

## Speakers:

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Andrew Artz, MD, MS

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**Andrew Artz, MD, MS:** Hello, everyone. So, I thought... we were discussing and we thought we could get ourselves back on schedule, obviously, continue eating because there is actually a whole hour allotted for lunchtime to allow you to ask questions. A lot of those questions, I think, were asked during the session, but we, the speakers and other people, will be circulating and available to address questions.

So, this segment of the talk that I'll be doing is new approaches to evaluate and optimize older patients for transplant and really builds on the presentations by Dr. Odenike and Dr. Kosuri. So, I'm another one of the faculty here at the University of Chicago. This is the building where we are right here on the seventh floor. I don't know if that foliage is true or pasted in there, but it looks nice. So, what we're going to do is talk about the influence of age on MDS and transplant use and then talk about what Dr. Kosuri alluded to, the use of physiologic age to optimize older transplant patients. So, an approach that we and others are increasingly taking to better utilize the benefits of transplant for the average patient with MDS who on average tends to be older because it's a disease of older patients. There was a comment that the font sizes might be a little bit small which is ironic if it's a talk for older people. So, it probably should be larger, but if you want you can circulate closer to the board. You can sit here and the font size is larger if you're closer, but it's a little hard to correct right now.

So, one of the questions well, what's older and, obviously, older isn't a number itself but it differs by who you ask and if you just ask people in general this was a *Wall Street Journal* published survey who's older, you can see the younger you are the younger old is and the older you are the older old is and so if you ask someone whose under 30 well, 60 is old and if you ask someone who's over 65 it's always older than you are. That's the bottom line. So, even if you're 100, then your 110 is old. So, that's the general rule. Now, just in the field of blood diseases, we historically utilized age 60 as kind of older not that that's older, but that's been a standard benchmark for certain reasons that are there. Irrespective as Dr. Odenike alluded to, most patients who have MDS are older. The average age of diagnosis usually people in their 60s, 70s or 80s and this slide just shows you what's called the incidence of MDS per age group, but most people who are diagnosed are in those age groups and a smaller number of people are in the young age group. These are the people that if the disease warrants almost always are recommended to get transplant if the disease warrants and the question is in this big group here if the disease warrants it's very uncommon for transplant to be utilized and that's one of the areas we're looking at is should it, can it, can we do better? If we look at all transplants offered in the United States just to give a broad picture of transplant and these are in the blue are the allo transplants, the donor transplants. We're not talking about using your own cells, autologous

transplant. We're talking about allogeneic transplant utilizing a donor. These are the reasons that people receive transplant in the US. MDS and MPD, which are myeloproliferative disorders. So, most of these transplants are done for MDS. It's a little over 1,000 in 2013 and if you think about the number of cases of MDS diagnosed probably somewhere between 60 to 100,000 or more diagnosed in the US each year. So, not that everyone needs a transplant. Some diseases don't necessarily warrant it, but you can see this big disconnect between the number of cases diagnosed and doctors always telling you well, transplant's the only way to get rid of it. So, transplant's not offered to a lot of people. The biggest barrier, if you will, has been age and that people are either too old to do it or we're concerned about offering it to people who are at a certain age.

I like that slide by Dr. Kosuri building on a point about what was too old and in the '80s, transplants were not done for people over 50 and older for allo transplants essentially and then the age was pushed up to 60 and then probably in the 2000s mostly pushed up to 70 and people really weren't doing it above 70 and now in the 2010 to '20 age period we're seeing more and more centers offer transplant for people 70 and older and people often say well, what's the oldest it is? What's the oldest you can do? The bottom line is is people are older they're more health conditions and we just have to be much more careful and using age is an easy way of just cutting out and saying well, we don't want anyone with bad health, we don't want to take any risks, but more and more people are understanding the variation in health and that from a patient perspective you shouldn't necessarily cut out all the patients from doing it when some might be able to benefit from it, but that was the historic approach. It was kind of a very doctor centric approach and a more patient centric approach is to look at the patient individually and say well, maybe a lot of people aren't in good health, but some are. Does that make sense? So, what you're seeing first from these slides is that if you look at 2010 and onward and the green one MDS and MPD but mostly MDS you're seeing this big uptick in use of transplant for MDS in those 70 and older. Still a very small number. We're talking 100, 80 or 100 transplants across the US, but this keeps going up and the biggest reason it actually went up was because Medicare started allowing coverage for it across different districts because there was a decision that allowed patients to have a covered benefit if they were on a trial and by signing a consent for your data to be captured not changing the way your doctor was treating it, just allowing the data to be captured was enough for CMS to cover it which is essentially Medicare to cover... say it's a covered benefit and the trial basically is looking at people who do get a transplant and getting data on those who don't to try to answer the question well is transplant beneficial.

Dr. Kosuri showed you his four legged table. I'm a simpler person, so I have a three legged stool for transplant, but they're the same concepts. We think about disease, we think about the donor and the regimen and we think about the patient and so in his slide it was fitness and social support. For me the patient and the whole what I call ecosystem around the patient that's... this is the patient. These are patient factors. When you think about older patients there's a lot of issues that intersect to present barriers to offering transplant to older patients. The one issue which is the biggest one is that as people are older there are more health issues. So, anyone

knows that people of your age you're going to start... as people are older you start to see more variation in health where some people are healthy, very active working and some people are less healthy and having more and more health conditions and as we age there's a splaying of variation in your health and then the long term benefits there's some studies that compare people who get a transplant and don't, but not really the type of studies that tell us definitively that the transplant is beneficial for older patients or how beneficial. We know... I think the data are very strong that show us that transplant controls the disease better than non-transplant approaches if the disease has a tendency to evolve to leukemia these higher risk diseases we talked about. It's still not perfect. The disease can return after transplant. The challenge is the side effects and Vidaza and Decitabine treatments which a lot of people receive they might seem like they have side effects but transplant's considerably more difficult than that and you saw Dr. Kosuri's slide you don't have to look at everything. You just saw a lot of stuff there. There are a lot of infections and things that happen that you will not encounter using Vidaza. So, we have to balance those dangers versus those risks.

The disease issues have been touched on, but basically it's a disease of older people. So, if we exclude older patients we're not offering a lot of people the benefit of transplant and then there's the issue of donor and regimen. The one major issue for older adults is that the issue of older siblings if we prefer a matched sibling as Dr. Kosuri said what about the siblings that are older and, again, ever center has its criteria. Is 60 too old? Is 70 too old? Is too old for the sibling who matches? Some siblings simply aren't alive or in poor health. So, that 30 percent he talked about it's even fewer older patients who have a matched sibling available and more and more people would use unrelated donors and, of course, we have to think about the alternative donors. We have a donor for everyone we say, but that doesn't mean we should use that donor for everyone.

And now I'm going to talk a little bit about calendar age and physiologic age because the rest of this is about peoples' health and how do we look at health. So, calendar age is how old we are and aside from my mother-in-law who never has birthdays, so I guess she doesn't age everyone ages each year and so we all have a predictable and objective age, but people differ. Here is someone who has a lot of health conditions who's older, a stock photo that I borrowed from the Internet, but it shows someone who's older and looks like they have health conditions if you just look at the whole picture. Your eyeball test says jeez, probably you wouldn't recommend that she do an intensive transplant I would guess and then to beat Dr. Kosuri's guy climbing Mt. Kilimanjaro here's Chau Smith and I actually like to use women in the presentations because I think there's especially big bias in transplant with age for women because a lot of the measures we use are eyeball tests for physical strength and you can't really on average women have less muscle mass than men and sometimes those parameters lead to some bias in people not offering transplant to women and we actually see that in the data that is people get older you see fewer transplants being offered to women. Some of that may be social support because men, no offense, may not be the best caregivers or social support in the room, but I think some of it's a little bit of physician bias and strength. So, here's Chau Smith, seven marathons she completed recently in March over seven days across seven continents. So, seven consecutive days, seven

continents, age 70, not so bad and these two people, obviously, have different health, but so those are the ranges in people who are older. The question is in between. So, we know on this end okay you'd say she's in good shape. I don't know if she had MDS if she could do that, but let's suppose she could only run one marathon, still good candidate. This woman not so much. What about in between? How do we assess age in between? How do we assess people's physiologic health? So, what we do is we use tools and methods to stage the age. You've heard of staging cancer. We have a way of staging age. That's looking at physiologic age and we use a tool often called geriatric assessment. People might not like the term if you don't, but it's a way of looking... originally developed to look at people's health status and predict longevity, but it can also be used understanding your ability to withstand treatments you're given her intensive treatment. So, basically the healthier you are the longer we expect you to live and that's how your doctor can say well, you're 60 and do we expect someone on average to live 10 years, 20, 30, 40? You can look at people's health and we can... we have ways of estimating it and we look at these parameters and so some of these you've heard about comorbidity. He showed... Dr. Kosuri showed you a scale. We get these from medical history. These are the medical conditions of your organs and your organ function essentially and other diseases, medical diseases, you might have that one would get from your... just in a doctor's summary, but there are other issues that are just as important and probably together the whole ecosystem as we call it, the whole picture of the patient and the patient family and the whole sphere defines our ability, our physiologic age. Polypharmacy, how many medications you take, too many is bad, few is good. Physical function is the mainstay of defining health. The more active you are the better your health is. That's straightforward. We can assess that though by what a patient says and so we do an eyeball test, but beyond that you have to ask someone if you tell us you're riding your bike 20 miles a day you're in good shape. If you say jeez, I'm having trouble getting upstairs, obviously, your health is not as good and that's important and we do bedside tests to grip strength, other things to really get a better sense of health.

