Speakers:
Harry Erba, MD, PhD
Sara Tinsley, PhD, ARNP, AOCN

Audrey Hassan: Hi everyone, I think we're going to get started with our program. **Dr. Sara Tinsley:**, Dr. Sara Tinsley, will be doing the next talk and I don't know if I mentioned earlier, although Dr. Goldberg is doing a talk on the iron overload immediately following this program, as an added bonus he'll be speaking during our lunch. So, we will get the program started right now with Dr. Tinsley. Thank you.

Dr. Sara Tinsley: I am so used to correcting people from when they call me doctor, because I've been a nurse practitioner so I'm like, no no, I'm a nurse. I'm a nurse practitioner, but now I can say I'm a doctor. I have a Ph.D., but my area, I'm a nurse doctor and my area of research was Myelodysplastic Syndrome and AML in older patients and I looked, I compared quality of life with different treatments.

(Inaudible 5:58)

No, no. I'm like a Dr. Ruth. My patients call me, they said, "Do I have to call you doctor now?" and I'm like, "No, it's like Dr. Ruth, only I'm Dr. Sara, but you can just call me Sara." So, I have an independent clinic and I also work with Dr. Lance and Dr. List and some of the people you've seeing on the slides and I've been taking care of Myelodysplastic Syndrome, patients diagnosed with Myelodysplastic Syndromes and their families since 2004 and so I'm very happy and honored to be here and to discuss with you what you're journey is like in being diagnosed with Myelodysplastic Syndrome and so if you don't mind, I used to be terrified speaking in front of people, but I kind of had to get over that if I was going do this, so I got over it, but each of you have, I think there's a microphone every two people, if you'll, there's a little button you push and it turns red at the top. That's how you know it's live. If you could just, as we go around the room, if you could tell me your name and whether you're a family member and what your interest is in being here today and if you're the patient, if you want to share a little bit, like, what subtype of MDS if you know what it is and how many years you've been diagnosed and what your treatment is, if you don't mind. So, who wants to start? We can go around or we can go this way. So, I started. I'm Sara. I'm a nurse practitioner. I'm from Moffett and I'm here in support of all the MDS patients in the world.

Q1: Hi, I'm (Attendee) and I'm here in support of my sister who has MDS.

Dr. Sara Tinsley: Thank you, nice to meet you … now it's live.

Q2: My name is (Attendee) and my sister, (Attendee), has MDS and I'm here to support her.

Dr. Sara Tinsley: Very nice. Nice to meet you.

Q3: My name is (Attendee). I'm here to support my mom, (Attendee).

Dr. Sara Tinsley: A lot of support.

Q4: (inaudible)

Dr. Sara Tinsley: Hi (Attendee), and that's your mom, okay. (Attendee) is the mom, right? Nice to meet you.

Q5: I'm (Attendee). I was diagnosed January of 2008 with MDS and rheumatoid arthritis. I have to get two units of packed red cells every two week, no every 10 days.

Dr. Sara Tinsley: About every 10 days you need a transfusion? Have you been on therapies before?

Q5: I've had it all.

Dr. Sara Tinsley: You've had it all.

Q5: None of it worked.

Dr. Sara Tinsley: Including clinical trials?

Q5: I haven't tried them yet.

Dr. Sara Tinsley: Haven't tried any clinical trials, okay, but the blood is keeping you alive and how about, are you on any iron chelation?

Q5: Oh, yeah.

Dr. Sara Tinsley: Yes, so you're familiar with that.

Q5: Yeah, every day.

Dr. Sara Tinsley: Well, very nice to meet you.

Q6: I'm (Attendee). I'm married to (Attendee). The key thing that keeps her from going crazy half the time.

Dr. Sara Tinsley: You're the levelizer. You keep the …

Q6: No, I'm the instigator.

Dr. Sara Tinsley: Oh, you're the instigator.

Q6: We've been married …

Dr. Sara Tinsley: That's wonderful you guys have a lot of support around (Attendee). Very nice.

Q7: I'm **Lena**. I'm another sister. We are sticking together. So we're here to support (Attendee).

Dr. Sara Tinsley: That's wonderful. That's beautiful really.

Q8: I'm (Attendee). I'm just here for information for my dad. Just any information, helpful.

