attacks, treat you with antibiotics and then say, "Okay. Now, we know the benefit is preventing a future attack," but I can't encourage you enough... it's really been... I find it very useful to organize my discussions with people around what are our goals.

Q7: I talked to Dr. (inaudible 39:59). He also (inaudible 40:03) and he's really... we also came to the conclusion that really (inaudible 40:13).

Larry Cripe, MD: Then you need to have him talk or her talk to the hematologist, diabetologist and everybody and find the safest path to do that.

Q7: Yeah, but he thought that South Bend (inaudible 40:26).

Larry Cripe, MD: There you go. I don't know. Ma'am, I think you had a question earlier.

Q8: Yeah. The question was about transfusions and I think I know the answer to it, but I'm assuming that (inaudible 40:42) up to frequency and how frequently would they be given and then it's just a readjustment to when it would be needed again. Is there a maximum or a minimum number span of time between?

Larry Cripe, MD: So, I have a couple of thoughts about that. One is that what's really helpful is once somebody begins to need transfusions if not before, is to keep a spreadsheet and to document what the hemoglobin level was, what blood units were received and how the person felt afterwards. Now, some of you may know this. I'm always surprised... not surprised. I can never predict. Some people I care for say, "I don't feel good the first day or so, but that third day I really pick up." So, you have to take that into account. So if you're losing a couple days with transfusions, you need to take that into account and then how do you feel once you feel at your best. Now, you can ask your oncologist. So, there are these scales, formal scales, called Performance Status Scales and there are abbreviated scales related to anemia. You can ask if that would help your oncologist or hematologist and then look to see... some of them are very easy to fill out and then I would... once I had a transfusion, typically we would check it each week to get

a sense of how quickly the absolute value is falling and then you can correlate how you're feeling with the transfusions and the levels and frequently you can especially with the nurse helping the doctor. You can come up with a plan and you can say, "Look. It looks like every three weeks I'm needing this," so I'll get a CVC every third week. We'll get the type and cross, but I'll change that depending on how I feel. In terms of frequency, the part of it is there are drugs besides the erythropoietic agents that can reduce the frequency and sometimes eliminate the need for red cell transfusions. For example, Vidaza. So then, the frequency becomes... So if I see somebody who's only needing only needing a transfusion every 6 to 8 weeks, I typically would advise the inconvenience, risks, of Azacitidine don't make sense. On the other hand if you're starting to need them weekly then I personally think it make sense. So, that sort of helps you come up with and then to go back, it's that question of so you meet a doctor at the first and then you say, "Well, how are things going?" and the doctor says, "Well, they're going fine because you're only needing a transfusion every 8 weeks," so then it seems to me that there is a question that begs to be answered eventually is okay, now that I need it once a week, what does that mean? Should we change our approach? Do I come to a different understanding about my life expectancy or my quality of life? So, they're both things we respond to, but they're also information to help understand the better the future. I'm going to take one more question. I just want to say this has been delightful. I came... Unfortunately the conflict was I have a retreat of 35 positions that we're trying to change how we do things and believe me this is like heaven compared to those discussions. So, someone who hasn't...

Q9: I was wondering. The doctor I go to, the only thing I've ever heard from them is when mine gets bad enough I can have transfusions. What I read in some of these books, there are treatments you could perhaps get and not have to have a trans... or put it off or whatever longer.

Larry Cripe, MD: I do not believe that there's a treatment that's so easy to take and so effective that I would treat somebody with a drug who did not have an immediate goal. So, observation is probably the thing that should be done in many situations, but once again I think that... so what I do is I'd print out the blood count report and then I'd just... I would bring a blood count report and say to the person, "Tell me what will be bad enough. Tell me what will be... that will make you change your opinion about what I should do." Does that make sense? So, define that and so then you know. So people get a blood count... I'm always surprised honestly how many people have gotten blood counts for months or years and they don't even know what we're looking at. So, the first check in would be you go to your doctor you get it. I would say to the doctor, "How are you interpreting this? When you look at this what are you really looking at?" and I worked with a nurse ethicist who had this idea, it didn't go anywhere, but basically for the ICU, she wanted to create a system that each day they would synthesize all the information for the family or the patient of conscious and it would be basically a thumb up, a thumb neutral or a thumb down and I think that's really what many of you are asking for. You just want to know the reason... That's a little crude, I guess, but given what you know about me are you optimistic about my future or are you pessimistic and... because none of the treatments I would say are so easy to take and so likely to help that it's worth doing until you have a goal that you know exactly what you're trying to accomplish. Alright? Thank you so very much for your time. I appreciate spending this with you and best of luck to you all.

(Applause)

Jean Ridgeway: Well, we're going to switch a little bit. I'd like to introduce myself and then kind of talk about the rest of the morning and early afternoon that the MDS Foundation has put together. You're welcome to stay for all of it. You can leave whenever you like. No one's feelings will be hurt. You're free to do whatever. My name is Jean Ridgeway and I'm a nurse practitioner. I have few Master's degrees and finishing up my doctoral degree, but I work with the MDS Foundation and have for many, many years as one of their board members. We do various things with that, but part of it is being engaged in patient forums and coming and helping to present information to patients and answer some questions if we can and kind of help put pieces together for patients and families, etc. So, my role here today with you is really a facilitator and somewhat as a presenter and the MDS Foundation has felt that I'm giving some information that is data based and data driven is a good thing for you all to leave with and then certainly interaction about answering some questions. So, that's kind of the forum. We have an hour now to kind of get to know each other a little bit better and look at some information. I do have slides for me I think they... it depends on the forum, but I think it can help present some difficult information in an easier method and then we've got a break for lunch and then we have some discussion. I think the agenda says we're due to end at 2:00. Is that correct? I have the agenda here. If you've picked up one the *Building Blocks*, I think that's what... If we're done early I think that's fine. So, that's who I am.

What I do is I work at the University and I work in the outpatient setting. I work exclusively with the folks who have blood diseases. The majority of my patients have either leukemia, MDS and about half of the patients I work with are transplant patients. So, I'm heavily involved in the transplant program and I see patients exclusively on the outpatient setting. So, I worked many years in the inpatient setting in the ICU, etc. I've been doing this for a number of decades and I am one of the people who performs those nasty bone marrow biopsies that some of you have had to endure. I'm glad to answer some questions about that if you have any. So, I think it's been helpful in the past and, Steve, right? I've seen Steve at some of these other forums across the country. So, we usually just start out kind of go around the table, introduce yourself and your family member and give us a little insight of why you're here, what you hope to accomplish and how about if we start over here to my left?

Roger Thomson: My name is Roger Thomson. This is my wife, Nellie. I have MDS. I was (inaudible 50:34) with MDS (inaudible 50:36).

Jean Ridgeway: Can you hear him?

Multiple: No.

Jean Ridgeway: So you know what? It's good we have these microphones. All of us are... we need a little assistance. So if you're not close to one, if you'd pick one up and kind of speak into it then all of us can hear what you have to say.

Roger Thomson: Are they turned on?

Jean Ridgeway: Is it on, Mr. Mike? Okay.

?: You got to talk into it.

Jean Ridgeway: I think you have to speak into it or you can take it off.

Roger Thomson: Okay. Start again. Now can you hear me? My name is Roger Thomson. I'm from Columbus, Indiana. This my wife Nellie. I'm the one with the MDS (inaudible 51:20) described with the MDS about four years ago at the Mayo Clinic. I was not completely satisfied with the treatment I got at Mayo's, so I came to Indianapolis and dealt with Dr. Berverie (sp? 51:58) for about a year and a half who is an excellent oncologist and what's the other word?

Jean Ridgeway: Hematologist.

Roger Thomson: Hematologist. He's an excellent hematologist. He did the...

Jean Ridgeway: Bone marrow or...?

Roger Thomson: He's done a bone marrow test, but he did the Dacogen and he did the Vidaza.

