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Sandy Kurtin, RN, MS, AOCN, ANP-C

Sandy Kurtin: So, I'm going to just get my slides up here. My name is Sandy Kurtin. I am a nurse practitioner. I work at the Arizona Cancer Center in Tucson at the University of Arizona. I am also the author of the *Building Blocks of Hope*, a great passion of mine along with my (inaudible 0:23). Many, many colleagues who freely gave up their time and effort and expertise in contributing to develop that tool, both physicians and nurses throughout the world. So, I want to acknowledge all their input and help in that. It is an evolving tool, so we're constantly looking to improve it. So, we're going to talk a little bit about that here in a moment. Let me get these... and how you can really become really a partner in your care. So, I have slides on my laptop, but not on the screen. There we are. Okay. Wonderful. So, I also am a member of the executive committee for the MDS Foundation. I've been involved with the MDS Foundation for many years. We started a nursing leadership board, which I'm very proud of which represents many countries throughout the world. So, these are all nurses or nurse practitioners specifically working with the MDS population in many, many countries and so together with our Centers of Excellence and our physician colleagues, we've been able to really share information across the world and also have been able to take a lot of our work and translate it into multiple languages. So, we're also very grateful to this group of volunteers. These are all volunteers. So, just to recognize those contributions.

So, you heard a lot from Dr. Bejar about the disease itself what we understand, what we're trying to understand and really how we're going to move forward and I know that's complicated. It's complicated to us, those of us who do this every day. It's becoming very molecular and so we all wish we would have paid better attention in our biology class and physiology class because this is all really coming down to genetics, but for you today what we'd like to do in the next little segment is just sort of take you through the *Building Blocks of Hope* a little bit and help you understand what's there.

So, there are tabs and segments in the *Building Blocks of Hope* that go through these specific elements – Understanding Your Disease Itself, How is it Diagnosed, so really going through some of the information that you just heard from Dr. Bejar. What are the treatment options currently available and what is on the horizon? Now, it has not been updated yet with all of the most recent data from ASH, the American Society of Hematology meeting that you heard him mention. That was just held about a month ago in San Francisco. So, the good thing about this tool is that we print as we go now and so it's a very versatile tool that it can be updated readily and so we will be doing that. So, look forward to that. I know somebody had a question earlier about how do you know if you have the latest version. We have talked about sending out alerts to people to say that there's an update and so we'll have to make sure that we go back and look at that again for anybody that's, certainly, that's attended one of these sessions or has ordered the tool through the mail. You can easily go online and use a digital version. It's actually a beautiful webpage like a Kindle where you can turn the page, you can focus, you can find a definition. So, it's actually very versatile in that way. You heard a little bit about the consequences of blood transfusions. I love the nail slide. I'm going to steal that. That's a great way to explain it. I think to help people really understand what's happening and then we heard a little bit about transplant centers. So, we'll talk more after lunch just about your specific individual

questions. We'll have some time here in a minute to talk a little bit about that, but the whole rest of the afternoon after lunch will just be you talking and sharing and having that conversation.

So, we'll skip through this. I think one of the things we look at is individualizing treatment and so Dr. Bejar mentioned the concept of risk adaptive treatment strategies and what that means to us clinically is that every single one of us is different and we need to look at the whole person, not just the disease characteristics, but you as an individual are you otherwise healthy and fit or are you... do you have several other issues going on, diabetes, hypertension, are they well controlled or not. We consider age. I personally never use the term 'elderly' anymore. I've been doing this for 30 years, so... and I did not start when I was 10. So if you just do the math, I just use the term 'older adult' because then I can say you are older than me. Somebody hopefully is older than me. So, I don't like the term 'elderly' anymore. So, we use 'older adult,' but age alone should never ever be the single deciding factor and we have done a lot of work on ageism. So, the idea that... I mean, I have patients personally that we started treatment when they were 85 years old and they're 95 and they are living a good, active, excellent quality of life. So age alone should never decide by itself whether we treat or not, but what we do is we look at the things that we know that tell us that your bone marrow is not working like we'd like and so when you become transfusion dependent, you're needing regular transfusions, we know that you're not making enough red blood cells by yourself and so we may need to give you some. They're borrowed. They're temporary. So, transfusions only last a little while. Those cells live certain amount of time and then they're gone. They're borrowed. Right? They're not permanent and we know that transfusion dependence brings out iron overload concern. So, that's a trigger for us to try one of these what we call disease modifying therapies. As Dr. Bejar mentioned, something that gets in there and tries to actually change some of those things that he described that make the disease happen.