So, these are some simple questions we might ask people. Can you do these things independently? If you lose one of these if you were doing it independently and then you become less well and you can't do one of these things or many of these things your health is taking a step back. It's also a measure of adaptiveness. How much you can adapt to your environment. It tells us a lot about your reserve. It's even partly about your social support, your house, everything else and these end up being really important into telling us what your physiologic age is. We can do these grip strength and a lot of things. Psychologic health. Emotional health is important, motivation, your thinking. So, for younger patients we really don't think about their memory or cognition, but as we get older some people have memory issues, some don't and those can be very difficult when they develop because if you go through a major stressor, your memory will get worse. Everyone talks about chemo brain because there's... whatever your memory is it will not get better when we give you 10 other medications and you become sick and other things happen. So, it may be temporary, but it can be very difficult. So, the more preserved that is the better you able to get through intensive treatments. Social support. It's one of Dr. Kosuri's legs. It's really essential. We have our social worker, Mark, back there who basically his time here is

dedicated to working on social and financial issues. It's so important for patients no matter what treatments they undergo. So, he's a critical team member here and wherever you are and nutrition. Your nutrition's really important. Fortunately, for MDS patients they tend not to have a lot of weight loss through the standard treatments, but issues in older patients such as dentures are really important when we think about transplant because that can interfere with our ability to obtain adequate nutrition.

So, that leads us to how do we use this information to make a transplant decision and you can think about moving to transplant as curing the disease which a lot of people say are long term control, the Fountain of Youth and then people maybe you want to take a more lenient approach, live for today. We call that the Fountain of Bacon. That's not on Lauren Ziskin's... It's on the 30 day plan or whatever that diet is, but let's you know if you're living for here and now that's okay.

So, the standard transplant criteria have historically been based on younger patients and we doctors have a lot of trouble moving from history. We're wed to what we've done for 40 years and what our mentors told us to do. They said okay, at some age you're just too old, whatever that age is. That's being lifted, but if your heart... look at the heart, lung, liver, kidneys. If it's bad you're not eligible for transplant. This is really good for younger patients because if they're okay they're eligible. They can do a transplant generally and then other cancer may or may not be an eligibility criteria and then the MD rating function. That's the eyeball test. Again, for younger patients this works very well, let's say under 40. These things tend to tell you who's a reasonable candidate. As people get older they don't stage the age well enough. They don't tell us enough about the health conditions just that you don't have something severe, fine, but it doesn't tell us we need a little better refinement to know.

So, when we started some work here about 10 years ago where we looked at people's health before transplant and these were 50 and older because that was the era where 50 was older. Now, it's 70, but as we just looked at people's health we staged their age before transplant. Everyone was everyone approved, moving to transplant. These are all diseases getting allo transplants, donor transplants and then we just applied this toolbox of different tools and what we found essentially was that there are a lot of impairments for people who are transplant candidates who are older that I'm not going to say the doctor isn't aware of, but they're certainly not... they're not tabulated in any way. They're basically as a patient's medically cleared and you see that measures of frailty where people don't have a lot of reserve. Fifty percent of people have some impairments. A quarter of patients before transplant were, frankly, frail. In a population that's what we would expect in people who are in their 80s. Essentially people going to transplant who have diseases being treated have some measures that make them look older than they perhaps would be. These are people cleared for transplant.

Limitations in emotional health, physical function by patient report, high comorbidity, high measures of inflammation all of which are really common in people who actually move to

transplant which tells us when people do go to transplant with limitations we just may not either be aware of them or know what to do with them. So, importantly how does this... does this mean it won't be successful and one of the things people often want to know is am I cleared or not to do transplant and clearance isn't really a great term because we don't know how people will do. Even people who are cleared who are young, who look healthy can have problems and those who aren't cleared occasionally might squeak through, if you will. So, it's really a matter of weighing the pros and cons. The whole picture has to be taken together, but for success meaning being alive without disease. Very important though is function. We found in our research that function by what the patient tells us meaning listen to thy patient is probably the most important factor for patients who are older especially 60 and older. Measures of inflammation or low albumen were very important and of some importance are other conditions like the comorbidity scales, disease control. Now, remember, of course, if it's not well controlled patients didn't even go to transplant and slow walk speed by some of the measures we do were of intermediate importance.

So, we... I don't want you to memorize this slide, but we've modified our eligibility criteria a bit for our patients 60 and older to look at other factors and essentially if you're probably up to about the age of 79 if someone was 80 and they climbed Mt. Everest, of course, they would be... we would look at them, but that would be very uncommon, but more and more we're accepting people into their 70s, but you have to be more aware. You have to have a system to evaluate people. You can't just say we're going to do it at people at this age or we don't think you should exclude people above a certain age. You just need a system to look at people's health in a comprehensive way. So, we try to look at all the different features to try to determine "eligibility," but I think we have to move beyond eligibility and we're trying to move toward optimization. That's what this last part is about is optimization because I don't really like the term "eligibility." We like to think about how do we get people to be the strongest they can be and then determine if transplant is a good option for them. Are they able to get through it with reasonable quality of life?

So, let's look first of all a young woman, 41, with MDS, IPSS 2. So, high enough risk to offer a transplant based on the data Dr. Odenike and Kosuri showed you, has a perfect matched unrelated donor. We like perfect matches. MD function was okay, has diabetes, depression, forgetful at times, knee and hip pain. We kind of ignore that in 41 year olds to be honest. Socially she was widowed. That's not good. She's young, has children in the area, but we assume she'll be able to get some family support for transplant, but what happens if I change it to 71 and now all the people in the audience are saying huh, I might be 71. I have all these things or I don't. Should we offer transplant? These are the dilemmas the transplant centers are trying to figure out is should we do it, how do we better determine and we have this information. So, for a younger patient it was plenty. I said okay, that's enough. She'll be eligible, but at 71 someone might be eligible, but we all aren't really sure the absolute risks to the patient and so this intermediate level of function we worry about whether it's going setback from before as a declining, is the depression how serious is that? Forgetfulness, does that mean something more

than just I say I'm forgetful or is there actual memory impairment and this being widowed, do we have the social support to pursue a transplant? So, those are some questions.

How do we address it here and I think each center's different, but I will say nationally more and more people are moving to some type of abbreviated model. I would look at our approach here as kind of the full buffet, if you will. We're testing this... I'm not saying it's better, but we pretty much offer everything at the buffet line. We don't know if we should do everything, but that's the way we're doing it to get people through, but we look at all transplant candidates 60 and older and they get this geriatric assessment, the staging the age, which I showed you. It's a survey. It gets sent electronically or it can be done on paper some bedside tests and then we see the whole team. Jean Ridgeway's part of our team. She's the APN. She's actually a Doctorate of Nursing, transplant MD, social work, Mark is here, a physical therapist, dietitian, geriatric oncologists, cognitive testing. These are fun Friday. So, this takes up good part of Friday and patients are seen. Historically, people just took the information and said is it a barrier or is someone cleared or not? We're trying to turn this model around and say let's not ask if the patient is cleared. Let's ask how we can clear the patient because patients want to be empowered. You don't want to be told oh, I can or I can't. How do you make yourself stronger? How do we go from eligibility to resilient? How do we make people more resilient, so transplant or not, you're stronger for whatever approaches are there. So, we have this interdisciplinary meeting where we call discuss what we found both the vulnerabilities and the strengths of a patient and we try to develop a plan tailored to what transplant might cause and then after that we try to see well in that context is transplant a good idea? How can we give people... how can we help people get to a point where transplant might be something that could offered to you, never pushing transplant, of course. This is our team, or at least our team as it was a year or two ago. We've had a few additions and departures and this is what we do when we someone.

So, let's look at this 71 year old woman. So, looking at her health conditions, comorbidity, diabetes, depression, arthritis. So, we would then say okay with the diabetes we need endocrinology, but also importantly she had been in the hospital for an infection, became weaker, arthritis that was mild became much worse because she wasn't out of bed and then she started taking ibuprofen when she went home which affects your kidney function. So, it's like Advil and so when we saw her she wasn't that active, but just by going through this and trying to not say you're not that active, you're not a candidate, how do we make you more active? Well, if it was from deconditioning from being in the hospital then let's get your arthritis better controlled with safer medication and let's take off the restrictions of concerns for infection and get you up and moving and that's something we often do. We often loosen the rein. Function, we talked about the importance. We did this full panel. The strength was good, but the endurance was limited because of the deconditioning that happened in the hospital and the arthritis, it was a cycle going the wrong way. So, by treating the arthritis, allowing her to be stronger, prescribing physical therapy you change the cycle, empower a patient. She was able to get much stronger and we turned what we call a vulnerability into a strength, an asset, a figurative and literal strength. Cognition, there was forgetfulness at times, but through the testing it wasn't

forgetfulness from cognitive impairment. There's no Alzheimer's. It was due to anxiety and a lot... is there anyone in the room who has this disease who isn't anxious at times about it? No, and thinking about transplant and the social support and hearing all the doctors say you need this, you need that, you have to do this. I mean, Mark in our clinic has to deal with... I tell patients you need these 20 things and now they are so anxious. We generated anxiety because of saying these are all the things you have to do. Once we got the bottom of it, it's the family, the concern that her children and she wanted her children to help and they weren't, but she had told them not to help and, of course, they didn't because she was told not to help, but she wanted them to and we needed a family meeting and the family wanted to help and she wanted them to help. So, once we put everyone together we agreed oh, jeez, we're willing to help and putting everyone together that relieved her anxiety and had the benefit of having showing us that her social support which we thought was a weakness could actually be turned into a strength. Does that make sense? So, we could go on, but this is just some ways you could do that and I want to just say nationally this is more and more people are starting to pick up this approach for the older patients. We don't have a perfect recipe as we say, but I think the critical point for the people in the room is to feel empowered, not to have someone tell you oh, you're not this, you're not that. What can I do to be stronger, to be more active, not have us do to you, have us do with you and sometimes you have to ask your doctor, sometimes you have to go beyond your doctor and work with the therapist, psychologist or other care team members to say what can I do. Let's not let the illness attack me. Let me come back and try to live.