Jean Ridgeway: Those are treatments. Those are different intravenous or subcutaneous treatments, both the Dacogen and Vidaza.

Roger Thomson: That's right and the downside of those is they are chemo effected and the chemo seemed to have a negative effect on my white blood cells. So, I... actually, he sent me. I went down to MD Anderson in (inaudible 52:50) which, I think, is considered one of the very best in the United States and was lucky enough to get treated by Dr. Rosara...

Jean Ridgeway: Manero.

Roger Thomson: Manero is I think considered the top guy in the nation. I still have the MDS, which I always will have, but I take blood transfusions anywhere from every six weeks to sometimes every four weeks depending and I kind of make my own decision on when I need a blood transfusion. If it gets close to seven, if the hemoglobin gets close to seven, I arrange for the transfusion because if it's eight or above, I live with it for a while.

Jean Ridgeway: And what brings you here today?

Roger Thomson: Well, just to get additional knowledge. One question that I wanted to ask maybe it's an incidental question, but I have a friend of mine who is basically in the same boat I'm in and determined that he had MDS about the same time I did about three years ago. He has been on Procrit, nothing else but Procrit for about three years. His hemoglobin stays up in the 10 to 11 range. He feels good. He's getting along fine which makes me ask the question should I be using Procrit. Do you have an answer to that?

Jean Ridgeway: I don't have a specific answer. What a global answer I'll give you is that MDS is not one specific type of disorder and it looks and behaves differently for every individual and so

perhaps for your friend who has a lower grade MDS that Procrit, obviously, have worked for him and it can work in the right situations.

Roger Thomson: We're both diagnosed with the low grade MDS. We've had... I've had four bone marrow biopsies and they all turned out the same. It hasn't changed, so it's still low grade.

Jean Ridgeway: And Dr. Manero says?

Roger Thomson: Dr. Manero says go into a clinical trial which I've been in two of them (inaudible 55:15). So now, in about six weeks, I go back to Dr. Manero for evaluation of standard treatment rather than clinical trials and the clinical trials may be fine except the ones I was in didn't do the job for me and I don't know whether any of you are familiar with Dr. Garcia-Manero or not, but I think he is recognized as the number one MDS doctor in the United States.

Jean Ridgeway: There's a lot of number one MDS doctors. It depends on who you talk to.

Roger Thomson: He's one of them.

Jean Ridgeway: He's certainly a leader. He's certainly a thought leader.

Roger Thomson: He's one of them.

Jean Ridgeway: He's a thought leader. Let's hear from your wife, your caregiver.

Nellie Thomson: He complains a lot about his legs aching and tired which is normal, but the doctors always say the leg pain has nothing to do with the MDS. What do you think?

Jean Ridgeway: I don't know. I'm not involved in your care.

Nellie Thomson: He really, really... I mean, there's times that he can't walk. I mean, he just shuffles.

Jean Ridgeway: Tell me about life as a caregiver.

Nellie Thomson: Oh, boy.

Jean Ridgeway: How many caregivers do we have in here? Linda's a caregiver. Caregivers. Caregivers. Big role, big important role.

Nellie Thomson: I do a lot of picking up blankets and pillows from all over the house.

Jean Ridgeway: Because he's cold?

Nellie: Pardon?

Jean Ridgeway: He's cold or just...?

Nellie Thomson: Oh, yeah. He does complain about being cold. Yeah. He does complain about being cold.

Jean Ridgeway: It's a big role. Being a caregiver is a huge component of a family dealing with MDS as a disease, an illness. Let's go onto your left.

?: What is a low grade MDS?

Jean Ridgeway: What's a low grade MDS? Can I answer that in a little bit with some slides?

?: Right. I just... I figured that must be what I have.

?: Just ask it as we go along, don't we pal. I understand that (inaudible 57:34) about it in five minutes.

Jean Ridgeway: Who's next to you to your left? Pick up a microphone.

Wilbur Tetzlaff: I'm Burt Tetzlaff and I'm from South Bend. This is my daughter, Hilary, and another daughter, Heather, and my wife, Debbie. I was diagnosed about a year and a half ago... and I was diagnosed about a year and a half ago and I think that it's related to Agent Orange.

Jean Ridgeway: So, you're a Viet...

Wilbur Tetzlaff: I'm Vietnam veteran.

Jean Ridgeway: Are you a Vietnam vet?

Wilbur Tetzlaff: Yes, I am. So, I don't know what else I can tell you.

Jean Ridgeway: You had exposure.

?: Agent Orange and benzene.

?: And benzene.

Jean Ridgeway: And benzene. Are you linked in with that whole VA program?

?: We're working on that.

Jean Ridgeway: Is everybody in here familiar with Agent Orange? That was the defoliant or ex... whatever, deforestation that they used and the VA if you're not... the VA has... the government has actually taken some ownership of that and for people in the service who were exposed to that they have a program for folks who are involved.

Hilary Tetzlaff: But they don't acknowledge that MDS as correlated.

Jean Ridgeway: Working on that.

Hilary Tetzlaff: I'm Hilary.

Jean Ridgeway: Where are you? Are you in treatment?

Wilbur Tetzlaff: Pardon me?

Jean Ridgeway: Have you received any treatment or transfusions?

Wilbur Tetzlaff: No, not yet. I think I'm getting close to transfusions by the doctor.

Jean Ridgeway: So, you get your blood monitored on a...

Wilbur Tetzlaff: Yes, every month.

Jean Ridgeway: Monthly basis. I'm sorry I interrupted you. I apologize.

Wilbur Tetzlaff: My hemoglobin is down to 10 – 9 right now.

Jean Ridgeway: Ten-nine.

Wilbur Tetzlaff: Yes. Well, I understand that, but every time I go it drops about five points.

Jean Ridgeway: Five-tenths?

Wilbur Tetzlaff: So, I go again Monday. Yeah, five-tenths. He's talking about 10. I don't know where the...

Jean Ridgeway: So, normal hemoglobin for men is 14 grams per deciliter. That's the lower end of normal, 14 to 17. Women, we run a little bit lower than that, but 8 in many cases depending on how you feel and the decisions you make with your physicians can be up .8 grams per deciliter where folks begin to look at getting a transfusion. There's some variability with that.

Hilary Tetzlaff: I'm Hilary. I'm with him and we have this dynamic in our family where we're sort of all caregivers for one another and fortunately since we're still in the observation stage, he's more of a caregiver for the rest of us than the other way around. So, there may be a role reversal in our future, but anyway, so, I'll just say that. He's great.

Jean Ridgeway: Just out of curiosity, how did you hear about this meeting?

Heather Tetzlaff: Well, that's a good segue. My name is Heather and Burt is my dad and I'm the researcher/technological/answer person/representative for the family. So when we got the diagnosis, I immediately found the foundation and registered and so we actually got something

the mail regarding that. So, yeah. The Foundation actually... I called and I said there has to be other veterans. Tell me what's going on and they actually were nice enough to hook us up with a person that he could talk to and now we're in the process with the VA. I looked up all the case studies for cases that actually have been approved or supported by the VA. My guess from my own standpoint is the numbers are going to go up for the Vietnam guys. Because of the onset of the disease starting around 70, they're all just starting to get there. Yeah. So, we'll see, but here we are. We're just like most people in our holding pattern right now.

Jean Ridgeway: Welcome. Welcome. Thank you all for coming.

Debbie Tetzlaff: And I really don't need the microphone.

Jean Ridgeway: Oh, yes you do. We're all in this together.

Debbie Tetzlaff: I'm an auctioneer by trade and honestly usually I don't need a microphone, but anyway, I'm Debbie, Burt's wife. The girl's mother, obviously, and it's... we just are doing what we can do and that's all we know to do. So, we find what we can and we... I'm thrilled believe it or not that we have found these people right across the tables over here that are from South Bend. They live about five blocks from us. We had no idea that anybody else had MDS in South Bend even. So I mean, and it's just one of those things that you just kind of try to pull and tug and find whatever you can find and no, we're probably not at the bottom of the charts here, but we don't know where it's going to go, how fast it's going to go. Everything's a big question and a big guess and we just take day by day. So, that's where we are.