Dr. Sara Tinsley: That's great. So, your dad has Myelodysplastic Syndrome?

Q8: Yes.

Dr. Sara Tinsley: And does he have higher risk or lower risk disease?

Q8: High.

Dr. Sara Tinsley: High risk disease. That gets scary for you.

Q8: He was supposed to be here, but he wasn't feeling well.

Dr. Sara Tinsley: Okay, nice to meet you.

Q9: I'm (Attendee) and I'm here for support of (Attendee) and I'm here for all the information.

Dr. Sara Tinsley: Very good, perfect place.

Q10: I'm (Attendee) and I'm here in support of my uncle and to learn a little more and we're here in Birmingham and he's out of town and just how we can help from here.

Dr. Sara Tinsley: Okay, thank you.

Q11: I'm (Attendee) and I'm here in support of my friend, (Attendee).

Dr. Sara Tinsley: Very nice.

Q12: I'm (Attendee) and the patient, MDS, July of last year, basically found that, went through all, through the heart, started with the heart because the symptoms I was having, and so went through all that first.

Dr. Sara Tinsley: You had shortness of breath in the chest?

Q12: Yeah, fatigue and general practitioner finally pulled my blood records from January to July and noticed that the blood levels were tanking, so they referred me to East Alabama where we did a bone marrow transplant and found the MDS and my real concern now is, I didn't mind the diagnosis personally. I accepted that because of my faith, but I thought it would be a little better quality of life in this short period of time, so I don't know whether we found what we need yet or not, but three times… one time in the hospital four days, three different… two units of blood and I just got off six weeks of iron (inaudible 12:07) and ended up with 7.2 hemoglobin last week and ended up having to get two more units of blood, so the ups and downs, and the biggest problem I'm having I guess we'll get into, is breathing.

Dr. Sara Tinsley: The breathing.

Q12: I can't breathe. If I do any exertion whatsoever, so that's my real concern because then I can't get out and exercise, help my arthritis, so forth and so on, but so far this has been very informative. I appreciate you putting it on.

Q13: Might I add that my dad worked with (Attendee) here.

Dr. Sara Tinsley: Oh really?

Q13: I'll tell a story right quick. We ran into each other at the infusion, right before Father's Day, and I had seen him a couple weeks before, I couldn't talk to him, but anyhow, I asked the technician in there, the infusion specialist, I said "Is that (Attendee)?" "Well, we can't tell you that." I'm sure for privacy, so then she goes over to him to work on him and the next thing I know she's saying, "Well he just asked the same question?" So, we got reacquainted. We hadn't seen each other since probably quite a few years, but I was open to see him, and I'm glad his son mentioned that we're here for him.

Dr. Sara Tinsley: Yeah, you can get a lot of support from each other.

Q12: Trying to support one another.

Dr. Sara Tinsley: Yeah, I think so. Alright, thank you for sharing.

Q12: Thank you.

Q14: I'm (Attendee), (Attendee)'s sister, just here to be supportive and learn all we can.

Dr. Sara Tinsley: Very good, thank you.

Q15: And I'm (Attendee). I'm another niece in support.

Dr. Sara Tinsley: Thank you.

Q16: Well, thank you. I'm (Attendee) and I'm from Memphis and I'm here to support my mother who lives in California and was diagnosed with MDS about four years in October, 88.

Dr. Sara Tinsley: She's 88? And what's your dog's name?

Q16: This is (Attendee).

Dr. Sara Tinsley: Hi, (Attendee).

Q17: Hi, I'm (Attendee) and I'M AML and I was MDS and so there is hope and there is a future. Have a wonderful Lord and have wonderful doctor, Harry Erba, and I'm just thrilled to death that I found him and I bounced off the wall a lot with him, so and I've asked the light between just 90 degrees right and 90 degrees left, but I'm here today and I'm fine. So, there's hope, I've seen hope.

Dr. Sara Tinsley: Thank you.

So we'll get started, well we got started already. Thank you very much for sharing. I know it's intimidating with the microphone and lot of people in the room that's you've not met before. What I'm going to go over is *Building Blocks of Hope* and helping you, the patient and the caregivers, live with MDS and try to focus on the things that you actually have control over and be more involved with your journey. These are the nurses on the International Nurse Leadership Board. You'll notice they're from around the world: Australia, Japan, Germany. We get together when we have our international meetings which is pretty interesting to get a different take on it instead of just the United States.