So, in short calendar age is important, but physiologic age is essential to really guide decision-making, to pursue transplant in older adults and I think we believe although we still need to prove this better, this multidisciplinary team approach I've showed you tailored to physiologic age so the strengths and weaknesses hold promise to expand transplant and transplant success for older adults so that we have more and more patients that are offered transplant safely and that's really what we want as long as transplant is a powerful modality to treat the disease and we don't have something better we want to be able to offer more and more patients this modality to do that. It means we have to be able to offer it safely and preserve quality of life which is, of course, what Jean Ridgeway will talk about next.

So, I want to acknowledge though at our team we have many of our team members here. I have to acknowledge the MDS Foundation. These are wonderful booklets I was just reading through, patient booklets that providing for patients. I think the resources really speak to the ability for you and the patients to be empowered by getting more information and people say well, my doctors don't know this. Well, you can. There's no reason why you can't... No, I'm serious. Then you know it and you ask it and if they don't know it then you ask someone else and you've got a room of experts in here. There are always people who can help you. The more you know, the more you can be helped. At least that's what I think.

So, this is our transplant team and our optimization program with some of our members over there who all work together on behalf of the patients. I don't know. That was an old slide. Dr.



Baldacci is not part of this, but he is the grandfather of geriatric hematology. So, I guess it's appropriate to have him there. So, thank you guys very much for your time.

(Applause)

**Andrew Artz, MD, MS:** So, Dr. Odenike (inaudible 30:47) on time. So, I think if you guys want, Jean's going to do the panel in a little bit. Should we take questions now or should we just go to the panel? What do you think? If there's one or two burning question then we want to stay on schedule because I know everyone have things to do. Good. That's good.

**Q1:** I would like to say something. (Inaudible 31:20) it's a question because you just answered it but just a reality check. I formulated questions some experts at Make the Match Foundation which is a great resource. Olivia is there as a social worker and Stuart, a researcher for clinical trials. They helped me put my questions together. I went to my local oncologist who I never see. I just see the PA. He took my questions. He couldn't answer any of them, so he referred me to a mental health professional to consider from his point of view that I had obsessive and compulsive disorder and adjustment to my disease disorder and he steered me in that direction rather... because he could not answer my questions. So, wow. What you said just now is wonderful. Thank you.

(Applause)

**Andrew Artz, MD, MS:** We have to... It's like everything in life and I realize more as I get to do this more and more I'm less and less as I talk to people I realize some of the aspects the scientific part which drove a lot of us into the field and I realize when you take care of patients though and we want patients to do well sometimes it's about being a bit of a life coach and that we... it's life strategies that help us deal with these illnesses, too, and as I think everyone in the room knows that that sometimes these call them life strategies as you adapted you've learned that you have to get the information yourself. Sometimes the system doesn't work for you and you have to fight back and you have to do what you need to do for your own interest and I credit anyone to do that. I think sometimes I hate to say this, but the patients who do the best are those that are mildly annoying because you really... you need to be on the ball and people have to be on the ball and I think we all know that, but sometimes I figure if my anxiety level is just a little bit up when I go into the room that's probably good because that means someone is keeping me on the ball and I don't brush things off and I try not to. We try our best, but people are busy and it's you don't need to bark in there, but it's just one of those things. It's like all things in life that you have to advocate and be proactive and sometimes people get lucky and they have these healthcare teams that really can shepherd them through the whole process, but that's a rarity to be honest. That's a rarity and happens mostly in the young adults where they have 20 different providers for one kid and even then you need the parent's support, but certainly in just regular old practice people aren't... there's the regular highway. It moves very slowly. It moves very

slowly. There's a lot of stops and goes and people ask you to yield and sometimes you shouldn't yield.

?: I think we all (inaudible 34:24)

**Q2:** Would you to agree that physical activity is very, very important to the survival of this thing? The more physically you can be activities helpful?

**Andrew Artz, MD, MS:** Yes. So, yes it is. I think one of the... Yes, absolutely. We don't have what we call the medical studies that show that how active or what's the prescribed regimen people should do. So, that's one of the issues that tailoring it for you the right regimen and a lot of people with MDS have anemia which does affect your energy level and you get a lot of conflicting opinions from people about how much you can and should do. They say, well, just take it easy or do what you do and then people need what we've learned in our program is that we really need to be give people a lot of times more guidance. Not everyone. Some people really know themselves well who have exercised their whole life and really understand it. For a lot of people the disease is a wakeup call to stop smoking, to stop doing this or that and to exercise more and they don't have a life history of exercise. They don't know their body and that's when we use physical therapists and other professionals to give you guidance on what to do and how much to do. So, the doctors will say sure you should exercise, but how can someone in that clinic visit know what exercise you should do, how long, how much. Someone, a professional, which usually is a physical therapist or professional can help people who need help. Some people don't need it. So, I think it's essential. I think if you're going to do transplants you have to be really resilient and the more resilient you are, the more reserve you have, the more likely you're to get through it with a good quality of life.

**Q3:** If I can make a suggestion. Also I believe that going to a phycologist for this process is really helpful because personally I'm going and sometimes it's difficult that I talk about having MDS or any kind of leukemia or whatever. It's kind of hard to talk to your family about it because everyone's going to be like oh, well, you can go through it, but sometimes you don't want to hear that or sometimes you just have to talk things out. So, I really recommend doing that.

**Andrew Artz, MD, MS:** Absolutely. If I probably didn't emphasize it enough I mentioned in the case example of the patient and the importance of being aware of the emotional aspects in bringing the family in because that was having as much affect as the physical and that's as important as the physical in getting through treatments and being successful and there's actually data on that that in the psychologist as your physical therapist for your mind and some people are reluctant to do it, but I think at least in my hands most people have been benefitted a lot. Worst case scenario you go you talk. You don't feel you need it, but you can't do these things alone. It's the bottom line. You can't do it alone and that's why the MDS Foundation and these organizations are so great to connect you to patients and other people, too. I think that resource, I

mean, as you guys know, but I've heard from other people who valuable just coming here you may have not found this useful but talking to someone else and if you establish a relationship with someone to help your emotional health to know someone else is living with this and had similar experiences I think really is invaluable and really helps people and seeing and you guys are already doing it. So, maybe your charge is to bring other people into the fold who are also suffering because you're kind of leaders in a way. You're here. You're leading the charge of patient empowerment and then there are a lot of people out there, the majority that we see that probably haven't taken as proactive of a role.

?: The next speaker (inaudible 39:09 – 39:28)

**Jean Ridgeway:** Good afternoon. I'm going to change gears a bit from my physician colleagues and I just want to say thank you also for coming and thanks for the MDS Foundation for choosing our site to host one of these. They strategically look across the country where would be a good place to offer this option for people to come together and it's kind of nice since I live here that I don't have to travel half way across the country. So, I find that very helpful. The girls are passing out an evaluation form. If you would be so kind before you leave today just go ahead and fill it out. You can leave it at your place, you can hand it in before you go, but the MDS Foundation is interested in your feedback, what you found helpful, what you didn't find helpful, suggestions for the future.

So, I'm going to ask you all if you feel comfortable and want to be a little vulnerable, we're going to go around this really big circle and we're going to introduce ourselves and there's a couple questions that I'd like you to answer, if you are the patient or the caregiver and then you have to give us only a 30 second snapshot of why did you come here. So, that's all you got, 30 seconds to let us know what drove you to come, not literally who drove you, but what brings you here. So, that will help me also to understand have we hit the mark, have we missed the mark, what other kind of things can we connect with you all. So, I'm going to start to my left. Please use the microphone. If you depress the button and it turns red on the collar you know you've done it correctly. Very good. So, give us your name, you can let us know who you're from. I have a couple ground rules in this. You may not doctor bash. Okay? So, sometimes people are really happy with their doctors and sometimes people aren't. Hopefully, if the latter is true we can potentially make some suggestions on how to look for a second opinion, but don't drop their name, but we'll try to help you through and that and just be mindful of the time. I know we're due to stop at two o'clock. So, we have an hour and 10 minutes. I will be mindful of your time. I will be sticking around afterward to answer questions if I can. I'm not sure if my colleagues what their commitments are. I also want to acknowledge two other people in the room. One is Lauren Ziskin. Lauren's another nurse practitioner here at the University and she works with MDS group quite a bit. So, she's a great resource and Mark is sitting next to her. Mark is our unsung hero because Mark's our social worker. We love him to death. He does a lot of work and I'm very pleased to be working with him. So, to the left, go ahead.

**Q4:** Hi, my name is (Attendee) and I am a...

**Jean Ridgeway:** Speak up a little bit.

**Q4:** Hi. My name is (Attendee) and I'm a caregiver. My husband, (Attendee), was diagnosed with MDS about five years ago and it's kind of evolved into some other problems as we've gone along. So, I came to get really more information about it today.

