



## Quality of Life Session

**Gainesville, FL February 25, 2017**

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Speakers:

Christopher R. Cogle, MD

Preeti Narayan, MD

Christina Cline, RN

Damian Alderman

**Christopher R. Cogle, MD:** Welcome back. Thank you for the rousing discussion we just had. We'd like to bring forward Christina Cline who is our clinical research nurse. She's an RN who's been doing oncology nursing for many, many, many, many years and has lots of experience both in the inpatient and outpatient setting. So, Christina, thank you for talking with us today about quality of life.

**Christina Cline, RN:** Thank you. Again, thank you for having me and thank you for allowing me to join you today to present some information to you. So, this is some information presented by the MDS Foundation and it's a *Patient and Caregiver Guide for Living with MDS*.

So, one of the questions we ask is when is the best time to start treatment? What are some treatment triggers and when do we start the disease modifying therapy. So, we MDS is based off of the individual disease characteristics, patient characteristics and, of course, the risk category and one we begin transfusion dependence, we want to monitor for progressive or any symptomatic cytopenias – do we see any blasts that are increasing in the blood as well as identifying if the disease is transitioning to high risk. So, individual treatment selection is the key and we identify this through some of the performance status that we do based off of fit versus frail as well as the comorbidities and, again, the IPSS risk category which identifies you into the four risks listed there on the slide as well as the kind of lifestyle that you have and your personal choice.

Key principles in therapy of MDS is allogeneic bone marrow transplant remains the only potential cure. Of course, it's not an option for many patients because age, donor availability also plays an important role in this as well as any comorbidities that patients may have. Age alone does not exclude therapies, but we are grade performance status. How long are you able to stay out of the bed, are you able to obtain activities of daily living? Fifty percent or more of the time are you in bed? So, these are things that can... we grade performance status off of. Comorbidities. So, if your overall organ function is it safe to take you to transplant. So, those alone can also impact whether transplant is suitable for you or not.

All active therapies in MDS require time to work and continue to indefinitely... and will continue indefinitely if they're not working. So, a lot of times it gets worse before it gets better. So, you start treatment for your MDS with Azacitidine, Decitabine and you notice that your blood counts are not coming up right away. They're kind of... they're getting lower. You're



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feeling more fatigued. You have shortness of breath and what we really encourage our patients is that to at least five four to six cycles of this therapy because eventually you see a dip in your counts, but then your counts start to come back up and they start to plateau and that bone marrow starts to make good cells. So, but again the blood counts often get worse before they get better. So, be prepared for that and mentally get yourself set to work through that because it does get better as you continue with the treatment.

Proactive management of the side effects early in the phases is also key to obtaining a good response. Some physicians may delay treatment a little bit to give your body some time to recover from the cytopenias that you have. You may need frequent blood transfusions still or platelet transfusions and that's okay because we want to give your body that support that it needs until it's able to do these... to come back to making these good cells on their own.

So, before treatment begins the blood count drops as the MDS progresses because the normal blood cells they're crowded out by these abnormal cells in the bone marrow and then when treatment is initiated that treatment is basically cleaning the marrow and the blood counts continue to still drop and then that's when you start to experience the hematologic toxicities such as the low platelets and the low red blood cells as and your neutrophil count also drops, too. So, your immune function, of course, does not have the ability to fight for infection and keep you safe from infection like it would when it was healthier.

So, as a patient... as you begin the therapy the bone marrow begins to recover and, again, this is that dip that I was kind of talking about earlier. So, your bone marrow takes the hit with the treatment and this is where you start to experience those cytopenias but then your bone marrow as you see starts to make good cells that then plateau out and your symptoms should start to improve. You start to not feel as fatigued as you were. You should start to be able to feel that you can kind of resume some of your activity of normal... your normal activity of daily living.

So, as the response continues, we can also begin to reduce the number of transfusions that you may need. We also can maybe completely take you off antibiotics if you are no longer are needing that antibiotic support because your neutrophil count is now coming back up and you're able to have an immune system that's able to support your body.