So, when do we start treatment? These are treatment triggers. If you're getting regular transfusions like very two weeks and you're not on therapy, then sometimes that's a reason to begin therapy, or if your blood counts are changing. I've had some MDS patients that have been stable for several years and really we haven't started any therapy, we've just monitored them and then their blood counts start to change. Normally at that point is when we repeat their bone marrow and that's if they're having symptoms with it as well and that may be the trigger that says we need to change what we're doing.

As you heard earlier from Dr. Erba, those blasts in your bone marrow if those increase that is a sign that the disease is becoming more aggressive. Blasts are really what we think of when they're greater than 20 percent is that strict cut-off, going from MDS and crossing over into AML. The majority of MDS patients don't evolved into AML if they have lower risk disease, but overall we have more lower risk disease than higher risk disease, and if you're diagnosed… if you remember the stating system, the International Prognostic Scoring System, one of the things that we look at, not just the blood counts, but also the how severe the cytopenias are, what the percentage of blasts are in the bone marrow, and then the cytogenetic abnormalities or the chromosome problems that are reported from your bone marrow biopsy. If those indicate high risk disease then that can be an indication that a person needs to start treatment even if the blood counts are not that bad yet because in that case when you have higher-risk disease, you're trying to prevent that person from evolving into AML and improving their survival when you treat them.

We also look, we talked about this already today, too, the performance status. Do you have a good performance status or a poor performance status meaning are we going to improve your life by treating you? If you're very frail and very old then it might not be appropriate to start treatment if it's a disease that we're not going to make a lot of changes other than we could make things worse for you. We look at how many comorbidities. That's a fancy word for how many other illnesses you have and, again, the IPSS-R stands for Revised because it had more categories now and lower risk disease, the goal of therapy is to improve hematopoiesis. So can anybody tell me what that means? What does it mean improve hematopoiesis?

(Inaudible 18:39)

Yeah, improve your bone marrow's ability to make normally functioning cells, improve your hemoglobin, decrease your transfusion requirements, improve your platelet count, improve the cytopenias. So, that's what improving hematopoiesis means. For higher-risk disease, like I said, we're trying to improve your survival, trying to make it not so soon that you change from having just Myelodysplastic Syndrome to evolving into acute myelogenous leukemia. We also look on the, there's primary versus secondary MDS. Have you all heard of that? Primary versus secondary? No, yes, maybe?

Q18: Yeah, I think I mentioned it earlier, the diagnosis by the hematologist, he's at (inaudible 19:42) Medical Center in Auburn, mentioned that she thought the other end was secondary based on the, possibly, the drugs that I was taking for RA, and she mentioned…

Dr. Sara Tinsley: Like they're caused from another type of chemotherapy…

Q18: … may or may not be, but then I came here and I think it was Dr. Barrett, who was here, I think she's gone and she concurred that I've got both of those. That's what they diagnosis secondary cause.

Dr. Sara Tinsley: Secondary meaning, this is a type of Myelodysplastic Syndrome that is caused when you've had treatment for another condition, another malignancy and sometimes not for malignancies, but we tend to think that if you've had another cancer and then you got treatment for that cancer or sometimes that the drugs we use for immune disorders can be in the class of chemotherapies, but the treatment for that disorder caused another one and you all may be familiar with Robin Roberts that's been on TV? She had secondary MDS. So, she got treatment for her breast cancer and then she developed Myelodysplastic Syndrome from that and then the cytogenetic status we look at. Dr. Erba talked about deletion of the long arm of chromosome 5 and how we use Revlimid for that and complex karyotype. That means when they look at those little squiggly lines with all those chromosomes and how they line them up, the cytogeneticist lines them up, when there's three or more abnormalities, that's when we call it complex karyotype and that's associated with more aggressive disease when you have three or more chromosomal abnormalities in your bone marrow.

And then we look at your lifestyle. I have patient now who we're treating with, he had AML first and now he's back into a Myelodysplastic Syndrome state and we recommended transplant for him, but he's a CEO of a company and it's very important to him that even if he could be cured with a transplant, he wants to continue to try to work as a CEO and right now his therapy includes a hypomethylating agent and that's allowing him, even though it's not his best chance of being cured and we don't know about survival because his disease did it the backwards way. He had AML and how he went into MDS, but by treating him with Azacitidine every month, we're controlling his blast percentage to where he can… and his blood counts, he's not getting regular transfusions or having infections that he's able to maintain a relatively work habit to where he's able to enjoy his quality of life and that's also his personal choice.