**Jean Ridgeway:** Thanks.

**Q5:** Hi. My name is (Attendee) and I really came to find out more information about my illness and I really like you said don't (inaudible) any names, but I'd really like to thank Dr. Artz who really has helped us so much.

**Q4:** I second that.

**Jean Ridgeway:** Quite a bit and have you been given the tools of more information during...? There's been a lot of information I understand. It's almost like you need to go back to school for a degree for some of the information that was presented, but hopefully you've met the goal of getting more information. True?

**Q4:** I think we have and I feel the hospital in general, the University of Chicago, has really been helpful in terms of being proactive and identifying (Attendee)'s disease and helping us identify what needs to be done.

**Jean Ridgeway:** Thank you.

**Q6:** My name is (Attendee). I'm the caregiver for my daughter (Attendee). This is the second time we're dealing with MDS. My son had it as well. So, we're kind of reconfirming everything that we lived through once already and like you said here at the University of Chicago has been great. They've given us a lot of information that we didn't have before with my son and we do now have with my daughter and, of course, Mark and Lauren also are part of things we've dealt with here and Dr. Kosuri as well. So, we're really happy to be here and learning more and more about the MDS that's in our family. So, this has been great.

**Q7:** I'm (Attendee). I'm the patient and I really wanted to learn more about the bone marrow transplant, the stem cell transplant, because I'm going to go through one in a couple of weeks. So, I really want to know more about it and I also wanted to... I know you guys say don't thank doctors, but I really want to thank Dr. Kosuri and also Lauren and Mark because they've been like so helpful with everything and on top of things.

**Jean Ridgeway:** That's great.

**Q8:** My name is (Attendee). I'm the caregiver for my wife, (Attendee). This is the third type of educational seminar we've been to learning more about the disease as we go along and I want to know about it. I want to know everything that (Attendee) knows about it and I can understand it and know what my role would be in all of this. This particular session for me and I'm sure for (Attendee) delved into a lot more with the age question on transplants which was not really ever answered before or still was put in terms of age limitations. So, I appreciate that part of this that we got a lot out of it I think.

**Jean Ridgeway:** Great.

**Q9:** My name is (Attendee) and I think he covered it real well.

**Jean Ridgeway:** Over in the corner. They got to fling the microphone around.

**Q10:** Hi. My name is (Attendee). The reason I came was because I read a lot, but most of them seem to be for the anemia part, the red blood cells and that's not my problem and I guess I thought that I would never be a candidate for a transplant and maybe I'm not because right now I'm low, but I guess one of my questions was if you start out on... you're on the chart where it's low, medium and intermediate if that ever changes when you get your bloodwork done and your bloodwork does go down if you go from low to intermediate to...

**Jean Ridgeway:** So, you're referring more to the risk levels. Correct?

**Q10:** Yes, I am.

**Jean Ridgeway:** In general when people are diagnosed with MDS they get a risk category assigned. If you get transfused it doesn't really change your risk category, but once you... If you start treatment and then you're reevaluated again sometimes people can go from perhaps a lower risk to a higher risk only because the nature of the disease is it doesn't get better. Right? It can stabilize, but it can progress. So, things can change. It's a bit dynamic even with treatment. Does that answer your question?

**Q10:** Yes. Thank you.

**Jean Ridgeway:** Okay. Next to you is?

**Q11:** My name is (Attendee) and I'm here to back my wife up and I think she got a lot of information out of this.

**Jean Ridgeway:** Good. Great. He said he's not a big talker when he turned off his microphone and for all of you who are here as caregivers and family members honestly my entire team would

second that. Do not underestimate the role you play in the success of your family member. It's just so critical and you also need a red cape for being an unsung hero because it's a tremendous amount of work and sacrifice on your part and so it makes such a big difference. Such a big difference. So, thank you for being supportive. Next.

**Q12:** I'm (Attendee). I drove here.

**Jean Ridgeway:** I'm glad you drove, (Attendee).

**Q13:** I'm (Attendee). I wanted to come because I'm wait and watch. I notice when I'm waiting and watching I'm actually getting older. So, I'm starting to worry about was I going to be eliminated from the possibility of transplant. So, some of that has been (inaudible) to hear that everybody's actively working to make transplant possible for older patients and the other bit of information I need is Kate was kind of a liaison between the University and myself and I lost track of who replaced her.

**Jean Ridgeway:** Kate Breitenbach.

**Q13:** I don't remember...

**Jean Ridgeway:** Who I know is now married, but I don't remember... I don't know if she took the name, but anyway. So, Lauren.

**Q13:** Okay. Good.

**Jean Ridgeway:** So, there's Lauren in the back. So, Lauren I don't know if she has any cards, but she could right on a piece of paper how to get a hold of her. Who's next? You want to press your button the red... Here. (Attendee), do you want to press the button real quick? I don't want any feedback. It would wake everyone up.

**Q14:** Yeah. Wake up. Okay. I'm (Attendee) and I'm 80 years old now and first discovered it around when I was 76. So, it's been about four years I've been going through some of the regimes. My primary is OSF in Rockford, but I have been here and I've talked to Dr. Artz and everything and everybody here has been very helpful. I'm just trying to learn as much about it as I can and I'm trying to stay as active, mentally healthy and physically because I think that's... we are so important. Somebody said this to all of us here that we are probably the most important cog here is to try to keep ourselves going and as healthy as possible and make things last as long as possible.

**Jean Ridgeway:** Very good. You know, for all of you have mentioned wanting more material and knowing more about it, I hope that you've availed yourself of an educational bag that the MDS Foundation has put together because inside of there is lots of terrific researches. There is

the *MDS and You* book, the *Building Blocks of Hope*. There's a hardcopy in there. If you haven't been to the website you can go to the website and download a free PDF copy of that as well as lots of other resources that are on the website. So, that amongst other things are in there.

**Q15:** I'm (Attendee). I'm here with my husband and I'm the caregiver, but he does most of the care himself and this is probably about the seventh or eighth one we've been to and each one is just more informative and I think helpful and least alleviating worries and giving hope.

**Jean Ridgeway:** Great and you've drive from Indiana.

**Q15:** South Bend.

**Jean Ridgeway:** South Bend. (Attendee)'s next.

**Q16:** Okay. My name is (Attendee). I'm the patient whose group and I've been here coming what, 12 years thereabouts and every time you learn something new. Okay. I've been to Mayo Clinic, to IU Indianapolis and never too, I guess, old to learn and that's what kind of working on.

**Jean Ridgeway:** And you've lived with your MDS for 12 years now?

**Q16:** Yeah.

**Q15:** That we know of.

**Q16:** That we know of.

**Jean Ridgeway:** That you know of.

**Q16:** And also... Well, both of my doctors, cancer doctors, have kind of lead me with the belief that 1) is do what you go to do but also kind of got me mentally thinking of there's nothing wrong with me, but you know, you do know there's something wrong with you on different things but at least mentally.

**Jean Ridgeway:** Very good. Thank you.

**Q17:** My name is (Attendee) and I am the patient. My wife is a very much caregiver and gets me through a lot of things.

**Jean Ridgeway:** Was there anything special that you wanted out of today?

**Q17:** I guess nothing really, but I was wondering what is the original cause of some of this or is there a reason for that?

**Jean Ridgeway:** Well, no one really knows the true cause of it. That's the million dollar question. When folks get diagnosed with MDS and really don't have any other blood disorder problems that were known beforehand there isn't any specific cause. So, people can't point their finger at was it diet, was it where I lived. So, in some situations there may be kind of a genetic... there may be a familial component to it. That's rare. The big question we really don't know why some people develop MDS and others do not.

**Q17:** I guess because I am a veteran and just questioning for Agent Orange.

**Jean Ridgeway:** Right. Now, and are you aware of the Agent Orange program through the VA?

**Q17:** I'm just getting involved with it.

**Jean Ridgeway:** The VA recognized that men and women who were exposed to Agent Orange were at a higher risk for malignancies and so they have developed a support program for those of you who aren't aware of them.

**Q18:** My name is (Attendee). I'm the caregiver, obviously, from what he has said. I'm glad we came today. I'm trying to find out as much as I can and we both can and I think the more you know about some things that are off you are the better decisions you can make and that's pretty much why we came.

**Jean Ridgeway:** Well, thanks for coming. (Attendee)'s next.

**Q19:** Hi. My name's (Attendee). I'm here with my husband, (Attendee), who's diagnosed about five years ago and I just wanted to find out I always want to know as much as I can about the disease and make sure we're not missing any treatment options.

**Jean Ridgeway:** Great.

**Q20:** My name is (Attendee). I'm the patient and I was interested in knowing how well organized the MDS world is in providing information and services that could optimize my condition or the treatment of my condition. Currently, I'm not 100 percent confident that I am receiving the best care or the optimum care that I could get and I wanted to be certain that I would learn about what the various avenues that were available to optimizing my condition and my life situation at the moment. As I see it here and now apparently this has become a University of Chicago function rather than an MDS function.

**Jean Ridgeway:** So, you know, they recruit volunteers.

**Q20:** Well, I'm a little surprised that nobody is here from Northwestern or Loyola.



**Jean Ridgeway:** I know. Me too.

**Q20:** And that concerns me because, obviously, the Foundation should be primary or I think primary in making sure that all of the information is disseminated completely and thoroughly throughout the United States and I'm not confident that it is.

**Jean Ridgeway:** You know, the girls from the Foundation can speak to this, but I know they use their mailing list and like patients who are registered then they send out like a blast E-mail and use that as their primary.

