

Speakers:

Erin P. Demakos, RN, CCRN

Erin Demakos: How's everybody doing? You're good? You're tired? It's been a lot of information. What we'd like to do is just kind of open it up to you guys and start the conversation, maybe share some stories or some helps. I don't know, (Attendee), if you want to... You have a lot of experience, you and your wife, and just try to let people feel like this is a... No questions are stupid. I don't know if I can help answer anything to my best of my ability not being a physician. I'm happy to do so, but I know it's very overwhelming. I know a lot of the words can be really confusing. So, in the booklet as well, we recently updated the glossary of terms. So, that helps. You can refer to that. I would highly recommend going to the website for other links and more information. Like I said, the booklet has embedded videos in it. So, it can explain what bone marrow biopsy is. It has user friendly tools. So, it's not so overwhelming. I think writing down your questions as they come to you immediately, do so so that you can bring it to your physician and to your nurse team on your next appointment because you're going to forget. I mean, I write down things all the time and have like little alerts and bells and whistles, knowing that you have to be your own advocate and to research and definitely ask questions. Physicians are not going to be offended. If they had this disease or any other type of disease, you'd get second opinions. You ask questions. So, I know their item is limited, so that's why I'm always saying try to make your priority your top three questions because they're addressing when you're being seen that day along with other patients and only have limited time and then maybe carve out some other questions for your nurses and your team, but I'd like to really kind of open this up for you guys to discuss some more, share stories or concerns and... Yeah, (Attendee).

Q1: The number one tip I give other patients which is take somebody else with you to your appointment. We discovered talk to the doctor, you ask your questions, you hear all this information and hope you can understand it and then a half hour later what did he say? What did she say?

Q2: Or you would only hear what you want to here.

Erin Demakos: Absolutely.

Q1: That's always going to be a problem. If you have somebody else taking notes or writing down or checking that you asked the questions it really helps.

Q2: If you can't take someone, you can tape it on your phone.

Q1: Or you can record it.

Erin Demakos: Let your physician know when you're recording.

Q3: Just go 'beep' periodically.

Erin Demakos: Like was in the slides, but not everyone, unfortunately, has someone that can go with them but you ask friends, you ask neighbors, if your family members I think that's why Lotsa

Helping Hands is a really great tool that's going to do the work for you and you can just keep adding phone numbers and E-mails and don't feel intimidated because the roles were reversed they would want to do the same thing for you. So when you're feeling well, you can repay them by doing some simple gesture by just making... having a little meal and say come and sit down because I know you have a lot of guilt. People have a lot of guilt. The caregivers, everyone that's helping you. It's so important... I'm in that age bracket where both sides, my husband's mother because his father passed away at a young age and my father passed away a couple years ago. I'm taking care of both of them and I have three kids and I have a fulltime job. It's very hard to balance things out and so it's important for us to think of ourselves as well in the process and making sure that we're taking care of our health because 30 to 40 percent of caregivers overall... there's caregivers.gov or org website that also has nice little tips to share with caregivers to help organize things for patients and loved ones that they're caring for, but like 30 to 40 percent have other comorbidities and are neglecting the dentist and are neglecting their own health. So, just remember the people that love you very much want you to be well and vice versa. So, we have to help each other and just make sure that you lean on friends to also come into the picture and help you to come and take mom or dad or your brother, your sister, your cousin to an appointment while you take care of yourself. So, very, very, important.

Yes?

Q4: There is a lot of cities that have caregiver conference units, etc. that you can contact. It's not only just for MDS. It's myelomas, etc. is done through the Leukemia Society, etc. You contact your local leukemia and find a caregivers conference. I know my wife and I go monthly.

Erin Demakos: That's wonderful. Can you share a little bit more that you've gotten from going to the conferences? Something that might...?

Q4: We get guest speakers in, etc. and we share our stories, etc. and how I burden this one right here a lot and they help out, try to... In fact, I just had a stint in the hospital last month in the last month because I crashed. I mean, all my blood levels went. I got four units of blood and spent a couple days in the hospital.

Q5: But he's still in the tank. He just keeps dropping.

Q4: I keep dropping, but the caregivers supposed to go into the conference. They send me a good wishes, hope you feel better, etc. They're waiting to come see me on Monday. Let's hopefully I can make Monday's appointment to see them. It's different sharing of different cancers all together.