If the other blood counts start getting bad, your white blood cells, your platelets. That's telling us the bone marrow is not working very well and we're going to want to try to fix the factory if you will, get in there and make it work better. If you have increasing blasts. This is something that we use in the IPSS and the IPSS-R to actually give you a risk category. Blasts are immature blood cells. We should never see them in the peripheral blood. They only occur there under stress situations or if there's something else going on in the bone marrow. So, the higher the blast count, the more aggressive that disease is behaving and you're moving more toward the AML trajectory. Now, somebody said earlier in the group here, I can't remember, I was in the back, so I didn't know who was saying it, but they had a low blast count in their marrow. That goes along with having lower risk disease. So if you have less than five percent blasts, that's considered less aggressive. So when the blast count is rising, we want to do something to actually treat the underlying disease, disease modifying therapy, not just supported care. So, supported care being transfusions, antibiotics, that kind of thing or if you just have high risk disease we know that that disease is likely to progress more rapidly toward AML. We're going to want to stop it.

So, these are our treatment triggers, the things we are going to actually talk about instituting one of these disease modifying therapy of which today we have three FDA approved agents - Azacitidine, Decitabine and Lenalidomide and/or a clinical trial which would be the fourth option. We talked about how we individualize this.



One of the things I always talk about is lifestyle. That matters. Quality of life as Dr. Bejar said always matters. That's important to us. I live in Tucson. We have a lot of winter visitors. We are... We're the zonies that come to the year right in the summer because it's way too hot, but in the winter we have a lot of people that come to us and they come mostly to play golf or just to be in the warm weather. So, I have a couple of patients that tell me, "Sandy, you can do whatever you want to me, but I play golf on Wednesdays and that's not negotiable." So, we work around that because that's important to give you... We don't want you spending all your time with us. I always tell my patients we are wonderful people, I know that, we are wonderful people, but we don't want you to spend all your time with us. We are... The whole idea is to have you have a life and do the things that you enjoy. So, we take all of these things into consideration.

Now, there is a really important comment or topic that Dr. Bejar mentioned and this is the whole idea that treatment takes time. So, this is what I call my ravine slide and I think it tells a very important story because I think today still we hear about people prematurely discontinuing therapy and given that we only have a few that are FDA approved, we want to make the most of each one that we actually have. So, this is where you start. So, you have this abnormal bone marrow where you have the MDS in there and the bone marrow is a little bit crowded and we're going to want to fix that and get rid of some these abnormal cells and so when we do that we actually make things worse initially. So, Dr. Bejar has mentioned that maybe you weren't needing platelet transfusions, but now you might. It doesn't mean that everything has gone wrong. It means that we're actually getting into the bone marrow space and we're cleaning out the bad cells so that we can try to help the marrow work better and make some good cells. So, you're in the ravine. So, you think to yourself, "Hmm. I was only needing red blood cells every 16 days and now it's only been 10." That's okay in the early phase of treatment. We started to accept that we're going to make it worse before it gets better and we have this conversation all the time in our clinic with patients because they'll say, "Uh oh. What happened?" and we'll say, "Remember, we talked about this." Things are likely to get worse before they get better. Then you get to the other side of the ravine and you notice that the numbers aren't quite what they used to be. So, they're not way up here. So, the other side of that ravine may mean that you don't need transfusions anymore. You're feeling okay, but your counts might not be normal and they might not be normal forever, but as long as you're feeling okay, you're not needing transfusions, you're not in the hospital, you're not bleeding, you don't have infections. That's okay. It's okay. They're just numbers. So, we need to get away from thinking that all the numbers need to be normal and that's a challenge even for many clinicians today because they are using numbers that we use in other cancers, certainly in solid tumors, which we can never compare to, but even within liquid tumors, the hematological malignancies, MDS is very different in that we may never see a normal platelet count again and it's okay as long as you don't have symptoms. Your white blood cell count might always be below normal but if you're not having infections that's okay. You're okay with that. So, we have to really emphasize that the way we measure response to treatment is very different than any other cancer and any other blood cancer specifically and we still don't have all of our colleagues across the country or certainly in the world that truly understand that. So, it's important to know this is sort of that new normal where your numbers might not be not normal, but if you are feeling okay that's alright. They don't have to be normal. It's just a number.