Jean Ridgeway: Okay. You're next.

Milton Gerber: I'm Milton Gerber from Fort Wayne, Indiana.

Jean Ridgeway: Did you hear that?

Debbie Tetzlaff: I did.

Jean Ridgeway: It's not too far away.

Milton Gerber: And currently my hemoglobin is at 9.1. I'm under the care of Dr. Sayer and Dr. Cripe's office.

Jean Ridgeway: Here in Indianapolis?

Milton Gerber: Here in Indianapolis. I use Simon Cancer Center and they said when my hemoglobin gets to 9.5, I should be considering treatment, but we're waiting and I'm there, but I'm not there.

Jean Ridgeway: And since diagnosis to now is what interval for you? How long?

Milton Gerber: Every 60 days.

Jean Ridgeway: When we you diagnosed?

Milton: I was diagnosed in February of this year and but I actually I track all of my... and chart all of my lab reports from way back. It probably started a year before looking at the hemoglobin levels and I lose about 1.1 points per year. So, I'm in some sort of a (inaudible 1:03:54) path. I have no idea where it's going to come out, but anyway and they just checked my EPO. That's 331. So, the kidneys are working, but there's a question as to whether treatment would do any good.

Jean Ridgeway: EPO means erythropoietin and for those of you who aren't aware, erythropoietin is an indigenous hormone that's created by the adrenal gland which sits on top of our kidney and if your kidneys are... folks who... for example in dialysis tend to have anemia and that's driven by their kidney failure and oftentimes when hemoglobin begins to drift down, checking the Epogen level will be looked at to see if you might be a potential person for therapy with Epogen, could it benefit you, but it's always... You have to check the level. Right? Because it'd be like why should I pour water in your bottle if it's already full? So, you have to look at the level.

Milton Gerber: So, they think it's questionable in any case and so anyway my interest is I've been involved in research all my life of different kind of... including cancer research, funded cancer research for IU Purdue and so I'm really interested in what is happening in the research end of it as far as the bone marrow situation. German scientists or researchers stated while the bone marrow is producing enough red cells, but they're being damaged in the transference to the blood vessel and I'm not sure. It could be a genetic thing that... they're working on it, but we're limited as to the amount of options we have for treatment, quite frankly.

Jean Ridgeway: This is true. Yeah. It's very, very true.

Milton Gerber: And there's a lot of research needed. So basically, I'm here to find out and learn what I can learn about where I'm at and what's going to happen. This is my daughter, Renee.

Jean Ridgeway: Hi, Renee.

Renee Gerber: Hello.

Jean Ridgeway: Caregiver, Renee?

Renee Gerber: Yeah and I'm kind of like you in that I don't really feel like I'm that much of a caregiver yet and because we're still in that observation stage and waiting but for those of you that have been there I'm sure the challenge is you want to do something and we're all about what's the action and especially being the daughter of an engineer.

Jean Ridgeway: I have some good slides. You're going to really like the slides I'm going to show you.

Renee Gerber: That's right. We write nice neat little boxes and two steps...

Jean Ridgeway: And charts, everything. Are you an Excel wizard?

Renee Gerber: That's how we function and unfortunately when we're up against the ambiguity of a disease like this and so I think a lot of it for us is how do you know and I don't expect and answer to this, but how do you know when to take those steps and it's everything is grey and am I wrong for asking for this next level of treatment? Should I... Should we wait and that's what becomes kind of the challenge. So I think for me, part of the benefit is being here today is being educated so that when those questions come up, I can help support him in that and really kind of get a sense of... even something like... tuck it away for maybe later, but I'm curious about on the hemoglobin. We talk about the swim so to speak. How much is a normal swing like across a day. So, I mean, would it... is it five-tenths?

Jean Ridgeway: In a day? Hemoglobin doesn't change very much in a day.

Renee Gerber: It doesn't change across the course of a day and so... so even things like that so that we can kind of measure and monitor. So, but I appreciate the opportunity to be here.

Jean Ridgeway: Well in illnesses and significant illnesses are they're very much a family event. What happens to one person, I think when... it's like that little pebble you throw in the water, the ripples are far reaching. So welcome and thanks for coming. You're next. Did they tell you that they record this? You all knew that. Is that true? Am I making that up?

Dee: No, it's recorded.

Jean Ridgeway: It's recorded. It's recorded and let me tell you one of the things that gets done is for research. There's some qualitative research studies we publish some things about what are people really saying, what are the questions people are asking and cross the country they're similar, they're very similar. So go ahead, but that's another reason for the microphone.

?: Can we get a disk?

Jean Ridgeway: Can you get a disk? Dee? See that gal back there? She's with the MDS Foundation. Ask Dee.

Dee: (inaudible) copy. It's going to be uploaded to our website. So, everybody can go www.mds-foundation.org. If you have just a business card at the back of your *Building Blocks of Hope* Foundation's website. It's not only this one, but all the previous ones.

Jean Ridgeway: Are hyperlinked on the website.

Dee: That's different (inaudible 1:09:14) perspectives (inaudible 1:09:16).

Jean Ridgeway: I didn't know that. Thanks. Thank you.

Dee: Yeah. They're all the questions.

Jean Ridgeway: Thank you and this Dee Marie, by the way. So, she's our representative from the Foundation and she put this together and unbeknownst to all of you she had this room reserved over at the medical center since the end of December and three weeks ago she got notice that she got bumped. So, she has done some mad scrambling to make this event happen.

Dee: The (inaudible 1:09:45) but we're lucky (inaudible 1:09:50).

Jean Ridgeway: Talk to us.

?: I'm lucky, too, because five years ago I was diagnosed with MDS in a very roundabout fashion which I'll tell you about and I am definitely on the very mild end of the scale. Have been treated with 500 mg of hydroxyurea.

Jean Ridgeway: That's a pill.

?: Which is sort of a chemo pill. I take it and that has very little side effect and has done the job of keeping me right where I am.

Jean Ridgeway: Did you have a high white count or a high hemoglobin? Is that why they put you on the hydroxyurea?

?: Well, I don't know and the reason I don't know is that I was in Miami at a wedding and I fell and broke my hip while dancing and so in Miami, a hip replacement is no big deal. However, when I got in there I had a heart event and embolisms in my lungs and it turned out five weeks later with MDS diagnosis. I was so out of it, I don't know... I do know that they did not do a bone marrow biopsy because of my other conditions. So, I went to see Dr. Sayer here at the Simon Center and he's terrific because I was thinking, gee, I don't think I even have this, but he said, "Yes, you do," but I'm just very fortunate and not having it progress during these last five years.

?: Can you spell the name of the (inaudible 1:11:30)?

Jean Ridgeway: Hydrea is spelled H-Y-D-R-E-A. It's also called hydroxyurea and it's usually not used... It's used more for something myeloproliferative disorders where people have lots and lots of red cells and...

?: I do know I did have lots and lots of... very not good red cells.

Jean Ridgeway: They're not good red cells, but and there tends to be if you could think of two concentric circles joining. There's a whole group of diseases that are considered myeloproliferative disorders and then we look at Myelodysplastic Syndrome and there's an overlap of them, but with folks who have low blood counts, Hydrea is not used because it does drive down the counts.

?: Anyway, my friend here is... we are charter members of the MDS club at our church. Adele is our organist and we just found out this summer, I guess, that we both had MDS and she's the one who invited me and told me about this meeting. So, I appreciate that. I was diagnosed in 2005 with MDS as a result of a bone marrow biopsy.

Jean Ridgeway: Something must have happened before that, though.