**Q20:** For example, I can't even investigate the particulars of my own doctor as to their expertise with MDS. I don't even know what that is and I don't simply want to ask her and I think she's in hematology oncology, but I don't know if her specialty is MDS or some of the other things. Those are some of the things I wanted to learn here today.

**Jean Ridgeway:** Well, this is what I want to do, (Attendee). I'm going to turn to the people who are sitting behind you, Dr. Odenike and Dr. Artz and ask them what would be a tactful conversion to have with your hematologist oncologist. What would be a good question?

?: (inaudible 57:50 – 57:57)

**Jean Ridgeway:** It's a very good question. You know what I mean? You don't know what you don't know and when you have a rare disorder you want to ensure that the provider that is giving you care really is an expert. That's a valid question. So, let's hear Dr. Odenike.

**Toyosi Odenike, MD:** Yes. So, I've always believed in being direct. So, my patients ask me that all the time what do you focus on? Are you an expert in this disease for which I was diagnosed or for which that I have just been diagnosed with and for which I'm seeing you. So, I think it's fair enough to ask your doctor are you comfortable with treating my MDS? Is this a disease that, you know, you see enough of and that you feel like you're abreast on in all the treatment options or do I need to seek a second opinion so that we can both feel confident that my... this is not a me versus you or we versus them thing. It's a doctor who is wanting to do the best for you and make sure you're on the right track with whatever it is you're doing for your disease. I approach my patients that way all the time. I never presume that I am the person who knows it all. There's a community of experts out there and we rely on one another. Dr. Artz knows that we talk to each other. We talk to colleagues around the world sometimes when the need arises, if it seems that whatever's going on with the patient is something that perhaps we're not sure about, we can't quite put our finger on it or is there something better out there. I mean, we're all in here for the good of the patient or we should all be in here for the good of the patient. So, I would ask.

**Jean Ridgeway:** I think a very honest question that can get asking them straight out like that I think is great. Putting the ball in the court of the provider thing. If I was your brother who would you recommend that you see? Who would you recommend that I see for my problem? Kind of flip the table a bit and make it a little bit more personal.

**Q20:** Well, that's easy enough to say, but if you confront your physician with a particular question like that they may, I feel, resent somebody asking them that and then you're kind of with that person for an ongoing period because where are you going to go? I mean, I had a physician previously that I had confidence in and she left, departed for another position and I was kind of handed off to the second one and the confidence level that I have in the second physician just isn't there and I can recite some examples of what have occurred that have led me to this appraisal at this moment, but I don't know what to do about it and I didn't even know there was a center or a authority or a group that will provide leadership at the professional level that I could also go to. I don't even know where to go for questions. My best source of information is Google.

**Jean Ridgeway:** Dr. Google.

**Q20:** Dr. Google.

**Jean Ridgeway:** He's very popular.

**Q20:** Yes.

**Jean Ridgeway:** He's plus or minus, but so let me put the question out to those of in the room. Suggestions for seeking a second opinion. I'll give you mine, but let's hear what you have to say. Anybody in here ever seek a second opinion? Oh, way in the corner over there. (Attendee), right? Is that your name?

**Q21:** Well, when we went... We lived in Mexico. So, when my son was diagnosed with this he was... he did not have anybody that was comparable to be a donor. So, we had to go through the haplo identical transplant. That's why I asked Dr. Kosuri his opinion on it. When my daughter was then diagnosed I was like I told the hematologist in Mexico, I said, "I'm not staying Mexico this time," not just... not because they didn't do a good job with my son, but just I didn't feel the confidence and I didn't have a support group in Mexico. My family is all here in Chicago. So, I said to him, I go, "Listen," and I said it to him just like this, I go, "Listen, you go to all these international conferences. You have to know who in the States in Chicago is the best, so I can take my daughter," and he said, "Well, you know, we're very close to Houston, to the MD Anderson Center." I go, "No. I don't want that. I want to go to Chicago. So, ask..." and I told him just like that. I said, "You ask your contact in the MD Anderson who is the best in Chicago," and he did and he came back to me and he said this is what he recommended and it was the University of Chicago here with Dr. Lucy Godley. So, and then now all her team, Dr. Kosuri and

Mark and Lauren, but we... I was very aggressive about it and I didn't really care what the doctor thought. I had to get answers and I wasn't going to go through this the second time and not have it the way I wanted it and my daughter she's very aggressive with the doctors. She, I mean, asks them everything. The first time we met Dr. Kosuri, in fact, she came with her list this long and he answered each question honestly and directly and she still E-mails him and says, "What's going on with my transplant? Is there the donor?" I mean, she's very aggressive with her treatment. So, don't worry about what the doctors are going to say. If you're not happy with your doctor get somebody else and Dr. Google is a good way to do it. Find somebody who's in your area or Google who's the expert or now with MDS, the Foundation here, they have lists of doctors and things. So, you have to be proactive like we said and don't be afraid if you're not happy with your doctor forget it. Get somebody else that you're going to be happy with because this isn't something to goof around with. You need to be feeling comfortable and get the answers you need and the attention you need. That's it.

**Jean Ridgeway:** Other suggestions? (Attendee)?

**Q22:** Yeah. I found out by trial and error I didn't go for one second opinion, I went for either four or five. I went from a... it's a small town east of here 90 miles, but with the... I was at the first doctor and he's good, but he's a one horse type of situation. So, we had a quiet waiting time to go in at ten o'clock in the morning. A lot of times we weren't getting out until seven – eight o'clock at night. No, I mean, it's a true story and I had to switch. So, I did... I interviewed this you probably don't know him the Ansari's from...

**Jean Ridgeway:** Right. Yup.

**Q22:** Well, I actually interviewed him before I switched and that's the first visit and the way I explained it to him is I got to know him just as much as he has to know me and plus there are a time period I went with an out of Indianapolis (inaudible 1:06:21) or something. He's...

**Jean Ridgeway:** I also know that some... You made mention that the MDS Foundation actually has on their webpage, you guys can help me figure it out, but they have like "Centers of MDS Excellence" and recommendations. Now...

**Q23:** That's where I go to (inaudible 1:06:41)

**Jean Ridgeway:** And I honestly... I mean, it is a bit of paring like some personalities work better with one personality and another. I have a lot of colleagues and sometimes patients feel more comfortable with one doctor than another and... but it's hard... it sounds like you're very frustrated and if you want to talk afterwards we can talk offline about maybe helping to find... I don't know how close or far you are from here. Some people travel pretty far it sounds like to come here, but maybe we can help you with some ideas. Sound good? Alright. Next?

**Q24:** My name is (Attendee). My original journey with this disease started about five years ago on a routine blood test. My hemoglobin was down at seven and I talked to the doctor and she calls me now the poster boy of Vidaza because I'm back up to 15.

**Jean Ridgeway:** Oh, my.

**Q24:** But in regards to this gentleman what he said about other doctors' opinions. When I first went to see her I remember this...

**Jean Ridgeway:** Come speak into the microphone a little bit.

**Q24:** I remember this. When I first went to see her I went to get another opinion and she found out about it and she was a little perturbed, I think, and she said, "Well, I'll give you another five people to see if you want," but that's the only bad thing I have to say about her, but she's been right so far and my wife and I do we come to these things or try to get as much information as we can about the disease and that's why we're here.

**Jean Ridgeway:** Okay.

**Q25:** My name is (Attendee) and I'm the caregiver and it's been very informative today and one of the things that you talked about was the transplants which originally because my husband is going to be 75. They told him because he was diagnosed at 70 that he really was not a candidate and, of course, he is doing well right now, but it still kind of gives me hope that if that, again, like you said there was a lot of assessments you would need to do before you make a determination if he would be a good candidate, but it's just refreshing to see that in a sense there still might be hope if the Vidaza does stop working which the doctor, unfortunately, says at some point it probably will.

**Jean Ridgeway:** And we live in an era, too where we're beginning to see drug development in these "myeloid malignancies" become a reality. For many years things were relatively stagnant. Vidaza and Decitabine over 10 years ago were the breakthrough drugs for MDS and now we're beginning to see a lot of other compounds targeting like what's wrong molecularly with the disease, go through clinical trials and, hopefully, some also to come to market relatively soon. So, one more person we have here who I heard that you live on an island.