Erin Demakos: Cancers, dementia, Alzheimer's. It's the same... It really is.

Q5: It's very good. It helps you connect with people that like... especially the caregivers so that they don't get so stressed out or feel like they don't have anyone else that can relate to them and they even sometimes will offer to give you a break so that you can maybe go off and have lunch with a friend.

Erin Demakos: They'd let you know locally what your resources are and that's wonderful. Thank

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you for sharing that because I think that that's very, very important and through this whole process. So, that's great if people can definitely look into the caregiver.com website. Thank you.

Yes?

Q6: I got something to share. Somebody talked about being cut off from a drug.

Erin Demakos: Aranesp.

Q6: I got a tip. My oncologist told me that to get Medicare to pay my hemoglobin has to be under 11 and it helps that I have another contributing factor, kidneys. So, I think sometimes you could go in there and be hydrated and not get your shot.

Erin Demakos: So, be dehydrated and go into the office?

Q6: Yeah or the testosterone. So, I learn all these little tricks.

Q7: You got to work the system.

Erin Demakos: And it is about working the system unfortunately, but...

Q6: I mean, it's unfair if you're hydrated, but you still have the low hemoglobin. You still get the shot, but the doctor can't get it approved, but I got a question about hydration. If I'm a little dehydrated now and I drink three glasses of water, will I be hydrated within, what, an hour or two or does it take a long time to...?

Erin Demakos: It takes a while. It takes a little while for that to be able to...

Q6: A half a day or so?

Erin Demakos: I mean, I would just be careful. I know what you're saying to shrink your... you're not on any medication right now.

Q6: I am.

Erin Demakos: You are. What are you on?

Q6: I'm on the same thing that...

Erin Demakos: Okay. Alright.

Q6: That's why I was concerned when he said they were going to...

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Erin Demakos: Well, like I said it's... I think it's depends on the case worker that's reviewing files because we might not have a problem with a bunch of our patients. It depends on the insurance carrier. It's very different, but again your physician needs to...

Q6: Well, he told me Medicare under 11 he can give me a shot and get paid for it, an expensive shot

Erin Demakos: It's very expensive. That's why when it's helping a symptom but not doing anything for the natural history of the disease where physicians are saying now it changes for you because maybe your blast counts are going up and we need to start a drug for you then they're going to make that decision, but sometimes it's added to the recipe. You might be on Vidaza and still get Aranesp in the beginning until you start to respond to treatment or to Decitabine, but these are very expensive drugs. In the beginning, physicians were using Erythropoietin and growth factor. Dr. Schiller mentioned some of that information in combination can yield really good results, but if you had a very high erythropoietin level which is inherently normal for patients with MDS, EPO isn't going to do anything for you. Your body is not able to tolerate that and then if you have a high transfusion burden on top of that and a high erythropoietin level you should not even be getting EPO. So, it depends on where you go. Again, you'd have to do your homework. You know the website is a reliable website and it has information because you can get a lot of wrong information, get a lot of wrong information from patient blogs, people will say certain things. It's not from a scientist. You have physicians that are going to practice differently and like any other type of cancer. You might get two different opinions and when to start treatment, when not to start treatment, but I just think a balanced diet, definitely trying to keep yourself hydrated. If that's working for you that's great, but I would be careful that you don't get too dehydrated because that can be an issue.

Q6: That's what I have the secrets. I walk to the doctor's office to get exercise and it was a hot day and I was dehydrated and I think that's what got me over 11. I didn't think about it to drink water.

Erin Demakos: Well, it's the same thing with your kidney function and things like that. We know that when patients are dehydrated then their creatinine and their other levels are going to go up and then that might not make them eligible for a certain chemotherapy treatment or we might have to back down on the dose because we think they're having kidney toxicity issues. Meanwhile, let's like let's hydrate them and then all of sudden things normalize. So, go both ways. Just be careful.

Q6: Well, a good doctor helps take it a long way. I was lucky I got one.

Erin Demakos: That's good. Yeah?