So, we basically then hopefully get to where the marrow is repopulated with more normal cells. Now, this is a... the graph up above is actually a slide that... Well, there's the reference. Dr. Sekeres who's at the Cleveland Clinic did an analysis of the data, the original data, from the Revlimid trials demonstrating this very thing where actually the patients who have Revlimid and had a drop in their platelet count after treatment actually went onto have some of the best response. So in a way, it's a good thing that your numbers drop initially and then reset and so that's something that we also look at in those patients.

So, the trick is how do you get through? This is basically takes about four months in most patients, maybe six. So, what we're saying to you is okay, you meet the treatment triggers. We want to use a disease modifying therapy. So, we're going to try one of these things. Now what I say to my patients is, "Okay, we're going to work together. We're a team and you're going to stick with me here for three to four months," because if all you do is give two months of therapy and stop then what we've done is we've exposed you toxicity without any potential for benefit or a minimal potential for benefit. So when you start a disease modifying therapy, you have to commit to those first four months, really, four to six months in some cases. For people with normal chromosomes it may take six months. So, we need to remember that and not bail out prematurely because then we're not doing the right thing for you.

So, there are many things that help us get through this ravine. Some of those we can do dose modifications or delays, so very important for instance in the Revlimid trials. I was actually part Dr. List who I worked with many years, Dr. Alan List, about 16 years at the University before he moved to Tampa and he's now the head of Moffitt Cancer Center there. We did the original trial with Revlimid, MDS001. It was the only site in the world and what we did in that trial is when we saw that peoples' blood counts dropped a lot, we took a break and we allowed that break to be as long as 21 days. So, when you or if any of you are on Revlimid, one of the strategies that we use to help get people through that ravine is a drug holiday which my colleagues in Europe think drug holiday, sounds very American and that doesn't mean you're going on holiday with drugs. It means we're taking a holiday from the drugs. So, we've had a lot of chuckles over that, but it can work very well to just take a little break. Now, that's very different if you're talking about Azacitidine or Decitabine because they work in different ways. So, we can use that.

Supportive care, we may again need more transfusions initially and then hopefully if you respond you won't need any. So initially, we might need more and then certainly setting expectations. So if we all agree that we're going to commit to this period of time and work together and get to the other side that's going to help all of us really do our best with whatever therapy they're using.

Now, I will put a challenge to Dr. Sekeres to say that I had a patient that figured this graph out before he did, but I want to use a couple of examples of patients that I've had. So, this is a very young patient, 38 years old, had just had her second child and was very fatigued and a little depressed and they just thought she had post-partum depression and the pink line is the hemoglobin, the goldenrod is platelets and the white count is in blue. So, you can see in the early part of the graph here that she had low, very low, platelets when we started her, 32,000, not... you know, normal is 150,000. We can go over some of that later, but you can see that things got worse. Everything kind of dropped.

These are transfusions. Each one of these little bumps here is a quick bump up is a transfusion, but nothing really got better until after cycle four. So, you could see all of a sudden after cycle four, she's getting Azacitidine, all the numbers got better. She happened to be young, had a sibling donor, her sister, and went on now to the bone marrow transplant. Had we said, "Uh oh, nothing's happening, nothings changing, so I'm getting worse not better." Is that enough to be pressing? No, am I hearing things? We would have stopped prematurely and we would not have gotten to that outcome where she could actually have a bone marrow transplant. So very important to understand to get... you got to connect to that initial period of time.