**Q26:** A 35 square mile island, Washington Island, 100 miles north of Green Bay and I am the patient who went through acute lymphoblastic leukemia as an adult in 2009. I believe I'm a miracle person having gone to Seattle Cancer Care Alliance in 2010 to go through a bone marrow transplant was my sister's perfect match and one day during that transplant for those of you who are headed that way I told the charge nurse that I needed the bed out of the room because I didn't want to be the patient anymore and just mentally in that 100 days of being in the hospital I needed to believe I was in my living room. So, I have been an advocate for myself

because my husband could not handle what was happening. A doctor prescribed a pill to sleep, a pill for depression, a pill for anxiety and he had a breakdown. I have been his caregiver since 2010 with Alzheimer's and now last November he's enrolled in hospice in our home and we have six adopted children ages 14 through 22, four of them in high school right now and it's amazing what God can do. When we talk about resiliency and reserve it is spiritually for me finding that way of healing and renewal through each one of the challenges we face, but in November of this past year my counts began to drop, I went back to Seattle. They gave me a DLI, two of them now, but as people begin to say this could be MDS and you never treat MDS with Vidaza and the counts keep going down. I started Vidaza... excuse me, yes, you never treat MDS with DLI. I went to a MDS specialist in Madison in April and he said you needed to start Vidaza yesterday. So, I went home and within two days I did began course two and I want to know about the Vidaza pill because during those first seven days when my clinic 100 miles away from me was closed I drove 400 miles in two days to get shot number four and five in Green Bay. So, I'm fighting for my life and I came here to meet the army. You are the first MDS patients I have ever met. I needed to see you face to face and I needed to get more information because where I live in remote rural Wisconsin the first RN who injected my Vidaza said that this could be tricky. The needle can clog up and her record is having taken one half an hour for the injection, but she has tricks with the plunger and I told her that my dad is a scientist and that I remember making earthworms with clay when I was kid. Let's make earthworms and warm that up. It's a viscous substance and it'll go in and I taught her. So, I'm trying to stay on point. I'm trying to be engaged. I'm trying to heal because I'm a caregiver for a family and I am not ready to die yet. This is my first forum, but I get a little information all the time and I discovered Stuart from the Make a Match Foundation. I got eight free counseling sessions with Olivia from the Make a Match Foundation and now Stuart is a clinical trials researcher and he told me about the MDS website where you can get all the forums with the transcripts and so I read the Tampa 2016 52 page transcript to get a bunch of information because he said you really don't need to go through the stress of traveling all day to get to Chicago to come to this forum, but by the time I read one of the transcripts I realized I had to get here because there's so much good information that we're going to learn. Thank you. I'm so glad to come here.

**Jean Ridgeway:** That's quite a bit of resilience. Unbelievable to come all the way. So, we're glad you're here.

I'm going to try to flip the slides. I have some slides. We don't have to go through them, but as I do that if there's another question, any burning questions before I kind of flip these things over. Questions? Pardon me while I do that.

**Q27:** I have a comment. I don't know in Wisconsin or anyplace by where you're at, but there's the Cancer Wellness Center that... well, that we go to that's here in Northbrook in the Northside here in Chicago and it's been wonderful. They're free services and they do psychological training, they do yoga, they do (inaudible 1:15:29). I mean, all kinds of things, massage therapy, all kinds of things. They have a library with all kinds of books in there. It's called the Cancer

Wellness Center and I know they have several of them here in the Chicagoland area. I don't know about Wisconsin or any other place, but they're great and they're free and we've been helped a lot there just meeting people also that have cancer and talking and that might be a suggestion for anybody, the Cancer Wellness Center.

**Jean Ridgeway:** Great. Thanks. It depends geographically where you live what's available. I think it's quite a rarity to find a "patient support group" that's geared towards folks who have MDS. So, this may be the closest thing that you find to it. There's an organization called the Leukemia and Lymphoma Society, LLS. Sometimes they have these WebEx forums where you can simply call in, listen to a national expert and kind of be part of a support group that way, but finding out what's available in your area if you just put in 'support group' plus your zip code. That can be helpful as well. So, I'm mindful of the time.

So, we touched upon this, I think. I hope that during my time of discussion with you that you feel free to be very interactive. A lot of what I'll be going through is material that's already been discussed by my colleagues, but hopefully it'll be a reminder and perhaps a more understandable format for you because it can be pretty advanced.

So, when we look at Myelodysplastic Syndrome oftentimes the question comes up when do they start treatment? You spoke that you're in a wait and watch kind of situation and so not everyone who gets diagnosed with MDS starts treatment immediately. Certainly, there are some and we talked about that scoring system, the IPSS scoring system, but not everybody has a high risk disease that needs treatment right away, but in general when the workup is done which requires a bone marrow biopsy we look at the need for transfusions and so oftentimes that transfusion need begins to be the trigger for when do you need to start disease modifying therapy. Another trigger might be for some people anemia is not a problem. Most people anemia is the problem. Right? More than 85 percent of patients have some type of anemia that's going along with their MDS, but for others it can be their white count that's low or even their platelets and so if those things over time when you come in for the wait and watch they're still drawing a CBC. Right? So, that complete blood count and what the team is looking at is the white blood cell count, the red blood cell count and then the platelets. If those things over time begin to decrease and you may even start to have an effect on your life you can do less, but you're not very active or perhaps you start having infections, speaking more to a lower white count then that might be a time to start treatment.

Another thing that gets looked at is the number of blasts that you have. So, in the biology of how our blood is created the mother cell for our blood is something called a stem cell. So, we talked a lot about stem cell transplant and what's going to... for that therapy you receive somebody else's beginning origins of your new blood and immune system. Now, in normal biology of the stem cell it goes through this transformational process where a stem cell becomes a baby cell and then it grows up and it lives its useful life. So, in MDS we look at white cells, red cells and platelets and part of that maturation process the cell becomes a blast. So, it's normal to have a small

percentage of blasts in your bone marrow, but not very many. Less than five our colleagues tell us. So, as that number begins to increase we know that the cells are being stopped in their maturation and re-accumulating and staying around for a long time. So, if the blast count in the bone marrow begins to rise that also is a trigger for your physician to say let's talk about starting treatment and when we look at... Dr. Kosuri made mention of that MDS is kind of a trajectory. It's a moving line. So, in MDS if you have maybe two to three percent blasts and then you may have five to nine to 10 when you get up to that 20 percent mark we say the disease has transformed or changed into acute leukemia and so acute leukemia is treated differently than MDS because the biology of it behaves differently or if you are diagnosed and you're diagnosed with a higher risk disease then your team is going to say we need to start treatment. (Attendee)?

**Q28:** Does the blast number show up on the CBC?

**Jean Ridgeway:** So, a blast can show up on the CBC.

**Q28:** I mean, is it one of the statistics on the CBC as you know the...?

**Jean Ridgeway:** If it's present it will be in the differential. However, what the doctor's looking at is the blast in the bone marrow because when people have blasts out in the blood it's like a warning sign. Things kind of go warning, warning, why am I seeing the blast? We shouldn't see blasts in your peripheral blood. That really is not normal. It's a sign of disease or disorder. If people are getting Neupogen sometimes the blast cells can be in the blood and some people live with low levels of blasts in the blood depending on their MDS subtype, but it's something that has to be individually teased out. Some people have like low levels, one or two percent. If it's present the differential will show it. Now, I can speak to our laboratory. When we see you in clinic we get your CBC, but that differential usually isn't ready until after you've left. So, if you have a patient portal and you can go on the website and you can look it up you may see it, but oftentimes when we're seeing you in clinic during the visit because it's done both by the computer. Right? All these tests are usually run by computer, but then the technicians they look at the slide under the microscope and are manually counting it. So, oftentimes it's later. Dr. Odenike.

**Toyosi Odenike, MD:** (inaudible 1:22:31 – 1:22:58)

**Jean Ridgeway:** Sometimes not. So, if you can't hear here over there Dr. Odenike is saying that in some centers when the CBC is all done via the computer it's not... it doesn't show up on the differential that it's categorized as something different. So, that was about blasts.

So, we talked a lot about treatment. So, those are some of the triggers. They're not all the triggers and, again, I think part of the relationship and the pairing of you with your physician team is they get to know you. Somebody made a mention of like they want to know their doctor and their doctor to know them so that they can really individualize their treatment because treatment

selection really there's a lot of all the factors that relate to your health feed into making the right decision for you.

And so we look at fit or frail. So, that's when we talk about performance status it doesn't mean put your suit and tie and give us a performance. What we're talking about is how fit are you. So, you don't have to be somebody who's running a marathon. It's more about can you walk a city block or can you walk down a country road for 10 minutes and not get short of breath? Can you physical do that? Are you fit or are you someone who's in a wheel chair who needs someone to help with bathing and food prep? Are you frail? So, those are different terms that we use fit versus frail and then you've heard the term now comorbidity. So, what other health things are going on in your life? Do you have diabetes, is it well controlled? Do you have something wrong with your kidney or your liver? Do you have a movement disorder like Parkinson's disease or MS? Those are all bundled into it and then it's all about the risk category. Right. So, Dr. Odenike talked quite a bit about the IPSS risk category and if you simplified it further you could say that MDS oftentimes comes in two flavors. Low risk and high risk. So, when low risk what we want to do is support your blood counts and that's more of the goal of that therapy. When you have a higher risk disease what we're trying to do is to control the disease and prevent it from evolving into acute leukemia and so we see therapies for IPSS to at high risk more geared towards starting the therapies. Clinical trial, Azacitidine, looking at transplant plus or minus. Whereas people who have a low risk disease may have anemia. Right. So, they need transfusions, maybe they're receiving Epopen for a growth hormone to make their blood counts go up. So, it's very different because not two people with the disease are exactly the same.

And then you want to look at primary versus secondary. So, (Attendee) was sharing that she had ALL which is a leukemia and her doctors have informed her that she now has something called a therapy related MDS and we say that because she's had chemotherapies for her leukemia that do we know what caused it? Oftentimes we'll point our finger at the primary malignancy and sometimes people get really aggressive treatment for that be it breast cancer, colon cancer, prostate cancer and those therapies that are used for this disease can give you... we point our fingers and say that could it have caused the MDS and so we kind of make this generic lump and sometimes your chromosomes help us understand that it may be a therapy related MDS, but is it a primary or a therapy related MDS and what needs to be treated and in general patients who have therapy related MDS usually begin on those treatments with the Azacitidine quicker than people who have a lower risk disease because we know how that their disease historically that's how it behaves.

And then we talked about cytogenetics. So, what's your DNA saying? (Attendee) had a question.