When you first begin treatment the toxicities of the cytopenias can be discouraging. You're having to come to clinic more. You're getting blood transfusions. Now, you're taking more medication. You might be taking some growth factor if your physician feels that you need some growth factor. Treatment might be delayed. So, there can be some toxicities that can be seen in the beginning that can be very discouraging, but we do encourage our patients to work through them to follow through with their transfusions to be compliant with the therapy because your



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body does begin to respond and hopefully have a good response towards the end after the four to six cycles are received.

So, key principles of therapy for MDS. So, time is important and this slide indicates a minimum of four to six months that allows the body to recover. So, again, the cytopenias they do get worse, but strategies for getting through these initial cycles are knowing this up front, being prepared. The more prepared you are the more knowledge you know, the more empowered you are with your care and moving forward as well as knowing that, yes, doses can be delayed, doses can be modified. Maybe it might... maybe you have a slight intolerance to the drug and the drug just needs to be reduced and now you're able to respond better. That can be done. It can also be delayed for a period of time to give your body the amount... an appropriate amount of time to begin recovering and as well as supportive care – blood transfusions, platelet transfusions, any antibiotic support that may be needed to provide support to your body.

I'm sorry if I'm talking a little too fast. I just... So, does anybody have any questions about this initiation of therapy up front or...?

**Q1:** I have a question about ANC. (inaudible 10:07 – 10:18) to me it looks like too... in the normal range.

**Christina Cline, RN:** I think that's going to be more off institutional policy practice as far as what their institutional practice is feeling that the flu shot is appropriate.

**Preeti Narayan, MD:** Some are uncomfortable with certain levels and (inaudible 10:34) usually I think around (inaudible) sometimes that works, too, but some other places want to hold it longer. So, it could just be that (inaudible 10:43).

**Q1:** Thank you.

**Christina Cline, RN:** But an ANC of 2,000 is great.

So, becoming a partner in your care and building your MDS plan. So, tools and strategies for success is to maximize each treatment option and become a partner in your MDS journey. Ask for help and to explore the *Building Blocks of Hope* which many of you, I hope, have a copy of and learn how to track the progress of your MDS. They have an MDS app manager... manager app that I'm going to talk about a little bit later that will also be able to provide some information on... and provide some tools and strategies for helping you.

So, to understand your disease. How can we maximize your treatment options? The first thing is to understand your disease. I know we keep repeating this IPSS/IPSS-R risk category. It's very



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important to know where you fall in this category, also to become familiar with the language. Know what hemoglobin, white cells and neutrophil counts mean. Get copies of these results from your physicians when you go to see them so that if you do get referred to another physician you can share that history with them as well because history is very important and also getting tools to help keep you on track. *The Building Blocks of Hope* has a lot of information in there that can help you track your MDS as well as this MDS manager app that I'm going to talk about a little bit later and then now we're coming into the world of technology. So, electronic health record patient portals are also becoming more frequently used to help you keep track of your care, see your bone marrow report, see your lab reports, any MRIs or CT scans, things like that that might be taking place.

So, we want to get the most benefit from your treatment. So, in order to get the most benefit from your treatment compliance is big. You wanted to make sure that you're taking your medications. You want to make sure that you are showing up at your appointments and that you are taking... being compliant with the treatment that you're receiving. If you have symptoms that are outside of what your normal baseline is it's really important to share those with the healthcare team including the mid-levels, the physicians, the nursing staff so that they can be reported immediately and you want to track your symptoms and I think this MDS manager app actually allows you to track your symptoms as well. So, you can see if they are getting worse or improving throughout the days. Also, ask about goals and expected duration of treatment. How long do I have to receive this treatment? What is expected of me while I'm receiving this treatment? And also ask about financial assistance programs in case some of these treatments aren't covered by your insurance or if there's an out of pocket cost that may be too... may be a financial burden. Are there programs out there that can help reduce some of these financial costs?