The key principles that we do now that allogeneic bone marrow transplant is the only potential cure. You heard that this is not an option for many patients. You have to have a donor, you have to be healthy enough. Sometimes just based on age you'll be excluded from a transplant. I think at Moffett our cutoff age is 75, and I think there are different ages set across the United States where people can get an allogeneic transplant, but you do also have to have an HLA identical donor, which not everyone has one of those, but we do all agree that age alone should not exclude active therapies. If there's a 70-year-old that's fit and has a donor and everything's lined up then transplant may be the appropriate for them. All active therapies for Myelodysplastic Syndrome require time and what that means is that you can't just get one cycle and say you've failed. You really have to administer these treatments, you heard there's three FDA approved drugs. There's Lenalidomide, Azacitidine and Decitabine. With all of these therapies it takes months before you will know, before you will know whether it's effective or not. For most of them we wait four to six months and in the first two months of therapy, the blood counts can actually get much worse before they get better and so if you have somebody that you know well that's going through therapy and they're feeling very discouraged, but they're in the first two

months of therapy, then it's still early. We haven't had enough time to know if it could help them or not.

My job really in my clinic is proactive management of the side effects of therapy. With Azacitidine you may be familiar with it causing constipation. That's what we hear and so I advise patients that this could be a potential side effect and to start taking something to keep their bowels moving regularly, like even starting the night before they start their next course of Azacitidine. They can also have some nausea. We give antiemetics prior to the Azacitidine to prevent the nausea and vomiting and then really scheduling patients in clinic on a regular basis to where they can come in, I can look at their blood counts and determine, and their symptoms, and determine whether they need a transfusion or advise them about neutropenic precautions. Are you all familiar with neutropenic precautions, and know how to read your neutrophil count? Yes, no, maybe? Yes, so when the neutrophil count is less than 1,000, that's technically neutropenic, and then when it's less than 500, that's severely neutropenic. So, we go over what our neutropenic precautions, what are the risks of neutropenia and what can you do to stay healthy while you have neutropenia and I think that helps with the anxiety that can go along with that. Does anyone have a story like with their neutropenia?

In the *Building Blocks of Hope*, there are recommendations for how to deal with the different cytopenias associated with Myelodysplastic Syndrome, so I would refer you to that and I think you all got that in your packets today. There's also an online version of that that you can download.

So, why is time required for all these active therapies to work? Before the treatment begins your blood counts drop at the MDS progresses and the normal blood cells are crowded out by these abnormal stem cells in your bone marrow and in your blood and you can see on the right there the neutrophil count, ANC, refers to absolute neutrophil count and how those go low in the beginning there, right up in here, and then come back to more of a functional neutrophil count and as the therapies start to work and clean the marrow of these abnormal cells, the blood counts drop and your blood counts can get worse before they get better. And then as the patient responds, the bone marrow begins to recover and allows your marrow to make more of your normal cells and that should help improve your symptoms.

And this is really important I think as far as a patient's schedule. In the beginning the first two months of therapy, we have some patients that are on a clinical trial trying to determine what the best number of days of Azacitidine is to administer for low risk disease and many of the people that start on this trial are needing blood transfusions like every two weeks or every ten days like clockwork, like we typically see with low-risk disease and so I schedule them with appointments to be checked by me or by another nurse practitioner in our clinic, so we can determine when they need a transfusion and intervene before the symptoms get so bad. If your hemoglobin's getting lower and lower, you usually don't feel so well although some patients tolerate it well and then the more months of therapy that they're on this clinical trial, I'll actually weened them

off of their every four week visits, I mean every two weeks visits, to once a month, just when they receive their therapy because their hemoglobin is now 12.2. So, that's one of the ways that we determine that's it's working as well is when the hemoglobin, they were getting transfused every two weeks and then suddenly that third or fourth cycle of therapy you notice that they didn't get a transfusion two weeks ago and the hemoglobin went up to 10.2 on it's own and so that's when you start to feel very optimistic that the treatment you're giving is working and then when you see them again that the hemoglobin is higher and these early toxicities can be difficult and discouraging like we talked about, but you really want to be supported through those first two cycles of any of these active therapies so that you can maintain, stay on the medications, long enough to see if you're going to have a response at four to six months.