Q8: For a new patients to stay off of the website because stay off the web because information is so all over the place and in California they've got a group called We Spark which is I think they've got groups all over the... in other parts of the country that give you free services. I'm part of a men's group of all kinds of cancers. So, it's good to know that you're not alone and that you do have support groups and they have a lot of free services as well as well for your caregiver and they're out there and as far as what's paying for your copay there are so many foundations out there that can help you a) for the copays if you reach out, talk to them and 1) always be advocate for yourself so that you

can talk to these people because some of the copays are 800 or 1,000 or more a month and if you play it right and you talk to the right people and if you get turned down by one, go to another because there's I think... Audrey sends out a list of like five or six or seven different people that are resources and if you're paying a high copay go to these resources you'll be able to get somebody to pick up at least part of it for you.

Erin Demakos: I know Celgene is very good. They have Revlimid and they have Vidaza. They do have some good network people in there that will help with that.

Q8: I called up the Patient Access Network, PAN, and over the phone they approved me and my CVS that provides me with right now JADENU they just bill the Foundation directly. I don't even see the invoice. I don't have to pay it and go try to get a refund. It's all taken care of. So, everybody lets the rules take care of them and what they have to do is they have to take care of themselves and if you get turned down get a preauthorization and so on.

Erin Demakos: The preauthorization is huge and a lot of nurse practitioners are licensed to be able to do that in lieu of the physician. So if you have nurse practitioners in your practice, bring it up with the physician. Say I'm having a problem and they will definitely guide. They won't know if you don't tell them. Don't be embarrassed. We're used to hearing all of this information. We want to help. Like you're saying you got to be your own advocate and you got to make it work for you.

Q8: The insurance companies are going to say no before they say yes.

Q9: What is a preauthorization? I don't understand that.

Q8: A preauthorization if your doctor sends a letter saying that you and your condition needs a specific drug that they perhaps have said no to they will take it to their board and they'll look at your situation and they'll approve it. When we have the Novartis meeting and I was Exjade and then when I got switched to JADENU which is the new version of it my insurance company said no and I got my doctor to do a preauthorization and now they're giving me the drug and it's covered for the most part. So, you got to get the approvals. That's all.

Erin Demakos: Sometimes they can be very difficult and they want lab results, they want all kinds of stuff sent to them. Sometimes it's just getting on the phone...

Q8: I had to go to four different levels to get it approved, but my answer to them when they said they can't approve it. I said then you're signing my death warrant and they... and I said, "Now, do you want to do that?" and they went, "Well, no. I can't do that." I said, "Who do we go to?" and every time they said, "No," I said, "You're signing my death warrant," until finally I found somebody who said okay and it sounds terrible, but you have to be that graphic with these people in order to get them to move on your behalf.

Erin Demakos: Have you not all been paying taxes and been paying for Medicare and getting the support? You're entitled to it. You have to sometimes, unfortunately, you do have to fight and I've

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been on the other side of the phone and listening to my physician as well saying, “You’re going to kill my patient. Do you understand this? He needs this. Give me somebody that actually knows what they’re doing.” That’s what he’ll say that actually understands what I’m talking about.

Q8: I actually said you’re signing my death warrant.

Erin Demakos: So, you have to ask. You have to ask. If you’re running into any of those problems bring it up to the nurses, bring it up to the doctors. They’ll know how to work the system as well and say this is what we need to do.

Q10: Just to let you know I was recently approved by (inaudible 16:23) electric company for reduction in my billing based on a compromised immune system. So, I (inaudible) that (inaudible)

Erin Demakos: That is great.

Q11: We didn’t hear that in the back here. What was that comment?

Erin Demakos: Repeat.

Q8: What, the whole thing?

Q12: Just the information about the...

Q10: I’m saying contact the gas and electric company. Have your doctor complete the (inaudible 17:30) and you’ll qualify (inaudible) compromise (inaudible). So, I (inaudible)

Q11: And they waive the bill every month?

Q8: Not waive.

Erin Demakos: Yes?

Q13: Now you (inaudible 17:58) health (inaudible) situation. I live alone and when I have to do the smallest test and the (inaudible) nobody will drive you because of the risk factor (inaudible). Is there any organization somewhere where you can turn for I don’t have help for like two or three days and so on? Who do you turn to?

Erin Demakos: Do you have Access A Ride and things like that? How do you access...?