Most importantly what can you do? You can stand up for your own health. Knowledge is empowerment. I can't stress that enough. The more you know the more you're an advocate for yourself and it's important to take an active role in your healthcare. You ultimately are making the decision. We are here to help and to treat and to provide medical advice, but ultimately the more you know the more power you have to make a decision that best fits your needs. For instance, clinical trials. Clinical trials require additional visits. Sometimes they require additional testing. Is that... do those fit your needs? Is that something that you have the time to commit to? So, these are questions that you should ask yourself. Have honest and open discussions with your healthcare team and make sure that you are very clear on what you want and what you expect out of the treatment, what your wishes are as a patient who's receiving the healthcare and be prepared for each visit.

So, the best treatment for the patient. This is shared decision making which can help guide patients and caregivers to included individual preference, goals and values. How to make the



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most out of every office visit. So, set an agenda. Ask yourself what do I want to get out of this visit? Write down things that you want to discuss. Sometimes you see a PA or your see a nurse before you see the physician. If they bring about some information that you have some questions, write those questions down for your physician when your physician comes in to see you after they've discussed something with you. It's very important to write down information and ask questions and focusing on the agenda will help to make the best of your time. Prior to coming to the visits, write down any questions you might have for your physicians. If you have any side effects that you might be experiencing that you weren't previously experiencing, what can you expect from the treatments as you continue to further go along? It's important to write a list of questions and prioritize them and take them to your doctor as well and it's always important to bring a member of your team with you, your wife, sibling, brothers, children to take notes and also listen because sometimes they hear things that you might not hear because it can be overwhelming information all at one time sometimes.

Bring information to share with the healthcare team. Update your provider on anything that's changed since your last visit. Some patients they have a primary care doctor that's local and then they might come see their other primary care doctor here at another center. So, make sure that you're communicating what's happening between both of these physicians because sometimes they don't always communicate amongst themselves or get records in time. So, update your provider on anything that's changed since your last visit. It's very important to keep an updated list on medications that you're taking, when you start them, when you stop them because it also helps us to identify if there's any interaction with medications that are going on that might be causing some side effects especially if you're taking any over the counter medications, vitamins, herbs or supplements. Also take notes on some of the symptoms and side effects that you're having. If you're having anything that's not norm or you started to have more headaches frequently then let your physician know about that. You're starting to feel tired more even after a nap. Let your physician know that these changes are occurring. Bring any test results from your other healthcare professionals that you could be seeing and any transfusion records if you're receiving any transfusions outside.

So, we definitely want to make follow up appointments and we definitely want to have a clear understanding of what the treatment plan is. If you're on a clinical trial when are your next clinic visits? What are going to be happening at those clinic visits? Is something going to require you to be here all day versus only being here for a couple hours. It helps you prepare for the visit. Also, any instructions that you have for taking new or existing medications. If a physician is adding a new medication for your treatment why are you taking it? It's important to have an understanding on why you're taking these new medications or why you might be asked to stop taking a certain medication. If you have any referrals to other providers having an understanding on why you're being asked to go see another provider and always listening to the do's and don'ts. All symptoms should be reported. If you get a fever, where do I go? Who do I call?



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What's an office number? Those are important emergency contact numbers to have on hand in case something arises. A lot of times if fevers are reported and your immune function is low we want you to go immediately to the ED. So, it's important to contact your clinical and let them know what's going on so that you can be instructed further on how to manage them.

Caregivers are essential in the care of our patients and they focus on your needs, too, and it's important for caregivers to maintain a healthy lifestyle, to exercise, to get enough sleep, to be relaxed as well as some of the other things that they talk about – intimacy, spirituality. Caregivers feel this, too. They walk through this journey with you as well. Some caregivers also can experience depression and it's very important to seek treatment for depression and anxiety, but it's important to keep a balance throughout each day. Being a caregiver, asking for help with some of the things around the house, seeing if family members can maybe come in and help cook food. I know a lot of people reach out to their community churches and their community churches do a lot to help alleviate some of the stress as the caregiver as they're taking care of their significant other.