Now, this is the Chet chart, the famous Chet chart. So, this was a gentleman who was on our original trial. He was. He just died, unfortunately, in October of this past year of coronary artery disease, not of MDS, but he had been on Revlimid about... At the time, probably longer than anybody in the world, 12 ½ years of transfusion independence, but he was a truly a rocket scientist, built rocket engines for NASA and he created this chart because I'm not smart enough to do that in Excel, but, again, you can see a very, very quick drop in blood counts early in the phase of treatment. So the other part of what we have to do when we start your treatment is we need to really keep a close eye on you. So, we get labs every single week for about eight weeks, sometimes 12, to make sure that we're doing the right thing to support you through that ravine. So, it doesn't mean that intensity will continue forever. It means just in the beginning we have to really pay a close attention, but there are two very important points here. Number one, so this is the platelet side here. This is why it's so hard to see. It has two different Y axis. So, normal platelets are 150,000. He had one normal platelet count in over 12 years and that's okay. He was never hospitalized, never had any bleeding, never had any serious infection or illness. The white count... So, his average platelet count was somewhere around 70,000. You could do just fine at that number. So, that's okay. It's just a number. As long as you feel well, you're not symptomatic we can keep going and it's okay. This is the white blood cell, so I'll come back over here. It's the white count or white. This is the white blood cell count and, again, normal white blood cells is 3.5. So if I put my hand here and more importantly neutrophils which are the most important infection fighting cells, you want your neutrophil count to be about 1,500 and we can talk about that later, but again you can see most of the time below normal, but he's not infected and wasn't having issues. That's okay. So, we have to rethink what we expect our numbers to be because I know you all probably ask for your copies of your counts and you say, "Oh, these aren't normal." That's okay as long as you feel okay and you're not needing hospitalization or having illnesses and such.

So, what can you do then is the most important thing and I have this conversation all the time with my patients. We do a lot of clinical trials is that half the battle is to be well and well enough for a trial and be here. So, one of the most important things you can do for yourself is to stay well and so along with us trying to do our best to control or treat the MDS, we also want you to do the things that are going to help you be well and so a balanced diet. There's all sorts of different crazy trends out there that people are trying to do. My personal recommendation to patients is balance. If you look historically at people that are 95, mostly they just get a balanced diet. They didn't have McDonald's. So, highly refined foods, junk food, lots of simple sugars. Again, it doesn't mean you can't have any sugar. The whole sugar thing is... so any extreme is probably not good for you whatever it is. So, just

a balance, good amount of calories and protein so that you can rebuild the normal cells and have energy.

Daily activity and exercise. Somebody asked about fatigue. So, I just wrote a paper on fatigue and we're beginning to understand some of the physiology of fatigue just like Dr. Bejar mentioned some of these molecular attributes. There are things that we think might be related to fatigue primarily they're inflammatory, what we call inflammatory cytokines which are basically just substances circulating in the body and so... but there are a million different things that people have tried for fatigue – pills, coffee. So, that's... coffee might work temporarily, but you'll pay for it later, but the one thing, the single thing that has consistently been measured to be statistically significantly related to improving fatigue is exercise. So it seems crazy. You're tired and we're going to tell you (clapping), "Come on, let's go, go exercise," but it doesn't have to be like going to the gym and doing squats and whatever, running for three miles. It can be little things, walking, a little bit of resistance training. I have my patients use those rubber bands, the flat ones, not the ones that are like a rope and you can do just one little exercise because one of the things that happens when you're not moving is you lose your proximal muscles. So, the quads which is what help you get up and down out of the chair, in and out of the car, walk up and down steps and these are the other (inaudible 24:27) muscles, the arms here which help you get dressed, shave, wash your hair. That's why they do all that aerobic stuff is they make these muscles work and they're a very important muscle group. So if you do one thing, just sit on a chair, hopefully that's not spinning and up here and you take your rubber band and you put it under your foot and you just do one motion like this then you're not going to fall. If you have like a fractured hip or something this is probably not a good idea. So, make sure there's not an (inaudible 24:58), but it's amazing if you just sit and do this while you're doing whatever it is watching (inaudible 25:07) how many of you? I just had a nervous breakdown because I couldn't download it on my iTunes when I was just traveling and almost had to have an intervention. I don't watch much TV, but I am addicted to (inaudible 25:23). So, little things like that can go a long way to build your stamina so that when you do something you're not exhausted. So, just try to get a little routine that you can integrate into your day to day activities.