Q8: I don’t know if you call the hospital and especially... (inaudible 18:36)

Q13: There’s social workers.

Q8: But the social worker will arrange for...

Q13: I'm there.

Q8: I'm not going there, but if you call your doctor or the hospital they will arrange for a pickup for you.

Erin Demakos: They have their own contacts, each practice, and it's true. Believe it or not a lot of places don't even have social workers. They just don't have them in every clinic.

Q8: But if you go to a hospital they do.

Erin Demakos: Right.

Q14: Major hospitals.

Q13: And of course there's only younger friends and they all work so here we go.

Erin Demakos: No, but they'll know and I know at our hospital we have an issue going on as of two days ago because one of the big Access A Rides companies went bankrupt and now they're trying to work, scramble around and work out.

Q14: You might call the United Way, too, because they sometimes have...

Q13: American Cancer Society.

Erin Demakos: American Cancer Society will have links local to your group.

Q14: The Leukemia Foundation, Caregivers.

Erin Demakos: The Caregivers. They'll all have links.

Q14: (inaudible 19:49) have people that will take you.

Q8: All kinds of social organizations.

Erin Demakos: It's not really that much work when you go to one site you pick up that phone like you're saying even the American Cancer Society is just general for all cancers or the Caregivers like you're saying. They'll know locally who's available that there are people that just want to help other people and they're saying I'm available to drive in this zip code region anybody that needs to be picked up to go to the treatment center. So again, if you put it in your plan and have those numbers down once you make that contact when you need it then you know. It's there. Sometimes I get too organized. I'm like, "Where the hell did I put that?" So, use your book.

You had a question?

Q15: I was wondering (inaudible 20:37) how far (inaudible)

Erin Demakos: She says some of her appointments are 60 to 90 miles away and that's a whole different...

Q16: You might find somebody that wants a day trip. There are people (inaudible 21:03). They're retired and don't have anything to do and they want to help.

Erin Demakos: Like I said the Leukemia Foundation because it's a blood disorder versus American Cancer Society which is like a lot. So, try... and the Caregivers site would hopefully be able to make the phone calls and make some... and like you're saying they might want to do a day trip. That might not be that big of a deal and people want to help. So, definitely reach out in that way and I'm sure than you realize out there. It's just very overwhelmed with all the information. It's yet another thing on your to do list, but it's an important thing then I think if you'd make that contact that would be very helpful for you.

Q8: You're really not alone. That's important thing.

Q17: My doctor says I have a low metabolic rate and that affects my bone marrow's ability to produce adequate blood cells. Could you comment on that?

Erin Demakos: How old are you?

Q17: I'm afraid to say. Eighty-eight years old.

Erin Demakos: Eighty-eight? God bless you.

(Applause)

Erin Demakos: That's incredible. That's great. Unfortunately, no one likes to hear this, but as you age things do slow down. You're 88 years old. Your metabolic rate that's just... it's probably appropriate for your age and so we have to just... It's the same thing as like when you're taking medication and you're taking certain things it's going to be absorbed and processed at a different rate and a different way. You might be a little bit more hypersensitive. When you get to 88 before you could take a certain drug, now you can't, you're intolerant. It's because your bone marrow is slowing down. It's called senescence. It's just age. It's just normal. So, that takes a little bit longer for your bone marrow to just function. You're 88 years old. So, it's just part of the human body and its function.

Q17: I have another question. I received some promotional material from the City of Desert Hot Springs and they say there was hot mineral baths can cure various blood diseases. Do you know anything about that?

Erin Demakos: I do not. Does anyone?

Q18: They do it in Europe a lot.

Q8: It's probably a scam though.

Erin Demakos: I was going to say it probably makes you feel better, the mineral stimulation, but it's true in Europe they're all about the sea and the natural waters, but it probably makes you feel a lot better and it is (inaudible 23:56). Yes?

Q19: I have (inaudible 24:05) going in for a bone marrow transplant (inaudible) and this has just been such a shock for us (inaudible) had three Vidaza so far and he seems to be doing okay which (inaudible) every two weeks he has blood transfusions. It's usually (inaudible). What do we get to experience (inaudible) I'm not sure (inaudible) get to really look forward to. I hear it, but I'd rather hear it from those who had the experience.