So, asking for help. Lots of helping hands. Here's a URL on how to access on the Internet to help with for help for the caregivers. Also there's a help calendar there that posts specific request for support and members of the community can also find ways to volunteer.

So, here is how this works. So, one person... I have not actually gone on this website myself yet, so this is the first time I've actually seen this. So, one person will sign up to coordinate the calendar. It takes a few minutes and it seems to be very flexible where changes can be made. Coordinators, it looks like you can add your name and E-mail addresses of family and friends and then you can also add the needs such as your rides, meals, things to that sort on the group calendar and then friends and family are able to check to see what that need is to sign up. Pretty interesting. And the calendar will update as well as to who's volunteering. I'm going to have to actually go log onto this site.

So, what things can you do to stay healthy? Well, enjoy the things that you love and live. Ask for help when needed and I know this can be sometimes this can be very hard because we're all very independent and then when something enters in our life that ails our independence asking for help can be very hard. I broke my arm not too long ago and my husband had to do a lot of things for me that I was like I just wanted the opportunity to do it myself and I felt that those were taken away from me. So, it's very important though to ask for help when help is needed. We want to have a balanced lifestyle. We want to try to eat good. We want to limit any alcohol. We don't want to smoke and if smoking is something that you continue to do there are lots of support groups out there. There are patches. There are lots of things that we can do to help get you to no longer smoke.



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Activities of daily living. Daily activity and exercise is very important and also will help with fatigue and also resting can help with fatigue throughout the day, too. If you're feeling fatigued take a little nap and that can also help alleviate fatigue. We want to do our best to avoid infection. When our immune system is low we're no longer able to fight infections like we were prior to and so making sure that we avoid large crowds, wear mask, try to not engage with loved ones when they're sick or be around people when they're sick and always wash our hands and also other ways to avoid infection also is with the kinds of food that we eat. We want to make sure our food is clean and we want to wash our fruits and vegetables and things like that. Make sure our meat is cooked all the way through. Avoid buffet bars when our immune function is low. Certain cheeses and things like that and also we want to avoid bleeding. When our platelets are low we're at risk of bleeding and we want to avoid activities that could potentially increase the risk of bleeding. We want to make sure that you, men, when you guys shave your face and you're not shaving with a straight razor or anything like that and you also want to make sure that you get enough rest. Rest is very important for our body to recover and recoup. So, learning to manage and report these symptoms are very important.

So, what can you do to stay healthy and with your lifestyle choices. So, again, lifestyle plays a very important role in your physical and mental health and you can help manage and lessen these side effects. You can keep your immune system strong and you can also improve emotional outlook as well. Decrease the risk of other medical problems that can complicate your health and fitness is a key. Walking could be very important factor in helping to keep the ability to continue treatment.

Again, exercise is one of the single most important ways to overcome fatigue. Sometimes your physicians have programs that they may be able to offer you. Strengthening exercise is very good. There's thing that you can do when you're just sitting around in your house that can also help strengthen your muscles and help fight fatigue. Also like I said earlier walking is also very beneficial to helping fight fatigue. Make sure you definitely get enough rest and if you're not able to sleep then make sure you communicate that with your healthcare team if you're not able to get good rest during the evening hours. We want to make sure that we also have good... just lost my train of thought there. Sorry. But regarding sleep. So, we also want to make sure we develop good sleep habits and eat light meals before we go to bed. Have dark, quiet and comfortable settings as well. These settings can help you relax.

Nutrition. We want to look at some of the nutrition that we have to staying healthy. We want to also stay hydrated. Drinking is very important. A lot of times as we get older we tend to drink less. So, we want to make sure that we drink lots of water, lots of fluids that can help us stay hydrated as well as having a balanced diet. Foods that we want to avoid are processed foods, foods that are very high in fat and very sugary foods. You also want to limit your alcohol intake



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and avoid fad diets and you can also communicate with the healthcare team on any food restrictions.