Avoiding infection and bleeding. Now, most of us would think that you get everything from everybody else and in reality in cancer in general and certainly in myeloid disorders which is MDS most of the infections come from your own body and unlike a leukemia patient where we get drugs that interrupt the gut, we don't do that in MDS. So, the most common infections that we see in MDS are infections that are common in older adults, so pneumonias and urinary tract infections being the top two. So if you stay well and you're eating right and you're exercising, you'll be less susceptible to those kinds of infections. It doesn't mean you have to close yourself off or put yellow tape around your house to keep people away. You just have to have common sense. So, don't go hanging out at the mall on Saturday with everybody. Don't play in the elevator, up and down. You could go to the movies, but maybe don't go on the day when all the kids are there. You can be around children, but you have to be smart about it. It always breaks my heart when people have the misconception that they can't see their grandchildren because... then what are we doing really? So, that's okay. Just if they're really obviously ill, not so many sniffles and kisses. So, common sense.

Avoiding bleeding. Again, if your platelets are very low generally this is spontaneous bleeding usually happens if they're less than 10,000. Most people are never at that level. At 20,000, you might be at an increased risk, but it... so we want to keep that in mind. Enjoy the things. Live. That's the whole idea is to make you well enough and give you the time to actually do the things that matter to you. So, we don't want to have you be trapped with us. I always just say I kind of double as a travel agent, try and figure out how to get people a transfusion in Singapore or wherever they're going to go if it's safe to do that. So, we don't want to have you feel trapped. We want you to live. We want you to do the things you enjoy and so ask and we'll try and help plan. It's important for you to do the things that you want to do. Now if you're trying to go to Machu Picchu, I can't help you there because I couldn't even get up that mountain. I would have to take the train, but if you're up for that then we'll work on it.

Get enough rest. So, balancing rest with exercise. Did you have a question?

Q1: Yes, thank you. I know that here in the hospital there are therapists, but what my husband has MDS is looking for his MDS wellness group so that he can get out and (inaudible 28:50) and anger to those people that he can relate to that have the same... are in the same situation.

Sandy Kurtin: So, (Attendee), you hit the nail... speaking of nails, you hit the nail on the head. So the trouble with MDS is that if you're in a... even in a big city and you go to a general support group you might be the only one there with MDS. Isn't that right? So, it's hard to really relate in many ways to other people that have breast cancer or lung cancer or whatever it is because it's very different. So, that's what this is about, these forums are about is that you are all sort of your own community, if you will, and it's important to be able to share that information and we're going to spend the afternoon entirely on that kind of thing just having a discussion, but I think that's a wonderful recommendation is that it should be a wellness group. It should be about how do I be as well as I can be and live with this disease and not be just focused on the illness, but me as a person and what can they... have more better days than not. So, I think we are challenged in that way in creating those kinds of group. Now, somebody here has a support group and so we'll... Do you want to take a minute?

Q2: My name is (Attendee) and we've been meeting up in San Marcos and my (inaudible 30:23). On occasion, we'll have speakers, but a lot of the time it's been just together and (inaudible 30:30) and talk and share what we're all going through with this disease. My own mom has MDS, so that's my experience. She's been living with it for three years and they key word is 'living.'

Sandy Kurtin: So, (Attendee) how often do you guys meet?

Q2: We try and meet once a month a month. So, this is actually our substitute meeting today.

Sandy Kurtin: On Saturdays?

Q2: Yes.



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Sandy Kurtin: Once a month on Saturdays in...

Q2: Every third Saturday of the month in San Marcos.

Sandy Kurtin: In San Marcos and (Attendee)'s last name?

Q2: (Attendee)

Sandy Kurtin: (Attendee). So, we might have you live... (Attendee), where do you work?

Q3: Here in (inaudible 31:09) Claremont area.

Sandy Kurtin: I have no idea what that means. All I know there's a lot of traffic wherever you go in California, but so maybe we can have you guys chat about what might be available near you for that kind of thing. I think that's the only way and you can also check with Audrey Hassan who introduced herself earlier because she keeps track of the support groups that are out there that are geared exactly to what you're asking about. So, I think that's a very important to be able to have those kinds of conversations.