?: Around Memorial Day, I had a annual physical scheduled and my doctor had blood draw and my red blood count was down to like 11.5 and he said, "Oh, we'll check in in 6 months," and my daughter is an OB/GYN and I told her about this and she said, "No, you won't wait 6 months. You'll find a new doctor." So, I found an internist probably in June or July of that year and she did every test available and by November she said, "I can't tell you what's wrong. I need to send you to a hematologist," and he did extensive blood tests. It came back suspicious of lupus. So, he sent me to whatever specialist that is.

Jean Ridgeway: Rheumatologist.

?: Okay and he read all my answers to the five page questionnaire he had sent me and examined me and he said, "You don't have lupus. The next step is a bone marrow biopsy." So, went back to my hematologist and he said, "We need to do a bone biopsy." I said, "Okay. When shall we set it up?" He said, "We'll do it right now," which is a good thing because I would have been worried to death had I known I had this scheduled, but he started me on monthly injection of Aranesp.

Jean Ridgeway: Which is... It's an Epogen. It's a longer acting Epogen.

?: Yes.

Jean Ridgeway: So, it's an erythrocyte stimulating agent to stimulate the red cells.

?: Okay. This summer, his practice decided to do away with Aranesp and just do Procrit.

Jean Ridgeway: So now, it's a short (inaudible 1:14:52). It's given more frequently.

?: Instead every month, I was getting it every two weeks.

?: What was the name of your shot that you were getting (inaudible 1:14:58)?

?: The first one? Aranesp. And I was starting to feel more fatigued this summer and I asked the hematologist, "How do you know when this disease is progressing?" He said, "When the numbers go down and don't come back up." So in August, he did a second bone marrow biopsy and at my next visit with him he said the news is not good and I don't understand these numbers. They meant something to him, but he said when I started when he diagnosed me, I was a five and now my number was seven.

Jean Ridgeway: Were those the blasts?

?: I don't know. Maybe so, but he said when it gets to 10, that means it's leukemia. Do you understand that?

Jean Ridgeway: I do understand that. So, blasts are immature white cells and in the... you can think of white cells growing up. They're born in the bone marrow. They mature and then they go out into the bloodstream and so all of us have less what's normal is the hematopathologist would tell us that less than 5 percent blasts in a bone marrow aspirate is considered "normal." When you get above 5 then you look at pathology. So, in the land of pathology what we're taught is that from 5 to 19 percent in this newer diagnostic criteria is considered still MDS and if you have 20 percent or greater that's leukemia. So, it's 20 not 10.

?: Not 10.

Jean Ridgeway: Not 10. It's 20.

?: Well, he wrote this out on the...

Jean Ridgeway: With a couple little caveats. Now, there's some other... There are a few other different types of abnormalities that can change that. So, you really need to get all the... There's so many specifics, but with... so in general, more blasts is... leads you to the diagnosis of leukemia.

?: Well, he told me that it become leukemia within 6 months. He told my daughter 12 months. So, I don't know... and he doesn't know.

Jean Ridgeway: He doesn't really know. What we do is we look at the data and try to take a time perspective of kind of what's the tempo, what's been going on to say is it going to continue to behave in this fashion or is it changing.

?: Well, he gave me two options. He said you can say I've had a good life, I'll just take what comes or we could do chemo. Dacogen, I believe.

Jean Ridgeway: Dacogen, Decitabine is one of the therapies.

?: And he said there's 20 percent chance that that would slow down the progression. I thought that's not very good numbers.

Jean Ridgeway: Not good enough for you and did you get another opinion?

?: No. I talked to my daughter who is a physician in Houston, but she's OB/GYN so she knows absolutely nothing about this, but she talked to him and we decided 20 percent chance was better than 0 percent chance.

Jean Ridgeway: That's another way to look at it.

?: Right. So, I've had 1... He said 5 days in a row every 28 days. I've done the 5 days in a row. It's been about 6 weeks now. For the last 2 weeks, my... last 3 weeks my platelets were down and then my white count was down. So, he said we can't do until we get the numbers back up and this week, Monday, Wednesday and Friday, I've had a shot to bring the...

Jean Ridgeway: The new white... Neupogen to bring the white blood (inaudible 1:19:02).

?: Yes. To bring the white blood count. So, I see him on Monday. We'll decide if the numbers are up, he'll do the chemo again. If not...

Jean Ridgeway: I have a few slides that talk about when all... when these therapies start, something that happens in the bone marrow environment when you have a malignant clone. So, with MDS 1 cell has gone bad and that cell has continued to multiply. So one of the naughty things about malignant cells is that they have an immortalized component that they don't die which is why when they multiply they don't do it linearly. They do it logarithmically like 1 becomes 2, 4, 16, 32, 64. So, you see much more of that, but within the bone marrow when you have that malignant clone in your blood counts, you still have blood counts. Right? Not all of your blood is abnormal. There's a component of it is, but oftentimes that malignant clone is pushing the hemopoiesis or allowing you to create blood cells and when you begin to remove that driver you're left with a bit of a void and so the blood counts in general get worse before they get better.

?: That's what he told me.

Jean Ridgeway: In general...

?: He said this chemo was cause it to drop.

Jean Ridgeway: It dips your counts. Right. So as you begin to kind of clean out the garden of the weeds, you're left with some kind of spindly plants that are going to eventually get better and you just have to give it time. So, it can take a while to recover.

?: He did say something about this... Is it Neupogen?

Jean Ridgeway: Neupogen. That's a white blood cell growth factor.

?: He said there was a downside to that that could somehow or other affect the bone marrow...

Jean Ridgeway: Blast cells.

?: ... and I didn't get...

Jean Ridgeway: There's a potential. It's not 100 percent.

?: And what does it do?

Jean Ridgeway: Well, it causes the increase growth of white blood cells, but since some of your white blood cells are diseased, you may also have an increase in diseased cells as well.

?: I see, but then he said...

Jean Ridgeway: But when we go back to that risk-benefit...

?: That's what he said. We've got to weigh the options and he said I think you need the chemo, so it's worth the risk. So, that's where I am.

Jean Ridgeway: Alright. Thanks. You're next.

Richard Arnott: I'm next. I've been diagnosed...

Jean Ridgeway: This is Richard, by the way. Hi, Richard.

Richard Arnott: My name is Richard Arnott and I'm from Rensselaer, Indiana, but anyway I've been diagnosed with this for about a year and my red blood cells is the only place I had any trouble. My white blood cells, platelet, apparently are alright. The doctor I was going to always ever told me is that whenever it gets worse, we'll give you a transfusion and I'm reading everything I can read about it. I find that there are some things you can do. I don't know what I should do or anything else, but...

Jean Ridgeway: Maybe you need to get a second opinion.

Richard Arnott: You're right. I think that's right, but that's why I don't know the role risk I have or what, but it does worry me because my legs bother me and my hips bother me. I can't hardly walk, but I'm a diabetic and I've had open heart surgery and had a knee replaced and shoulder replaced and everything.

Jean Ridgeway: So maybe it's all not the MDS, maybe?

Richard Arnott: Yeah. I just don't know what's what and I'd like to find out what's going on.

Jean Ridgeway: Well, maybe by the end of today you'll have a little bit more information.

Richard Arnott: I hope so.

Jean Ridgeway: I think touch back in the back of your brain you should say second opinion. I'm a firm believer... I work in the medical field and I think if your practitioner is intimidated at all by you getting a second opinion, you definitely should be running out of the office not walking because we're consumers and you have to have a good relationship. Everyone's a little bit different and you want to go to somebody who's an expert. This is a rare disorder. Even though we represent a group of individuals that have this disorder, it still remains a rare disorder and so to seek out someone who has expertise in this is I think worth your time and effort.

Richard Arnott: Okay.

Jean Ridgeway: Just a suggestion.

Richard Arnott: So anyway, I'll pass it over to my daughter.

Jean Ridgeway: Alright. A lot of daughters here. Where are the boys? Where are the sons, those rascals?