**Christopher R. Cogle, MD:** Can I ask about... You didn't talk about red meats, restrictions, iron.

**Christina Cline, RN:** No, (inaudible 27:50)

**Christopher R. Cogle, MD:** I would just add to that nutrition slide for those of you that are getting lots of red blood cell transfusions we recommend trying to limit the amount of red meat we eat to limit the amount of extra iron. You don't want to me taking a multi vitamin with iron in it if you're also getting red blood cell transfusions. So, just keep that in mind, too.

**Christina Cline, RN:** So, how can we avoid infections? I've covered most of this information already just a couple slides back, but you want to make sure that we avoid people who are ill and we want to wash our hands often. We want to wear masks, avoid large crowds when our immune function is low. If you develop a fever we want to make sure that we notify the healthcare team right away and talk to your healthcare team about symptoms that need immediate attention.

For immunizations, this kind of... that gentleman over there was asking about the flu shot. Dr. Cogle, his ANC is 2,000 and his, I think, provider was hesitant on giving him a flu shot an ANC of 2,000.

**Christopher R. Cogle, MD:** I'm so glad. Did you bring this up?

**Christina Cline, RN:** The gentleman sitting right there.

**Christopher R. Cogle, MD:** We're missing each other. Great. I'm so glad you got the flu shot. If it's a shot, it's a dead virus. So, there's no risk of somebody getting an infection from the flu virus. Any kind of reaction that you get means that your body's just been tricked into thinking it's flu and that's actually a good thing because it'll be prepared for the next time when the real thing comes by. That's the first big question. The other question to have about it is do you have enough of an immune system to mount a response to the injection and a lot of times when people's immune system is very low especially after right after a bone marrow transplant the thought is that the new immune system is not up and running yet. So, it's too early to give an injection, but for people that are on chemotherapy your immune system is not knocked down that low. We still recommend getting a flu shot even if you're on therapy, but we like to give it up when your counts are recovering mostly for platelet reasons more than anything else.





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**Christina Cline, RN:** So, we also want to get our pneumonia vaccine as well as the... there are two pneumococcal vaccines that are recommended for adults and you want to also... the shingles vaccine is generally not recommended for patients who are immune compromised and we ask that you have talked to your provider before you get a shingles vaccine.

**Christopher R. Cogle, MD:** Yeah. That's live virus.

**Christina Cline, RN:** It's a live virus.

So, what can you do to stay healthy and avoid bleeding? Well, we want to try to know that if your platelets drop below 50,000 you are at risk for bleeding and we want to monitor those blood counts at each of your visits or when clinically indicated. We also avoid aspirin and aspirin containing medications. If you are any of the following blood thinners then we want to talk with our healthcare provider about the medication schedule.

Managing your comorbidities. You want to stay very involved with the primary care provider and specialist and managing the diagnosis also necessary to stay well. So, we really encourage you to keep a list of providers that includes all of their contact information including facts and phone numbers and now E-mail because a lot of us can communicate via E-mail and you can share this information with all of the other providers so that they're able to communicate amongst one another involving your care because you can be seeing many physicians for many different things.

Palliative and supportive care for cancer. The World Health Organization recommends that patients with life threatening illness could that they can benefit from palliative care and the focus of palliative care is to prevent suffering and improve quality of life and a lot of people tend to think palliative care and hospice are two of the same thing, but they're not. Palliative care can get involved very early when you are diagnosed and can help manage your care throughout so that you have quality of life. That is one of their ultimate goals is to make sure that you have quality of life throughout the entire care. So, they're focused on both the patient and the families and the stages of life and the palliative care can also be known as supportive care. That's another common terminology that you might hear of palliative care.