Q3: It would be nice if perhaps I know it's a very sensitive area, but people that gone through it or have gone through it can kind of interact that person (inaudible 32:03).

Sandy Kurtin: And that's, I think, what support groups do and there are support groups throughout the country for just MDS where they're not lumped into...

Q3: But not in California.

Sandy Kurtin: I'm sure there are some. So, these two ladies in the back are going to find you during lunch.

Audrey Hasson: (inaudible)'s group is MDS specific and then you can also go on our website and you'd show that on our event calendar is up to date. (Attendee) contacts me, so I put all of the meetings up on our website calendar as well.

Sandy Kurtin: So if you didn't hear that what Audrey is saying is we have an event calendar on the MDS Foundation website that lists all the available support groups that would be specific to MDS. We'll have them talk to you at lunch, (Attendee).

Q3: Great.

Sandy Kurtin: So, this is (Attendee) and so that gets us to getting... taking advantage of those available resources, asking for help. I'm a doer. My grandmother said, "You're a doer." I do too many things, but I love them all, so I can't stop but you have to stop and ask for help and you need to be specific. So, take advantage of people that are offering and say, "I need you to go to the dry

cleaners on Tuesday and do this.” If you’re very specific then that’s something meaningful to you. Otherwise, people are saying, “Oh, can I help? Can I do this? Can I do that?” and then you don’t ever really know how to organize that help. So, make a list and when someone calls say, “Check... check,” whatever it is. I personally don’t do dry cleaning because I don’t like to take stuff there and I don’t like to iron. So, I’m going to have to just wear knits.

And then be an active participant. I think one of the things that we’re hoping to do is to taking book five which is in your *Building Blocks of Hope* and really operationalizing that so it allows you to track your counts, track your disease, keep track of your progress over time. Now if you’re Chet who was basically a rocket engineer, he already color coated and tabbed. You can always tell the engineers because they come very well... Anybody an engineer in the group? Okay. So, I’m sure you have a very organized booklet. They know how to do Excel spreadsheets and whatnot, but there’s a lot of different tools that you can use and one of those is this book five and we’re actually going to work on making that into an app. So, just a show of hands, I’m curious, how many of you own a smartphone, so a Droid or an iPhone. So, a good percentage of people. How many of you are on Facebook? Wow. Impressive. Okay. What about Skype? Right because you communicate with your family and your grandkids, right? And how many of you tweet? Exactly. Like who has time for all this stuff? I’m not a tweeter or a Twitter, I guess... that would be bad to be a Twitter I think, but tweeter. I think you’re a tweeter if you tweet, right? So basically what we’re trying to do is take book five which includes the tools for you to actually log and keep track of all of your information about your MDS in a digital format. It will also allow you to link to these resources that are live. If you go onto the website for *Building Blocks of Hope*, you’ll find these links that are live. So in the book itself on mine, you can click on this and it would take you to these healthy body/healthy mind websites which talk about wellness and diet and exercise and all the things that we just discussed. So, you can check that out. The web link is in your... I don’t think this is hooked up to the Internet here, so I don’t think I can do it from here.

I mentioned Audrey. So, this is her E-mail and the toll free number that is available to you through the MDS Foundation website for additional resources and information and she can link you to all sorts of people and things where it comes relative to MDS. I mentioned the MDS plan and then we’re going to stop there. We have a couple minutes before we break for lunch and then when we come back from lunch we’ll have really sort of a just an open discussion, answer questions if there are things that you heard this morning that weren’t really clear to you. We can go into that in more detail, but any other questions before we take a break for lunch? Anybody? Alright. Think about it over lunch. Write them down so you don’t forget. I encourage you to really chat amongst yourselves at lunch, so you might take an opportunity to share some of the things that (Attendee) was discussing earlier in terms of fears and thoughts or good outcome stories. So with that, we will take a break for lunch. The bathrooms are all the way down to the left apparently. You can grab something to eat. I think there’s a patio outside and we will see you back here at... Let’s see in an hour. Okay. Thank you.