So, time is required for your best response. A minimum of four to six months. The cytopenias or the low blood counts, the neutropenia, anemia, thrombocytopenia, low platelet count often gets worse before it gets better in those first two cycles and during this time we might have to modify the doses and for sure the supportive care with the transfusions, if you're having nausea and vomiting side effects. There are medications to prevent nausea and vomiting and then administering them on a schedule if you're experiencing that side effect. And also in the beginning setting the expectations that we're going to start you on this therapy, things are going to get worse, but they should get better if you're responding around the four to six month mark.

This is just an example, one of Sandy Kurtin's patients that has had a response to therapy and it took four cycles of Azacitidine before that occurred. And this is one of her patients, I think you have 5Q minus who's on Lenalidomide that has had over 10 years of response and you'll notice if you look at those graphs, the hemoglobin is in pink, so this person who's been on therapy for over 10 years has a hemoglobin that started out in the beginning you notice it went from nine down to 7 1/2, but now that hemoglobin is up in the 12 gram range. I don't know if you can see that. Over here, this is the start in 2002, and this is where she's at now, if you look at the hemoglobin, and you'll know though that the other cell lines are a little lower and that is very characteristic of treatment with Lenalidomide. The white blood cell count and the platelet count may be run a little lower than what they were before they were on Lenalidomide, but it helps improve the hemoglobin to where this person is not requiring transfusions.

So, what can you do to stay healthy? I really try to hit on this with my patients as far as you don't have any control about your disease. A lot of times we don't know what caused it, but once you're diagnosed, I think, you can do a lot of things that give you back some of the control of doing as much as you can to keep yourself healthy. A balanced diet, daily exercise or some activity. I realize if your hemoglobin is in the seven and eight gram range, it's very hard to be active. So some of the patients that I see, if they, if it's unreasonable to expect them to take a walk every day, which many of them it is, even just scheduling regular activities where you're more active like every two hours, you know, stand up and sit down like 10 times. Some kind of structured activity that gets you moving or upper body some of those bands for stretching, for

keeping your muscles active. Things like that over time can really make an impact as far as making you feel like you're doing something to stay as healthy as you can.

Avoiding infections. When patients have a neutrophil count less than 500, we normally recommend that they wear a mask, but if your neutropenic for years, that might be an individual choice, and we do have people with Myelodysplastic Syndrome who have a neutrophil count less than 500 almost their entire disease and so they can… as long as they know they're neutropenic, then I let the patient's decide if they want to take the risk if they don't wear their mask, but we generally avoid going into crowded areas where there's lots of other people during cold and flu season where they could get infected with something that we don't have a treatment for.

Avoiding bleeding. We go over the different types of medications that interfere with your platelet function, like you're nonsteroidal anti-inflammatories. Can you tell me some of those? Aspirin for sure, what about Advil, Aleve, those types of medicines, so I go over medications very closely to make sure that things you're taking on a regular basis. If you have a low platelet count that these are medications you should avoid and also when you're neutropenic we usually will advise you to monitor your temperature to see if you're experiencing a fever and making sure that you contact us quickly, you know, if you're having an elevation in your temperature greater than 100.4 and that you know the numbers to call if you're having an event like that. That will help if you're planning for it, then when it happens then it won't feel so like a panic attack, you know, like you're preparing for worse case scenario, but living like as good as you can and I really try to encourage patients to do the things that they enjoy still. I had one individual who hadn't been to church in like two years because she was concerned about being neutropenic and being exposed to other people at church that could make her sick and so we had a discussion about that, about ways she can minimize her exposure to other people who are infected, like maybe go to a service that's not as busy, you know, or maybe not shaking everybody's hand or if someone's obviously sick avoiding them. Those type of things that really make a person feel normal are really important considerations, you know, as far as their quality of time, quality of life, with the time that they have available.

And then take advantage of the available resources. You have this *Building Blocks of Hope* that there's lot of really good information there that will help you, guide you through this journey. Also asking for help when you need it. If you're not able to do your normal activities, to reaching out. It's wonderful that you all have like a whole group of support with you, really, very nice. I admire your family. I just hope one day if I get sick I have really good support. That's beautiful.