**Q29:** Yeah. I believe I'm in low risk. Will that eventually go to high risk or is it...?

**Jean Ridgeway:** I don't know.



**Q29:** Okay, but...

**Jean Ridgeway:** You've lived 12 years with low risk disease. Right?

**Q29:** Yes. Yes.

**Jean Ridgeway:** I will like... I don't have a crystal ball. I can't tell the future.

**Q29:** No, but I mean I just...

**Jean Ridgeway:** But for 12 years if you've had a low risk disease it speaks to that your disease is a low risk. So, your chances of evolving to a high risk especially because you have this long history speaks to that that's relatively low.

**Q29:** Now, I got miscellaneous things off of it, but it's not to that thing.

**Jean Ridgeway:** Right. Did that answer your question?

**Q29:** Yeah. Thank you.

**Jean Ridgeway:** Alright.

And then when we talk about individual treatment we look at lifestyle. Right? I live in the city. That's where my life is planted right now, but life and lifestyle really determine where you can be treated, what your treatments are. I live in the city. I just will own that. I would like to live on an island in the middle of nowhere, but I think it can complicate things. I mean, you live really far from a center that can treat you, but and that's not unlike a lot of people who live in the United States. They say 20 percent of the population in the USA lives rural, but another 20 to 40 percent live kind of in a sub-rural population. So, that makes a big difference and your lifestyle. Are you working? Do you want to work? When can you come in for your treatments? Can your clinic accommodate you? So, those are all working questions that need good answers and then what's your choice. What would you like to do? Are you willing... if an option for you is to do a clinical trial is that something that tickles your ear and you're kind of interested in or do you say I don't want to do that? So, lots about choices and other choices as well. Do you have to travel to Madison to be a participant in the clinical trial? You just live too far.

So, we talked a lot about this. These are pretty much the key principles in MDS. We know that an allogeneic transplant. So, that means getting somebody else's stem cell and that could be a sibling. It could be someone who's unrelated to you. We call those people MUDs, matched unrelated donor. You had a sister, so that would be a related or umbilical cords are another source of stem cells that we're looking more and more to, but all of those together create that

allogeneic transplant group, but we've heard a lot for some it's an option, for some it's not for lots of good reasons, but the horizon is expanding for folks who need an allo transplant.

And again, performance status, health and then fit versus frail.

The other piece is for those of you in this room who are in therapy and Dr. Odenike alluded to this is that it takes time for these treatments to work. If you're on Vidaza the standard is to complete at least four to six cycles before you made the decision is it working or is it not working because of how the medications work and how the bone marrow has to regenerate. So, these are therapies that unlike taking an Extra Strength Tylenol for a headache are not quick. They take time and it's hard to be patient when you're continuing to go for transfusion or your still on prophylactic antibiotics, but knowing that's an expectation that your blood counts may get worse before they get better I don't know if that was your experience or not...

**Q29:** (inaudible 1:31:26)

**Jean Ridgeway:** So, he's saying that with his treatment he got immediate benefit and that's great. We know from the clinical trials that for a lot of people that's not true, but it's great it was true for you.

**Q29:** (inaudible 1:31:40)

**Jean Ridgeway:** They're you go. They're going to start like taking your blood out of you soon. Right? But setting a realistic expectation and some of that is what Lauren and I do. When we help patients through treatment we share the care here. We see patients with our physician colleagues and we talk with them back and forth and at times you're able to see both of us, sometimes you see one of us and not the other but to know that that's a relationship that's really a conjoined relationship and it's a joint management, but to help you through to know those expectations are expected and then looking at being proactive and being here is being proactive about your treatment as well and helping to get the best response.

So, this is a little cartoon. We haven't seen hardly any. We saw a couple funny cartoons from Dr. Artz, but if we look at what's going on in the bone marrow. So, this first slide it's going to build on each other. So, before the treatment begins what this little piece of the slide is showing is that the red disks those are red blood cells and then those purplish kind of cells those are healthy and non-healthy neutrophils or blast cells and the little yellow cells those are platelets, but usually as the blood counts in MDS begin to drop most people will seek care for their MDS because of their symptoms or there's two groups of people, people who have like a new provider or are seeing a healthcare provider and they get a CBC done which a lot of times in primary care is not the norm. They check our cholesterol and... but they don't a lot of times check the CBC. So, other things are going to drive you to go see the doctor. You're short of breath, you're really tired, weight loss isn't something that necessarily goes along with MDS. Some people have infections

and so as the normal cells get crowded out by an overproduction of abnormal cells we begin to see the blood counts drop. So, they actually get crowded out in the bone marrow. So, the bad cells overtake the good cells. It's kind of like the weeds in my garden at least. Somehow the weeds just tend to do better than the normal plants and left untended they tend to really have a survival advantage and it's the same thing with the cells in your bone marrow that the abnormal cells tend to have a survival advantage as they crowd out the normal cells.

So, as you start treatment what begins to happen is that the bone marrow stops producing the abnormal cells, but it begins to be a little empty and so not a lot of cells are being produced at all and so you can see a drop in your blood count and so the figure on the top is just showing that that this person had a neutrophil count of like 3,200 when they started, but then you can see the dramatic decrease as they were working through therapy and so even at the eight week mark this person's blood counts were very low until the next couple of cycles as they began to level off and what then begins to happen is that the bone marrow can regrow and the normal cells are beginning to grow as well until it shows up to be a healthy bone marrow, but that's where the key is. The take home point is that it takes time with treatment and that's that challenging part if your blood counts are going low and you're not feeling well that hopefully that you're prepared to know that and that people can help you get through that part.

So, sometimes what happens to people, but not all people is that during that time they may get an infection and so then the treatment has to go on a pause. It's not to your benefit to treat you if the blood counts are low and you have an active infection. So, there's a bit of a delay and that can be really frustrating for people because it's like I have this problem, I want to get treated, let's keep moving. So, there can be delays or there can be a decrease in the amount of the drug that you're getting the dose and know that supportive care which is your transfusions and your antibiotics those are going to stay on until your blood counts demonstrate that you don't need them anymore. So, when did they stop? So, what we do routinely is for people who have lower white blood cell count we'll put them on usually a combination of prophylactic or preventative medicine so they don't get infection. Something for bacteria, something for a virus specifically the herpetic virus. So, we put them on Acyclovir and then oftentimes something so they don't get a fungal infection. That might be Voriconazole, it may be Posaconazole. So, those medicines stay on to help protect you knowing that your blood counts aren't yet ready to recover. So, four to six cycles usually if you're starting out with either Azacitidine or Decitabine.

So, that was a simplistic overview of all the stuff you heard at the very beginning.

So, looking at being an active partner in your care can look very different for every patient. Really, I think more than anything helping you to be successful in your treatment is helping you to maximize your treatment option. So, (Attendee) was saying he's looking for a second opinion. At least that's what I thought I heard him say. I don't want to put words in your mouth, but trying to strategize what's really best for me and going forward with that and so maximizing your treatment option for some may be taking the initiative and asking your physician about

clinical trials or asking about a second opinion but really being involved in your care and a partner and you want to always ask for help and you want to stay well. So, one of the things if you're not active already by at least walking I would say one of the best things that you can do to help yourself is begin some type of carve out daily activity. So, walking is medicine. It's a great place to start. It doesn't cost you anything. You can do it at home. So, you can try to use the excuse of bad weather, but you can walk up and down the hallway or you can walk up and down the driveway and it's a great place to start. Just remember when you go you have to come back, so don't go too far and you want to turn around and come back. So, we recommend even with our patients in transplant. So, when we see our patients in the Top Clinic, we tell... our expectation for them is having 30 minutes a day of intentional exercise. You can ride a stationary bike, you can ride a regular bike, you can walk, you can swim. There's a lot of different options, but that will greatly help you. Yoga is great. There's a million different exercises and so if you live far away, YouTube is a great resource. You can put Pilates into the YouTube and do a Pilates class at home. You can do a basic exercise class without joining a gym by just flipping to the YouTube channel and put something in there, but it's very, very helpful for you and we know that the number one way to battle fatigue believe it or not is to be active. So, I would encourage all of you to do that and then in your little packet was the *Building Blocks of Hope* and that's book that's all about MDS and different facets of wellness care to help empower you to stay healthy. So, take a look at that and if you want more of them you can order them or you can download them off the website as well.

Now, how many people in this room own a smart phone? Most people. So, there's a new app on the MDS website. I'll see if I can do it live on the computer to show you all the different options. So, one of my colleagues, Sandra Curtin, has been working really hard with the MDS Foundation to take all the pieces of being an MDS patient and MDS care and put together it as an app. So, you can put your contacts in there, you can track your lab values, you can manually enter them. It has a live interactive access to like the American Cancer Society. There are cancertrials.gov. I think you got a flyer in there. It's a free download. You can do it for an iOS phone, so like an iPhone or you can do it for an Android or you can put it on a tablet and so you can go through and actually like put in your CBC and then you can kind of track your numbers as well. So, it's a great new tool that's out there for you and you can download it either through the App Store or from the website.

So, how do you maximize your treatment option? For those of you in this room with the diagnosis or even the caregivers, you want to ask the provider what's my IPSS score or what's my IPSS-R score. So, learning that about yourself. Your health information belongs to you. It's totally appropriate to ask for a copy of your blood counts. A lot of institutions on electronic medical records. You can get copies. You just have to get into the patient link, the patient portal I call it and then you want to learn about your blood counts and most people... most patients have a better understanding of like where their blood counts are than anyone else. That's your health information. So, you kind of... have things stayed the same? Have they got better? Have they got worse? So, people track their blood counts and then using tools to help you track it. So, you can

put it on an Excel spreadsheet. There's all different types of tools. If you look at chapter five of that little book, you don't have to right now, but it gives you some tools to do that as well.