Mary Arnott: I'm Mary Arnott. I'm his daughter. I really don't know a whole lot about this disease. I haven't really researched. I've just been busy, but you asked about a caregiver. I am a caregiver to him, but I also work in the caregiving field. I have a ton of questions, but I can wait till the end.

Jean Ridgeway: I see you picked up the book, *The Hundred Questions*.

Mary Arnott: Yes.

Jean Ridgeway: That's an excellent book. It's an excellent book.

Mary Arnott: I don't know. My dad's just ornery. So, as of right now I don't have a lot. I just know that he aches and pains and bellyaches like everybody else.

Jean Ridgeway: There you go. Well, welcome, Mary.

Barbara Arnott: My name is Barbara.

Jean Ridgeway: Hi, Barbara.

Barbara Arnott: And I'm the mother and the wife to the two sitting to right next to me. Before I really make any comment about his disease, I would like to say I have thoroughly enjoyed this much more than I saw you we were at Rush University. There was too much on the... All this stuff that I really didn't understand. Now, the doctor that gave the presentation was very good. She's a little hard to understand. When you came on everybody... It was like this. It was all questions and it was more personal and so I have enjoyed this immensely. My second comment is if I can remember I have not kept track... We have all the papers and everything at home from every time we've gone to the doctor, but I have really not kept track like some of these other people have. Like you said, he's only been diagnosed about a year. He goes every three months and has his blood work done. The first time we went to this Dr. Bates in Rensselaer, he has an office here in Indianapolis somewhere. He's a very nice man and people think very highly of him. First time we went, we really didn't know what kind of questions or anything we were supposed to ask him. So at that meeting that we went to up there, I wrote some things down and one of my other... our other daughters went with us and she said, "Now, Mom. You ask." Well, a lot of things that I asked him he answered and they have also been answered here. So now, this makes a second daughter that's been at this meeting. One daughter just goes usually with us to see the doctor and what I feel that the doctor tells him so far is it's just a waiting game. We're

just waiting to see until his white blood count and his platelets something happened with that then we'll talk about transfusions or we've even asked about some of the medicines or treatments, whatever, and both the doctor and the nurses that were there say, "Well, you know, he's not at that stage where he needs..."

?: But I agree...

Barbara Arnott: And I think now a second opinion is what we really need to... we really need to get and just see.

Jean Ridgeway: It's up to you. I'm not pushing that, but I'm strong advocate of it.

Barbara Arnott: I understand that. I understand that, but I mean it's like now he goes back next month to see the doctor and I'll ask some of these things and the doctor will answer, but we still won't know...

Jean Ridgeway: No and someone mentioned about living in the grey zone. There's not a roadmap. There really is no one who can say tomorrow will be like this, next month will be like this, six months will be like that and I'm intrigued by the whole process of first kind of understanding with your practitioner what are goals of care, what are you looking to get from this and then along with that though comes the disease and the process and from a practitioner perspective there are clues and there is data that helps us to understand what the disease is and how it behaves and there's a spectrum. There's a spectrum of when people get diagnosed and how the disease behaves and for some individuals that are fortunate enough to have a low risk disease which means yes, you have the abnormality and we watch you, but if you don't need anything, you don't need anything. When do you need something? When either your blood counts are low enough that we know that either you need a transfusion or you can live with low white blood cell count, but not until you get infections is it... do we really need to treat you.

?: I agree with the second opinion. I just said to him... I just said to my mom (inaudible 1:29:20) I think you need to get a second opinion.

Jean Ridgeway: You're next, my dear.

Andrea Hodges: My name is Andrea Hodges and I'm here with my husband. We're from Greenwood, Indiana.

Jean Ridgeway: Tell me where that is.

Andrea Hodges: Just across the border south. Do you know where Columbus, Indiana is?

Jean Ridgeway: I do.

Andrea Hodges: Alright. Greenwood's not... It's just out of Indianapolis before you get to Columbus. It's kind of little...

Jean Ridgeway: Smaller town from where I live.

Andrea Hodges: Smaller town probably from a lot of towns, cities. I was diagnosed with MDS five years ago. However prior to that I was diagnosed with asthma about two years prior to that because I was having a lot of difficulty breathing. Well, I keep flunking my asthma test and so they were treating me for asthma and so two years after I was diagnosed with asthma, we were at home and I started fainting. I mean, like...

Jean Ridgeway: Passing out.

Andrea Hodges: Humpty Dumpty kind of... bloom... I'm gone and because I was diagnosed with asthma, we just kept doing breathing treatments thinking I'm just not doing enough of those or something and Tony had left and made me promise I would stay in bed until I got back and I thought I've got to go to the bathroom. The bathroom door was real close. I can do this, you know? So, I get to the bathroom and I'm headed back to bed which is like feet and the next thing I know I'm looking under the bed and I thought what in the world? What am I looking under the bed for? Well, about that time he came back and needless to say I got kind of scolded for that and then I just felt like I was fading out into no place and he kept giving me the treatments and so anyway he ended up calling 911 and I was taken to ER...

Jean Ridgeway: And they did blood tests.

Andrea Hodges: Yeah, they did, but that's not when they found the evil little guy in there.

Jean Ridgeway: Were you anemic at that point in time?

Tony Hodges: Five.

Andrea Hodges: Five.

Jean Ridgeway: Five. No wonder you were... So, that's very, very low by having an anemia of five is very low.

Andrea Hodges: They took me to the oncology... Well, first of all the... I hope nobody goes through this, but the ER doctor, I mean, I am just grey just like no color and I just...

Jean Ridgeway: No blood.

Andrea Hodges: Horrible and the ER doctor was giving me the devil because I had fainted a few times and didn't get in there quicker. Well, you know if you think you have another problem that could cause this it's... so I was ignorant and he was a smart Alec. So, we didn't have a good... I don't even know who he was and it doesn't matter, but I hope I don't meet him again. They admitted me and they put me in the oncology floor and I thought, "They must be full. Why did they put me on this floor?" So that when I got in there the nurse says, "My gosh, honey." She said, "They told me I had an anemic patient coming up, but they weren't kidding. Your hemoglobin's five." I thought, "Oh, my gosh." So, they kept me for a week. They thought I had a

bleed some places. So, they called a gastroenterologist and they did every conceivable test there was.

Jean Ridgeway: Take a look this way, take a look this way.

Andrea Hodges: And many times in between. I drank everything there was I think and had x-rays done and they could find nothing. So, I went home and the gastroenterologist even called me at home at 9:30 one night and I thought, "What in the world...?" Wonderful man, just awesome and he said, "Andrea, I'm wondering how you're feeling," and I said, "Well, I think I'm feeling better," and I thought... He wanted me to do... I can't think of the proper name, so you'll... swallow an encapsulated camera, so it would go completely through my digestive system to see if there was something in the smaller intestine and I declined. I said, "You know what? If you haven't found anything by now, I'm not..." It was so hugely grossly expensive and I just said, "No, I'm not going to do that." So anyway, 2 years later my... after that time, my primary care physician who was also internal specialist sent me to get blood work done at the lab every... I think it was every 2 weeks. Well, my hemoglobin... They had to get me up so far to let me go home and then they had to give me more blood because overnight it dropped back down a whole number. So, my hemoglobin was hanging around 10. So, it dropped a little bit and he sent me... He said, "Sue, I think you..." my doctor calls me Sue, my husband calls me Sue. Sorry, my name is Andrea Sue. "I think you need to see a hematologist." So, he sent me to the first hematologist that I went to and we didn't have a good relationship and...

Tony Hodges: Quack.

Andrea Hodges: Pardon me?

Tony Hodges: I said a quack.

Jean Ridgeway: And that was how long... So, this was a couple of years ago.

Andrea Hodges: This was five years ago.

Jean Ridgeway: Five years ago.