And then to be an active participant in building your own hope. Try to look at the things you can do something about. There's this MDS manager that's in your book. It's on, I think it's Chapter 5. There's an online version of it that you can download, an app I mean, that you can go to that app store and it's free and it helps you track your progress if you're interested in that. The exploring, in the *Building Blocks of Hope*, it helps you understand your disease. Know what your stage of your disease is, know if you're low risk or high risk and it goes over the treatment

options, what the schedule is, so Azacitidine and Decitabine are normally given every four weeks. So, you get a week of treatment. Lower-risk disease we normally give five days of treatment, higher-risk disease we normally give seven, and then you get three weeks off, so trying to structure your life around that and plan events that are important to you. Looking at the potential side effects of those treatments and how to be prepared for potential side effects and the strategies for managing those and, again, asking for help, and becoming a partner in your MDS journey.

So, this is the tab. It's tab 5 or Chapter 5, Your MDS Plan. It has a transfusion tracker on there and also a treatment tracker, so you'll know when you received treatment, when you'll be due again. So, if you have a smartphone or a tablet, you could go that app store and look for My MDS Manager. It has professional and personal contacts all in one place. You can track your symptoms. Many times when you show up at the doctor's office or some of the patients I see, if they've been waiting a time, you know, in the waiting room for a long time, they don't want to be in there with me for a long time, so they tell me everything's fine when actually they may have had a lot of symptoms. So, this symptom tracker can help, you know, put it on the top of your queue to remember to bring it up at your scheduled appointments. Medications with reminders. Tracking your labs, your transfusions and treatments and you can even download the reports to print and take to your visit and there's also an opportunity to participate in this virtual support network. You have to have a Google account, but it's putting people together based on their IPSS-R risk category and comorbidities to where you can meet other people that are in similar situations with you and you can get support that way and you get live support through the MDS Foundation.

And then Audrey, I don't see her in here, but you all are familiar with Audrey as she's the patient liaison and you can call her or E-mail her directly. She sends out links to clinical trials that are available to us that are at Moffett Cancer Center and I can inform patients that are looking for a specific clinical trial that the physician thinks will benefit them and I can direct them there.

And, let's talk about you. That's all of my structured slides. So does anybody have questions, comments, concerns?

Q19: You were speaking about a fever and taking Motrin. What would be… my dad's been running like a 100.7 fever up and down. What would be something good that he could take to break that fever? They say call and he's called the hospital and that's what they tell him to take.

Dr. Sara Tinsley: Normally if the platelet count is not an issue, they may, your health care provider may think Motrin is fine. We normally would have a patient hold Motrin or any of the class of drugs categorized as nonsteroidal anti-inflammatories, not to administer those when the platelet count is like less than 50,000 and we… as long as he's been worked up for an infectious ideology and he's otherwise stable, you know, and has checked in with the health care provider, we do allow patients to take acetaminophen.

Q19: Right, and he takes the aspirin for his heart daily, so that would be the same thing?

Dr. Sara Tinsley: That one is a tricky because it is a nonsteroidal anti-inflammatory so it makes your platelets not stick together, so really you want to talk to his cardiologist and his… the doctor that… his hematologist to see the risks and benefits of the aspirin because some people with, who have fresh stents that need to be on aspirin then even if their platelets are low we've continued that, but that's a case-by-case kind of …

Q19: Individuals

Dr. Sara Tinsley: Individualized approach, yeah, based on his health problems and what's going on with him.

Q19: Thank you.

Dr. Sara Tinsley: You're welcome.

Q20: I have the same situation. I'm on a low dose.

Dr. Sara Tinsley: Low dose aspirin?

Q20: Yeah, but I have to follow up with the cardiologist in about two or three weeks, but I had another question. I experienced a… I guess probably several weeks ago, where I couldn't swallow and even water would hang right here and then I'd spit out what was in my mouth and ease the other down. I couldn't hardly eat. I lose about six pounds. Nobody seemed to know. Well, I finally asked for a scope and my intestinal track was significantly covered with fungus, yeast infection.