The other thing I would suggest to you and I agree with Dr. Artz people who are a little pesky they probably have the best control over their healthcare because they're taking charge of it. So, write down your questions on a piece of paper. It's like going to the grocery store. If you don't go with a list you're going to forget the thing you went for. So, when you come to see the doctor write your questions down and ask the questions that you need answers for and be prepared. So, you can write it on a simple piece of paper, you can put it on your iPhone in the note section, but go prepared and ask questions. Many people have different prescriptions. So, if you're prescribed something ask questions and follow up with the medicines that you're prescribed. We're going to ask you about your symptoms, how tired are you. I try to use a thermometer. It goes from zero to 10. Zero is nothing. Ten's like either the worst or the best of something. So, if I ask a person how tired are you today? Well, I'm at a five. Well, are you always at a five or are you at a five today and is there something special? You had a busy weekend with Mother's Day or you were out late last night, something but help people understand how the MDS is affecting your life with your symptom and then you also want to... as you're going through the treatment you want to ask your doctor what can I expect from this treatment? What are the expected side effects? Am I going to feel better? Am I going to lose my hair? Am I going to feel worse? And then like Mark helps us it helps me especially like what type of financial programs are out there for people with MDS? Are there grants to help with transportation? So, the Leukemia and Lymphoma Society does have some patient assistance programs that can help with travel. If you track your miles. Right, Mark? If you keep a receipt from your parking that they will reimburse you. So, Mark's in the back and he told me he has cards with him. So, if you have some questions he's free to take... you can take his card and his E-mail and if there are questions that Mark might be able to help you with I'm not really sure, but he's made that available. So, because there are some grants and many times organizations will have some type of grant assistance that I just don't know about, but Mark does. So, that's helpful.

What else can you do as far as your health? You should definitely be your own advocate, be active, ask questions, have honest discussions with your healthcare team, make your wishes clear. Are there things you definitely want to do? Are there things you definitely don't want to do? One of the things that we do in the Top Clinic is we talk to patients about advanced directives and power of attorney. So, power of attorney is if you can't make a medical decision for yourself, who is going to do that for you and in many states that if you're legally married to someone that defaults to that person or it defaults to your next of kin. So, I would encourage all of you to have conversations with your family members about what you want done and what you don't want done. I say that gives them the freedom of carrying out what your wishes are instead of trying to read your mind when they can't talk to you. Questions?

**Q30:** Not really a question, but a comment also. With this disease and also with any disease there's so much terminology and so much information that it's hard to keep it in your brain all

the time and I know that I've asked the same question probably three or four times to our doctors and I say that to him. I go, "I think I asked you this the last time I was here, but can you explain this again to me?" because it is so much and your brain can only hold so much of it and sometimes even your brain just shuts down because you don't want to deal with it anymore. So, don't be afraid to ask the questions as many times as you need that answer and the doctors will... they understand that because they know this isn't easy and the different aspects especially of MDS is difficult. So, don't be afraid to ask the same questions over and over until you really understand it.

**Jean Ridgeway:** That's good. I find that writing things down is helpful. I think not only for myself, but then for people as well to write those things down. We have an electronic medical record, so we can type a little note and so when folks go to leave they can pick up the written information. So, having a record kind of keeping system is good and so the shared decision making is like what's best for you as a patient and what is really well understood in the medical community is that shared decision making is the best. That's you having a conversation with your medical team and coming to the decision of what's best for you with all the available options and all that other stuff that we've talked about before because what your preferences, goals and values are and your medical condition have to be paired together. So, it's really us. It's a team effort and it takes your active participation in what to do.

This is just more about how do you make the most out of every visit. Think about yourself. As you're driving to the appointment since most people have to drive somewhere. Not very many people live around the corner the doctor's. Most people don't make house calls. Think about what is it that you want to get out of the visit. Why are you going? What's the information that you want to know and write down the top three things that you want to talk about on that visit because focusing on that, again, is going to make the most of your time. Preparing questions for your visit is a good idea. Start with this list and take it with you and then when you go home at night you can review it again. We have some patients who record the conversation. If a spouse is working or a caregiver and they can't be at it it's not uncommon where we'll go ahead and Facetime somebody in or they'll call in to hear it. Going in you think you're repeating the information correctly, but it's easy to forget information. So, don't be afraid to do any of those things and that personal support that Dr. Artz made mention of having like a life coach. The caregiver life coaches is another person some people bring an additional person, that's fine, in with the visit.

So, you want to keep your oncologist most people see a hematologist oncologist. You want to keep them up to date. So, if you're somebody who's doing really well, maybe you're not in therapy. I mean, you haven't seen your doctor in a really long time do them the favor of saying oh, yeah, what's happened since the last time we saw you? Oh, well, I fell down and broke my hip or whatever. So, keep them up to date with what's going on with you. You may think it's insignificant or I was hospitalized three times with pneumonia since I saw you last six months ago. Some of the information that you give you may not think is meaningful, but it can really be.

Hopefully, keep a list of their prescriptions. We go over medicines every visit. The number one cause of re-hospitalization in the United States is medication errors and if you see more than one doctor you may have more than one prescriber. So, some things play well in the sandbox together, other things should not be together. So, make sure that you're keeping everybody informed. Make notes on the signs and the symptoms that you're having if it's something alarming for you can E-mail your provider, you can phone them or just make mention of it. If you're in between visits, say, you're not coming back for a month but something happened then call and say you know what? I think I need to come in. Something's happening. And then transfusions. For people who live far away maybe they're seeing a doctor really far from where they live and they get care in a couple places. If you keep track of your transfusions for those of you who get transfusions that's very helpful information. I didn't get any transfusions since I saw you last or I've been going in every Monday. I get a unit of red cells every Monday. So, that kind of thing are helpful and any tests. If you ever like say you saw your primary care doctor and they're like, oh, we need to do a cardiac stress test, bring the results in. It's very, very helpful. And hopefully when you leave your physician you're going to have a clear understanding of what's going on and what the next steps are, what to anticipate. That should really be an expectation on your part when you leave the visit and who do you call, how do you call them, how do you get into the system.

We talked about caregivers already and like when to ask for help and I'm just going to go quickly through this, but there's actually a painless way to help organize help for you. You can do it on the web. So, one of the things if your white count is low that you really shouldn't be doing is like active gardening and mowing your lawn and cleaning out your gutters and so when people ask you jeez, are there anything I can to do help? You say, well, as a matter of fact there is and there's a painless way to organize help. This website is actually linked into a calendar and people can sign up to help you and do whatever. So, for people who are going into transplant it may be providing meals. So, they do kind of like a meal train and then you can post specific helps that you might need on the calendar for people who like to do that. So, that's something that's out there and available so that volunteers can do that. So, this is just kind of how it works. They get linked up to a calendar, it coordinates the calendar. It doesn't take that long.

Other things. What can you do to stay healthy? Please move and walk and do what you like to do. Be an active participant in all the things that you like to do. A good balanced diet, eating healthy. If your platelets are low you want to avoid things that may cause bleeding like no rugby. You wouldn't want to do that. So, infections, bleeding. Make sure that you're getting enough rest, but that you're also being active.

These are just some of the other lifestyle things that you potentially could do to improve your outlook with the diagnosis. Exercise. We talked about this already. So, it's the most single most... it's the single best thing that you can do help combat your fatigue as well and then nutrition. Stay well hydrated as we move into the warmer months. Get your nutritional ingredients from food. So, like eating a whole food diet. Make sure that you ask if there are any

food restrictions because of your blood counts that may or may not and just limit your alcohol. If you haven't quit smoking, please quit smoking. That's a good thing. You want to get a flu shot every year and people who live in your household should have a flu shot. If you haven't had an update on your TDapp. That's that tetanus and diphtheria. Your caregiver should do that, but if you have MDS it's not recommended you get the live virus vaccine for shingles because it's a live virus, but people who live in your household can do that if they meet the age requirement. This is just about bleeding, manage other things that are going on with you. Make sure you've got a good list and a current list of who your doctors are if you have a kidney doctor and a different doctor having that list available is healthy. The World Health Organization talks about palliative care which is really supportive care for patients and then this is the book and kind of goes through the six chapters of what it all is. The Quick Tips offers some quick tips about nutrition, exercise, gas, some constipation. Number five is really looking at your plan about MDS and this is the manager, the MDS Manger app that you can download as well.

So, I told you I'd get you out of here in time. It's two o'clock. So, and then there's the website for the MDS Foundation. So, it's two o'clock. If you feel like you need to leave you can leave. If you want to ask further questions that's fine, too. Otherwise just about maintaining hope with your diagnosis. Hope is... and this is from Emily Dickinson that hope is a thing with feathers that perches in the soul and sings a tune without words and never stops at all. So, hoping that you can all remain hopeful as you go forward and that if you need more information we're here to help you.

So, that's it.

(Applause)

So, Dr. Odenike and I will be around and Lauren and Mark are in the back as well.

**Toyosi Odenike, MD:** Thank you to the MDS Foundation organizing this. Thank you.

**Q31:** Is there a chart or where does one find research about when to lower a dose or withhold a dose of Vidaza?

**Jean Ridgeway:** (inaudible 1:56:58 – 1:57:05) but the doctors have their guidelines, their prescribing guidelines that the physicians can follow for dosing.