Andrea Hodges: (Agreement sound) And he did a bone marrow biopsy and when I went back into his office he told me, he said, "We have got the results back from your test," and his RN comes over. She stands there. Tony didn't go with me because I didn't think... you know and she stands there by me patting me like, you know, I thought, "What's she doing?" I guess I... they thought I was going to react. Well, I never have heard of what... I never heard of that. So, it was no big deal to me. Well anyway, I had a relationship with him for I think about a year and I just had a lot of bad feelings because he didn't want to discuss anything, he didn't want to hear my questions and as you heard, he told me I ask too many questions. He printed out something and says, "You look it up if you want to know..." That's exactly what he said in those words.

Jean Ridgeway: Who old is...? Is he an older gentleman or a younger (inaudible 1:35:39)?

Andrea Hodges: He's another nationality and I just think that he's a fairly young... He's not young, but he's not...

Jean Ridgeway: So, you've moved on.

Andrea Hodges: I'm sure he's not as old as I am.

Jean Ridgeway: But you've moved on from him and you see another hematologist now.

Andrea Hodges: Yes. I told him I said... he started talking chemotherapy and he started talking other things and at that point in time my hemoglobin was at 10 and I just didn't feel comfortable with that and so I thought I want to get a second opinion. So, I asked my primary care doctor again and he's the one that sent me to this guy. He said, "Well, honey... Sue, he's awful smart." I said, "Well, he may be, Dr. Bender, but I want a second opinion." So, he sent me to Dr. Dugan and I don't remember the physicians with them. That guy is awesome. He, myself, my husband, my daughter and her sister-in-law went for this discussion and her sister-in-law is a nurse practitioner, so we felt that terminology would be helpful and that man spent over an hour with us and what he did was just explain as well as he could what I had, where it was going and he didn't feel that what the other doctor was "acceptable..." Well, I'm not going to get into that, but he had reason for it and he began and told us who he was and blah, blah, blah and then he sets a recorder down and this I thought was so awesome. He said, "We're going to record this so when you get home you can play this again and listen to what I've told you..."

Jean Ridgeway: That's a good idea.

Andrea Hodges: ... because...

Jean Ridgeway: Patients bring in recorders, but that's not something that we do.

Andrea Hodges: We all get home and then we think, "Now did he say this or this or that?" you forget. So, I thought that was just awesome. So, I went back to him again and find out about his practice. Well, he practices with two other physicians and they do clinical... different things. So, I would have to see three doctors and I didn't feel good about that. I just really like... I just like to see one doctor and so he sent me to somebody he thought I would match up well with. He's very thorough. I really think he's a good doctor and I feel comfortable with him. He never rushes me. If I want to ask questions, I can and...

Jean Ridgeway: And how did you hear about this meeting? Where you on the website?

Andrea Hodges: I went to MDS, the association...

Jean Ridgeway: The Foundation.

Andrea Hodges: Yes, and signed into them a long time ago and I got it through E-mail.

Jean Ridgeway: And this is your husband.

Andrea Hodges: And this is my husband, Tony.

Tony Hodges: My name is Tony.

Jean Ridgeway: Hi, Tony. You have to use that. We all do. Sorry. No one's excluded.

Tony Hodges: My name is Tony Hodges and I am her husband and what she did tell you is that she is as much of a caregiver to me as I am to her because sometimes I have as many problems, not MDS, as... I have Parkinson's and a lot of other things, stance and all that. So, she takes as good of care of me as I try to do for her and I... Since this is being recorded, I won't tell you that doctor's name who I dislike intensely and I don't think he has any business even practicing and I mean that sincerely because he told us that she had about two to three years to live normally with this condition and she's already had it a long time.

Jean Ridgeway: Five years. Right?

Tony Hodges: Yeah.

Jean Ridgeway: That's what you said was five years ago.

Tony Hodges: What scared us all to death, the whole family, we were all disseminated. We didn't know what to do and we went to these other doctors and got another opinion as she said and it turned out differently not that she doesn't have it, but she's not going to die tomorrow or for a long time we hope. So anyway, as I say, she's as much as a caregiver as I am for her.

Jean Ridgeway: Yeah. We're in this together.

Tony Hodges: That's what it's all about. Judy? You're next.

Andrea Hodges: Just one more thing. I don't want to talk too much. I want to tell this family here do get a second opinion. I'll tell you what. Even if you don't go with that person you get an... That, just getting a second opinion, just takes such a load off of you whether he says the same thing or something different. I would really encourage you to do that.

Jean Ridgeway: Just make sure you go to a reputable second opinion. I know the MDS Foundation has a list of MDS Centers of Excellence, but they'll also provide you with a list of names of... Again, it's a rare disorder, so you want to seek somebody who does a lot of that. Judy.

Judy Sears: I'm Judy Sears and I...

Jean Ridgeway: We need the microphone, Judy.

Judy Sears: (inaudible 1:40:54) microphone.

Jean Ridgeway: Nobody likes the microphone including me.

Judy Sears: My name is Judy Sears and I'm here with my sisters... my sister, Jane, has the disease and she found out about this and we are... you have all gave me so much information and understand a lot more than I did and I feel like there's a lot more hope than I originally thought. So, I appreciate everything.

Jean Ridgeway: That's good.

Jane Spring: Hi. I'm Jane and luckily I'm here with 2 of my sisters. I have more and I'm from Cincinnati and I was diagnosed in... or had my biopsy in January of this year in Cincinnati and I'm really at a stage right now where I see the doctor every 3 months and he just looks at my results and schedules me for the next 3 months which I like and my family physician sees me in between that time and as my family physician said and I think it describes it so right. He said, "You're doing well. You're at a low risk stage, but the difficult part is waiting for the other shoe to drop," and so that's sort of... and I've just done a lot of studying, a lot of reading online till sometimes I just say to myself, "I have to stop." I have to just walk away from it, but this has been really informative. I've loved every minute of it. I'm in the stage right now where I want to get a second opinion. I also want to talk to a transplant doctor. Being 72, I thought the cutoff date was like 67.

Jean Ridgeway: I mean, I can try to speak to... I work with older patients and at our transplant center we do transplant patients into their 70s. We have a collaborative team approach when we evaluate anybody over the age of 50 for a transplant goes through this geriatric evaluation which includes cognition, social support and medical testing, psychosocial, social work because it's a difficult...

Jane Spring: I asked my family physician said when I ask him and I did ask the cancer doctor also. My family physician said... He put it as like you might have more years of life fighting the disease along the route here than... a transplant's not always the answer because they... what you have to go through, your body has to go through for that transplant.

Jean Ridgeway: Depending on where you are with the disease and how your disease is behaving, that's very true.

Jane Spring: Right, but just to get a second opinion now and I would like to go to the Center of Excellence, but I'm out of the network and if I go to a Center of Excellence, there are none in Cincinnati.

Jean Ridgeway: Can you go to Columbus and see one of the...

Jane Spring: I can, but I'm out of network there also. I talked to them and Alison Walker, I think, was in Columbus. So, I don't know. I guess I will just do it and pay out of pocket, but when you said there was a list of doctors other than the Center of Excellence?

Jean Ridgeway: But the MDS Foundation has a list of... They have the Centers of Excellence and then they have like other physicians that in the area that they can provide you with. Isn't that correct?

Dee: (inaudible 1:44:25). We got other (inaudible 1:44:25).

Jean Ridgeway: And I know OSU does a lot of transplants. They have a huge transplant program.

Jane Spring: And this is my sister, Jenny.

Jenny Hilgeman: Hi, I'm Jenny. Judy, Joyce, Jenny. This has been very informative. I'm just so glad I came.

Jean Ridgeway: Ladies, we're saying who we are, where we're from and why we're here.

Carmen Burnam: My name is Carmen Burnam. I'm from Bowling Green, Kentucky and this is my sister Kelley Burnam Lee and we are both here on behalf of our sister, Claudia Burnham who lives in Louisville, Kentucky and then we have another...