Dr. Sara Tinsley: Yes

Q20: and the surgeon that did the scope put me on an antifungal which has helped, but he said stay off of it for a while. Then he wrote me another. It's come back a little bit, but is that a fungus infection, can it be elsewhere, spread elsewhere from lungs or whatever?

Dr. Sara Tinsley: Normally, you can if you have prolonged neutropenia, patients can be more prone to overgrowth of, or sometimes invasive fungus, or fungi, they're not fungi though, it's not fun, but you can… and also antibiotics when you're on antibiotics that can make you more prone to yeast overgrowth.

Q20: What about steroids?

Dr. Sara Tinsley: Steroids definitely can do that also.

Q20: We made a change in steroids with my rheumatologist. We went from Prednisone to Decadron and I'm wondering if that, because the Decadron oral tablet was .75 mg and… but I also was not longer after four days in the hospital and about six bags of antibiotics that this began, so I'm suspecting it was a combination.

Q21: And which my dad had encountered the same things as (Attendee) there.

Dr. Sara Tinsley: Something similar with the yeast overgrowth or he got antibiotic and then...

Q21: In the throat and it was hard for him to swallow.

Q20: It's awful. Thank you.

Dr. Sara Tinsley: Thank you for sharing. That can be a side effect of… Well, sometimes you can get yeast just from having a compromised immune system, but steroids and antibiotics are known problems. So, thank you.

Do you have anything to add, Dr. Erba?

Dr. Harry Erba: I have a question. One thing that I find my patients (inaudible).

Dr. Sara Tinsley: Did you all hear the question about the neutropenic diet? Like if you're, there's a specific diet that's, I agree there's a lot of controversy about the neutropenic diet and that means that if you're neutrophils are low, some places use less than 1,000, some less than 500, your absolute neutrophil count then they will tell you you can eat any fresh fruits and vegetables and you can only have cooked meats and if you have these certain types of foods then you're going to really put yourself at risk for infection. I did that, I wrote that part of the Staying Well, in the MDS, the *Building Blocks of Hope* and the recommendations are not based on science. It's just based on thinking that one type of food is going to make you infected. So, what I advise patients… so there's no science, there's no data to tell us you need to eat and follow this diet and you're not going to have problems or you're going to decrease your risk of getting an overwhelming infection. It's just people make up what they think is the best thing to do if you're neutropenic, so in our institution for the transplant unit, they do have a low microbial diet, but they still have fruits and vegetables that are well washed under running water, there's a specific amount of time that they're supposed to wash their fruits and vegetables, even your thick-skinned fruits, cooked meats, but so I kind of, I talk them through it, I get the dietician involved and refer them back to the Building Blocks of Hope. What do you all do?

Dr. Harry Erba: So, I am not a believer in the modified microbial diet for patients who have MDS and AML who are not on the donor stem cell transplant and there are multiple reasons for

that and one reason is that there is no scientific proof that if you have a piece of lettuce on something that you're going to get sick from that. The second is at first time it makes sense. Everyone has seen those commercials about (inaudible 48:10) bacteria on a piece of lettuce, things like that, trying to wash it off, but at first glance it makes sense. Obviously you're not going to eat that. They've been eating it all their life and are told (inaudible) and you're not going to get rid of them. In fact to get rid of them is not good to get rid of the normal flora of your intestine and so it never made sense to me (inaudible) makes a difference and then the third it's not only is there assumption that it's beneficial and not harmful to have a low microbial diet if you wash you (inaudible) fresh fruits and vegetables, but there's an assumption that connects (inaudible) and I'm not so certain. I've had plenty of patients who have very well regulated (inaudible) patterns and eat a lot of fiber in the diet and then they come see us and we put them on anti-nausea medicines, chemotherapy, sometimes put them in the hospital and say you can't eat anything, keep your bowels going and you wonder why they all get constipated and I'm not certain that's not a bad thing for you actually, straining, have a bowel movement (inaudible) it tears and bacteria get in. So, I'm not even certain that it's without harm to tell people to have a low microbial diet. So, I actually spend much of my time dispelling the fear about a low microbial diet.

Dr. Sara Tinsley: It is a topic of discussion a lot about what can I eat or not eat and so... Did you all hear his response? Okay, good. So, I think its past time to eat. Are you all hungry? If there's no more questions then I think we'll have some lunch. Thank you.

(Applause)