So, onto *The Building Blocks of Hope*. As you probably all received some information on *The Building Blocks of Hope*. I see you guys all have these three ring binders out here. So, this right here just talks about the chapters that are listed in the book that can provide some information – Understanding Your MDS, Seeking Treatment as well as Tips on for Monitoring and Managing Your Symptoms. Chapter Four reviews iron overload which many patients can experience from the number of transfusions that they're receiving for their treatment of the MDS and so there's lots of information in there including how iron overload can be treated as well as the MDS Plan



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and this helps understand the diagnosis, the part that the caregiver plays in the treatment plan and also provides tools on how to track and manage your journey. Chapter Six discusses the MDS Foundation and what the MDS Foundation is, how they're dedicated to serving MDS patients and their caregivers as well as the professionals that are working to improve the lives of patients with MDS and then there's a glossary of terms that was also in the packet as well.

So, Chapter Five is discussing My MDS Plan which helps understand the diagnoses and the role of your caregiver and the active part that they take in your individual plan. It also provides several tools to track and manage the journey.

So, bringing Chapter Five to life as a mobile application and this is what I was talking about earlier how they have a mobile app now that's available for smart phone and tablet capabilities and what it's going to feature is the MDS profile. So, this is where you will have your score, your bone marrow results and molecular profile. It also will be able to track labs, transfusions and treatment. It can contact both professional... contacts for both professional and personal all in one place. It also has a symptom tracker that will allow you to see how your symptoms are improving or if your symptoms are declining. It also can send medication reminders and the reports are able to be downloaded to be printed and you can also upload reports as well and it syncs with a calendar that can manage your appointments.

There's an opportunity to participate in a virtual support network. So, a Google account is recommended for saving the data across the devices and the tailored information is based on your IPS risk category and comorbidity scores and it also provides some updates on clinical trials and personalized system management support and you can get live support also through the MDS Foundation.

And so if you want to contact the MDS, you can contact the patient liaison, Audrey, and you can directly call her at this number or you can E-mail here at this E-mail address.

And so here's a saying that "Hope is a thing with feathers that perches in soul and sings the tune without the words and never stops at all," and that was quoted by Emily Dickinson.

And so that is the end of that presentation. Does anyone have any questions or anything that they would like to openly discuss right now?

**Q2:** On your app is it saying how you can track your (inaudible 37:16)? Is that just for Shands or is that for all reports?

**Christina Cline, RN:** This should be for all.



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**Q2:** Okay.

**Q3:** Is all that functionality available now because it said coming soon?

**Audrey Hassan:** Yeah. It's coming soon. It's not available yet. We actually have some of our patients in our audience who have worked on the app. The enlisted patients and their caregivers (Attendee) and his wife, (Attendee). It's not out yet, but very soon. I would say in the next couple of weeks it should be out.

**Q3:** Is it going to be separate from the score app from the IP...?

**Audrey Hassan:** It's all inclusive. It's all on that app. It's all inclusive. I don't know if there's anything that you can share. I know you were (inaudible 38:10) quite a bit (inaudible).

**Q4:** No, but what they said is it's very easy to get through and you'll love it.

**Q3:** Okay. Good.

**Audrey Hassan:** We have the patients participating in (inaudible 38:22) on the ease that they're putting in their input. So, it's been very well thought out. It includes everything that... It's all inclusive and everything will be there. We'll make a big announcement. I'm sure we'll send out some kind of E-blast when it's up and running so we'll let you know.

**Q3:** Thank you.

**Christopher R. Cogle, MD:** So, if there's no more questions you're welcome to come up after we adjourn and happy to talk with you privately. I want to thank the MDS Foundation, Audrey, Dee, thank you so much for being here.

(Applause)

**Audrey Hassan:** Help me thank Dr. Cogle (inaudible 39:02)

(Applause)

**Audrey Hassan:** (inaudible 39:08) on a Saturday to be with you and you can see their passion in helping the MDS community, so thank you all very much.

**Christopher R. Cogle, MD:** Thank you.



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**Dee:** Evaluations, if anyone has any evaluations.

**Audrey Hassan:** And I just want to make one more point that after today we're not leaving you alone. We'll be in contact. (Inaudible 39:29) in touch with one another. My hope is to create a support group. So, if anyone's interested I will definitely be touching base with everyone after this. We'll keep in touch.