Jean Ridgeway: You got to use that microphone. You may think we can hear, but we really can't.

Carmen Burnam: So, you didn't hear me. My name is Carmen Burnam. I'm from Bowling Green, Kentucky. This is my sister Kelenor Lee from Bowling Green, Kentucky. The person that has been diagnosed with this is my other sister. Her name is Claudia Bernam and she lives in Louisville, Kentucky and then we have one more sibling, my brother, and we're so close in age, we (inaudible 1:45:43), but I'm going to let my sister do the... speaking about my sister, my sister was diagnosed, I guess... My sister is... My sister is 56 and she was diagnosed in March and this (inaudible 1:46:04) from just having a... from a toothache... from a tooth...

Jean Ridgeway: A tooth that was infected.

Kelly Lee: Hi. I'm Kelly. I think this is really, really wonderful. I've now put a face to this disease besides my sisters. I have read, I have researched, I have talked to people and today this has really, really helped me. My sister right now is at the stage she's going to have to have a transplant and God being great as He is, out of the three siblings, of the two... three siblings, I happen to be a match. So, we're getting ready to go down that path, but it's a lot. Like I said, even families, this is something that I wish it was closer for us in Nashville because like I said, you try to educate yourself, you try to make sure you know the right questions to ask. Sometimes you just walk away confused and like you were saying, you back up, you stop, you say this is enough, let my brain absorb all this because when she gave us the news and called us all in, I felt like I was spinning in a vortex is the best way to kind of describe that and I've learned also, too, with this is if you're someone that's at the place that you've got to have a transplant that doing donors drives are really, really important. Like I said, you know that when you're diagnosed with something you try to wonder what somebody's mind frame is. You try to be real supportive to people. Sometimes you may shy away from your family, but like I said it's been a journey on the

outside. So, I can just imagine for you all that are patients that have been diagnosed what you're going through. Like I said, again, back to donors, drives are very, very, very important and like I said this has been a learning lesson for me because when you look at numbers and studies and things like that, siblings as a match, the numbers are kind of low. Also understanding what it's exactly involved in being a donor. It's just kind of a whirlwind for you, but like I said being able to sit and talk to people and hear other peoples' stories has really been a benefit for us even though we got here late, but I still wanted to be here.

Jean Ridgeway: So when we talked about transplant earlier, the question was asked is there an upper age limit and certainly it varies on the health of the individual and really pushing that envelope from mid60s to early 70s is being done across the country if the person is truly a candidate and it's the appropriate therapy for younger MDS patients. Robin Robinson had her transplant a year ago and her sister was a match.

?: (inaudible 1:49:00)

Jean Ridgeway: The sibling was a match and just to kind of give you a little information about stem cell transplant. We carry a unique genetic identifiers and in order to gain someone else's hemopoietic system, ie. their blood system and immune system, you have to match them relatively closely in a genetic matter. Otherwise, your body rejects the graft or you can get this syndrome where you, graft versus host disease. So, it's a very complicated process and the first thing that we do at a transplant center is when the patient comes in and they're interviewed, we talk about siblings because if you think about it, I received my genetic information half from my mother and half from my father and so did my brothers and sisters and so knowing biology and knowing genetics there's basically a 1 in 4 chance that 1 of your other full siblings will match you. Now, you can have 1 sibling and match and you can have 10 siblings and no matches. The odds statistically go up if you have more siblings, but there's no guarantee. So, for our younger patients who are appropriate candidates and then if there isn't a match, there's something called the International Bone Marrow Registry and when we talk about a drive what we're talking about is... I believe you have to be 60 and under to be a donor and if you are considering to be a part of it all it is it's basically taking a Q-tip and swabbing the inside of your cheek if you're entering the registry and that information goes into a database and you answer a very thorough questionnaire. You have to be healthy enough to go through it. You can't have a history of cancer and there's some other criteria, but basically that information gets banked so that if I needed a transplant and none of my siblings match, they take my genetic profile and they put it into the computer system and try to look for the best match and then if someone's identified they contact you on an annual basis and say are you still willing to donate and is your information current and then a donor, a potential donor, then is contacted and so that's kind of the process with that and usually around Mother's Day or if someone in your community is in need of a bone marrow transplant, oftentimes you'll see in the newspaper that there's a drive being held, but it's not a blood test. It's a simple swab inside the cheek and there's no cost for you in a drive situation to be part of it. So, just a little information for you.

?: (inaudible 1:51:40) bone marrow.

Jean Ridgeway: They do not. About 99 percent of all patients who are donors get Neupogen injections. What Neupogen does is it mobilizes white blood cells and the most immature white blood cell is something called a stem cell. That's the mother cell and so what we want to do is get those mother cells out into the bloodstream and then they're collected. So, donors get 4 days of injections. It's just like a little insulin injection you give yourself either once or twice a day and then they get ferese (sp? 1:52:18). Now, a fereses (sp? 1:52:19) process is similar to if you've ever donated platelets. An IV gets inserted in 1 arm and an IV gets inserted in the other arm. The blood gets taken out and it actually gets centrifuged and it's done by weight. So, the stem cells have a certain weight and they're collected in a big and it looks like a blood transfusion basically and we usually do 4 total blood volumes. So, that takes about 6 hours of the person being on the machine and in general 1 day is enough. Sometimes you have to go 2. A lot of it is depending on is the donor is big as the recipient? Is the recipient bigger? So, there's a little bit of math that goes into the calculation, but it's not... I'm telling you 99 percent of the time it's done that way. We can do it to get aspirates from the person and then that person goes to the operating room and there is a practitioner on either side of the iliac crest and we do about 50 aspirates on each side to get...

?: (inaudible 1:53:19).

Kelly Lee: (inaudible 1:53:23) up and down just from my personal experience, I have Sickle Cell trait and for me I'm not going to be able to do it (inaudible 1:53:32).

Jean Ridgeway: Peripherally.

Kelly Lee: Right. And just for me that was kind of a downside because I had made up in my mind that if I happen to be the one, of course everybody says it's pain free and whatnot. So, okay. That would be a good route to go, but it's not my choice. (Inaudible 1:53:48) and so we're tagged as Sickle Cell trait I wouldn't be able to do the medication as far as those injections without that causing problems. So, mine is going to be...

Jean Ridgeway: In the operating room.

Kelly Lee: In the operating room.

Jean Ridgeway: So, the donor then gets anesthetized and then the procedure... the harvest is done while the person is asleep basically.

Q11: (inaudible 1:54:008) saying that the like the transplant (inaudible 1:54:11) you're saying you say you draw (inaudible 1:54:14) 70s do not go up any...

Jean Ridgeway: Seventy-two has been our oldest recipient.

Q11: Okay because he's 82.

Jean Ridgeway: Seventy-two has been our oldest recipient.

Q11: So, we were just kind of curious about it.

Jean Ridgeway: Is there an age limit? I'd say in practicality, yes. I think if you start looking in the early 70s. Beyond that is the risk...

Q11: He might not be a candidate.

Jean Ridgeway: The risk is...

Q13: The white blood cells versus the red blood cells in the situation, too?

Q12: The reason I... Yes for the trans... because he actually... My husband was actually ruled out for a transplant not only because of the age. He's 69, but they just said he's not a good candidate because his white blood cells are what... I mean, (inaudible 1:55:02) which I never about all the red blood cells versus the white and how different some of these things can be with the MDS.

Jean Ridgeway: So, the answer... if I'm understanding your question, does it make a difference whether the white cells are low, the red cells are low or platelets low. No, it doesn't because all of those cells begin in the stem cell. So, MDS is a stem cell malignancy. Okay. That's the problem and where the error occurs and how it looks in individuals, there are a lot of different presentations to that, but a transplant is so you're replacing the stem cell and you're going to give a healthy stem cell that's going to recreate a normal pathway so normal red cells, white cells and platelets.