Q20: Let me tell you a little bit about what happened to me. You have to keep in mind that it was 17 years ago and the kind of treatment that I had is very different than what they do now. What they do now is much gentler in many ways on the patient. The patients keep their health throughout the process. They don't feel... I was in the hospital for seven weeks which doesn't really happen to people now without some sort of serious complication. A lot of times people are in and out in 10 days or less to me is just totally amazing, but it's because the treatment is much more focused. So, they're a lot better than they used to be about minimizing the toxicity of the pre-transplant protocol, doing enough without really making it so hard to recover or taking so long to recover and they're much better about managing the patient's side effects. So if you're someone who's very prone to nausea, there are a lot of really good drugs now to handle that, blood pressure problems, itching, whatever it might be nurses are very focused on patient care and all of that makes it much easier to tolerate and much easier to recover from. The other difference is will you be having stem cells do you know?

Q19: No. They said there's going to be five days... two days of one kind of chemo then you rest a day and then there's five days and then they give you the IV for that. They keep you then for approximately two weeks to four weeks depending on how you're accepted somebody else's bone marrow and then we move to another house outside of the hospital because we don't live here in Los Angeles any longer. We just have to move... just at the wrong time, but that's (inaudible) and we stay at this other place for anywhere from two weeks to a month which is very close to UCLA and I'm hearing about things where your skin is itchy or tight or from the... all these little things that I really hadn't anticipated and I appreciate hearing how you managed through this.

Q20: After the pre-transplant chemo, I had total body radiation which is not something they typically do anymore. It's a more...

Q19: They're going to do some kind of chemo then something...

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Q20: Radiation for me was the worst part. The chemo was not a problem. The radiation was, honestly, the most difficult part of the whole thing for me, but once that was over I didn't really feel bad. I wouldn't do anything. I just had no energy. So, (Attendee) can tell you better because the parts I don't remember he remembers really well, but it was really from that point just a matter of recovering and it took a long time. It was just not really being sick, but not being able to do anything which is frustrating.

Q19: Is that about a year?

Q20: It was less than that. I mean, when I was first home I just slept. Got up from the couch to eat dinner with the family and went back to the couch. Not like having the flu, just it's a different kind of a fatigue then when my counts...

Q21: If you survive the first 100 days that's the key.

Q22: Yeah. One hundred day is a big milestone.

Q21: One hundred days is the key.

Erin Demakos: That's when you start to engrafted.

Q20: Well, my graph came on the 17th day. So, it was 17 days with no immune system, zero white cells. I was in isolation in the hospital. People had to be gowned to come in and visit me and on the 17th day you're doing regular blood tests... on the 17th day I got .01 or something. Okay, this is the beginning of it and it just went up gradually from there. For me the platelets were always the hardest part. So, my platelets came in last maybe 50 – 60 days down the road.

Q21: Actually if you got a computer you can go to Robin...

Q19: I'm really mentally challenged when it comes to...

Q21: If anyone knows Robin Roberts from "Good Morning America," etc. she actually had MDS and went through a successful transplantation, but it was slow work riding her (inaudible 29:21).

Q20: I think her sister...

Q23: Her book is excellent.

Erin Demakos: Sally Ann, her sister and it's on the MDS website.

Q20: (inaudible 29:29) on her in here.

Q19: Okay. Great. I will.

Q23: Her whole book is very well done. I would definitely read that.

Q24: There's one other thing probably worth pointing out. When we looked at the forms they gave us that said here's all the possible side effects and effect of your transplant. Everything that can kill you from A to Z. If you worry about every possibility clearly you won't survive, but actually every patient has some subset of those problems. You may not get the itching. You may get a rash. It may turn purple, but what usually happens is very individual. You only have to cope with the few things that are for your case. You don't have to worry about every possible thing that can go wrong. Some people have GVH in a different part of their body than another. It's completely related to how the other person's feeling. So, you only have to deal with the little subset that happens to you and all the nurses and all the doctors are there to help you. It gives you a lot of confidence knowing it's just one thing to get through.

Q19: Looking at all that stuff because it was making me crazy. I just thought oh my God. This is insane. So, I just kind of started going day by day doing whatever the doctors say. I just can't get into a lot of that stuff. It's so overwhelming and I mean, it's...