Q12: Thank you. I didn't meant to interrupt.

Jean Ridgeway: No, that's okay.

Q12: Is there any age requirement on the donor?

Jean Ridgeway: So if you're a related donor, usually they'll go older for the related donor. So, we've had donors into their 70s. There's some science that's appropriate that sometimes our donors who are a little older, we have... they have to be mobilized for more days. You're looking at an older marrow. So, it may take a little bit longer, but in the nonrelated donor, so if the... the cutoff is 60, I believe.

Q12: They say it is a cure but what is life... the quality of life after a transplant?

Jean Ridgeway: What's the quality of life after a transplant? Boy, that looks a lot different for a lot of different people.

Q12: My physician is my...

Jean Ridgeway: Is he a transplanter?

Q12: No, he's not.

Jean Ridgeway: Well, you got to go talk to a transplanter, but it's all roses when you talk to... That's not true. I would see a transplanter who really specializes in older adults because transplant for 20 year old or a 30 year old is different than a person who is 60 because you come to the... the person is coming to the table with diabetes, coronary artery disease, some other impairments. The better...

Q12: How do you find that person?

Jean Ridgeway: How do you find that? So, there is a... It's called the International Bone Marrow Registry, IMBTR. You kind of contact them and say who in my area is a transplanter who specializes in older adults. There are a number of transplant centers across the country who draw the line in the sand at like 62, 65. It used to be 50 and so that's been pushed forward, but what does it look like? It looks a lot different. Some people go through transplant and... Yesterday, I saw a gentleman who... he has MDS. He had 2 cycles of Decitabine and went into a complete remission. So, he did really well and had a matched sibling donor and he was transplanted and he was discharged 20 days after the reinfusion of the stem cell to home and common side effects after transplant, the number 1 is fatigue. People just are really very tired. You get big doses of very toxic chemotherapy, diarrhea, nausea, vomiting as you can imagine is something that these folks have to endure. Taste changes, transfusions... You don't leave the hospital unless you're infection free and transfusion free so that you can come back and forth every 24 to 48 hours and meet that criteria. He's not quite a month and he's doing quite well. He told me he drove his car. We usually don't like people to drive their car right away because if you're too tired to walk up the stairs, I think you're too tired to drive a car. We're going to read about you going through the window at Walmart.

?: (inaudible 1:58:50)

Jean Ridgeway: He's 69.

Q12: So, that's another benefit versus risk type thing. That's how they throw it out to you.

Jean Ridgeway: It is. It is and it's all about timing. For low risk disease for people even who are younger, there's a timing factor, but I don't know if your sister kind of a more aggressive higher risk disease.

Q12: I think it's probably more aggressive.

Jean Ridgeway: It's more aggressive. And so with a younger patient with a more aggressive disease, the natural evolution can be that people cross the line into leukemia and again strictly from a definition perspective, 19 percent is MDS, 20 percent is AML. So if you're 19 percent, how far away are you? You're like this close. Right?

Q12: I don't think I understood that.

Jean Ridgeway: In pathologists, the definition of leukemia, acute leukemia, currently. So, there's a couple of classification systems, but the currently accepted classification system is something called the WHO, World Health Organization, and that's been a system that's evolved over many decades. Blasts in the bone marrow with the aspirate tell you where people... what's going on. Right? What does it look like under the microscope? If you ever looked at your pathology report, it may say something like a normal cellular bone marrow, reticulant fibrose, 4 percent blasts. If it says 19 percent blasts then you know the diagnosis still fits with MDS. If they have 21 percent blasts, they'll say consistent with acute leukemia.

Q12: I just read last night that's the first time that was mentioned to me although I had read it online. Mine said zero blasts.

Jean Ridgeway: Zero percent blast. Now, you got some, right, because the normal differentiation...

Q12: Yeah or I wouldn't have been diagnosed.

Jean Ridgeway: Right. The normal differentiation is blasts. So, we all have them. If I did a bone marrow on myself which would be really hard. I would have some. I have some because that's just normal. That's normal. Alright. We're going to finish over here and then I think it's lunch time. Right? Do we have to go someplace else for lunch or are they going to bring lunch in here?

Dee: The lunch is out here. It's ready.

Jean Ridgeway: Alright. Well, let's finish up going around the table.

Linda Berger: I'm Linda Berger from South Bend and my husband, Stephen, has MDS. This is about our fifth or sixth symposium we've been to and I would say the best so far and I agree with the comment made about July. I appreciate and have learned a lot from the presentation on the screen, but the interaction and actual question and answering and things, I think, is much more informative and I would like to thank Deborah for all she's done planning all of these. They've really... Everyone has been wonderful. One more comment, the second opinion. I really pushed very hard and finally got Stephen to get a second opinion. I just wasn't real thrilled with the doctor. He ended up changing doctors later, but...

Stephen Berger: For other reasons.

Linda Berger: Yeah. For other reasons, but we went to the Mayo Clinic and we're very impressed with what they had to say and do and I do agree. The second opinion, even if your doctor's doing everything perfect, it's just even for piece of mind it's a blessing. I'll let Stephen tell you about his situation.

Stephen Berger: My name is Steve Berger from South Bend, Indiana. I have been diagnosed for seven years and in order to make that diagnose at seven years, they're looking for stuff for a year and a half and that's just out of regular physical for work and they just saw a low blood count and as for second opinion, she has better opinion of... what was that place? Oh, yeah, Mayo

Clinic than I do. They're too theoretical at Mayo Clinic. I mean, they'll sit there... One of the side effect... One of the other things that I have is Leiden Factor V.

Jean Ridgeway: Factor V Leiden.

Stephen Berger: Leiden.

Jean Ridgeway: So, Factor V Leiden is a benign hematology disorder that prones you to get blood clots and it's usually familial. So, that means probably somebody else in your family maybe have it or they may have the trait, but it's not uncommon like you say, "Oh, my mother had blood clots. My sisters had blood clots." If we did the genetic testing, we'd find out that they had Factor V Leiden.

Stephen Berger: The one doctor was telling me, "Oh, just don't take any more Coumadin." This is from Mayo because you went 63 or 62 years without and you never had a stroke and I says, "Yes, but yes, but this might be the 64th," and then I says, "That's crazy."

Jean Ridgeway: Coumadin is a blood thinner. So, people who have clotting, high risk of clotting and having either a stroke or pulmonary embolism, get put on this oral medicine, Coumadin.

Stephen Berger: And it also helped me, the Coumadin helped me with the MDS. It actually helped in conjunction with testosterone to lower... I mean, to raise the number.

Jean Ridgeway: Your hemoglobin number.

Stephen Berger: Hemoglobin went up and they keep on thinking well maybe it might be the fact that I was developing enough hemoglobin, but like somebody else said over there what is transferring to the blood system there are being damaged and he says maybe... this is the oncology guy, "That might be what's helping you out. It's doing something helping... going into the transition," but as for being whole heart for Mayo, I wasn't.

Jean Ridgeway: The patient perspective. There's the family perspective and then there's patient perspective and MD Anderson is kind of becoming the new age Mayo Clinic. I remember when I was a kid is the Mayo Clinic. We all bowed down. It's an excellent place. I'm not saying that to downgrade them and all, but I think over these past number of decades with oncologists being trained at large academic centers and going into the community healthcare is much more available at an expert level even if you have to look for like a real expert in a rare disorder, but it's much more available in the community than having... although there is merit to traveling to some places and I mean, MD Anderson and also is an excellent place.

?: It's a long way to go.

Jean Ridgeway: It's a long way to go. The University of Chicago is... I mean, the big universities usually have clinical trials, etc. So alright, it's noon and your lunch is out there. So, why don't you go ahead and grab your lunch and then we'll reconvene around the table. How's that sound?

?: Can we leave our stuff here?

Jean Ridgeway: You can leave your stuff here. I think you're going to come back in here and eat. Right?