Q22: Get your support system up and running now so you can... because it's going to be a daunting task.

Q20: And you're going to have days where you're going to be so exhausted from taking care of him that you don't want to deal with anything and that's where your help make you a meal and bring it in.

Q19: Thank you.

Erin Demakos: That's why that's Lotsa Helping Hands so you don't have to be on the phone all the time. That's your chain and everybody can look at their schedules well in advance and say I'm available this whole week and I'm available between 3:00 and 6:00 even if it's in the beginning to be with you at the hospital or just to relieve you so that you can go home and get some rest and somebody's with your husband. Let that be the work. Appoint somebody that you really trust to be able to be the gatekeeper. If you don't want to do that there's somebody, one of your best friends, would be more than happy because most of the time as you guys know people want to help. They just don't know how to and there's a lot of people that are task oriented and just saying give me an assignment. I am there for you. So, whatever your needs are. If it's just the food shopping, somebody helping around the house, walking dogs, whatever your needs are this is... you just get to make it. So appoint somebody your ambassador because then... and don't worry about it. Don't feel guilty about it because all your friends and their family members they love you and they want to help. They just don't know how and they don't want to bother your brain. Like you're saying it's so overwhelming

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and that's okay. So, listen from the schedule. If all you can handle is what do I expect? What do we have to do this week? What do I have to...?

Q19: Or five minutes...

Q25: That's more or less where I am.

Erin Demakos: And that's okay. A lot of people have been in that situation. Even me standing here I didn't even though I was a nurse and my grandfather was diagnosed, I knew nothing about MDS. I didn't know anything about oncology. I was open heart surgery and all these words were just as foreign to me as they are to you guys and this is all we do in my practice. So, it's MDS and leukemia and I do it every day and I've been doing it for 20 something years and every patient is different.

Q19: (inaudible 33:15)

Erin Demakos: But I just I think you're okay and it's good that you're expressing that because I bet you a lot of other people are sitting around here and you're saying exactly what they're thinking.

Q19: I know that I'm not alone and I know that I'm thinking the same way everybody else does. It's just that it always helps when you hear it from others who maybe experienced something that I'm going to be falling into or not. I have a pretty good idea. We took care of parents all the way through. So, we know what that's all like, but at this point when it really starts getting even closer to home and you're just kind of where are we? I appreciate it. Thank you so much for sharing.

Q26: One of the other things you might want to do too is get to know your neighbors.

Q19: You know, we just moved and the neighbors there are extremely nice and they all kind of stepped up. So, it's very surprising, but they do. I mean, it's amazing. It's just amazing.

Q26: In my community here if they don't see me out and about they let her know.

Q20: Or they'll come an knock on the door and they ask if there is anything we need. Do you want us to take the dogs for the day or like to come to the conference our next door neighbor kept our dogs so that we could come down early so he could rest.

Q19: Thank you. I am kind of cultivating at this point. Thank you.

Q26: That way they can check on you and make sure you're doing okay.

Q27: So, we go to a lot of information and data and this and that. Many times I went to a crossroad where I really, really, really wanted to go to a mental health professional to get me on an emotional thing (inaudible 35:22) that information (inaudible) and either I don't know where to go or the health professional is really not edged towards illness or something. So, is there an avenue that specializes in that and do we have connection to it?

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Q28: You're in LA .Correct?

Q27: I'm in Newport Beach.

Q28: Okay. Well, I don't know if there's a We Spark down there, but if you call up We Spark they provide counseling for both men and women and they have a tremendous... they have a lot of people there especially women with breast cancer and all kinds of cancers and MDS and they provide counseling services and it's free. We Spark. So if you call them they might provide a sister company or another branch down in Newport Beach, but I know they're all over LA and they give you exactly the services that you just said you need.

Q27: (inaudible 36:28)

Q28: They do it and they have it both in group and individual.

Erin Demakos: Leukemia Foundation, too. I mean, all of them you ask the question they can get you the direction. Social workers will get you the help, but it's nice that they provide that for free because that's what patients really need. They have enough bills dealing with everything else.

Q28: It's all donation based and they do a great job.

Erin Demakos: That's awesome. Thank you for sharing that. I didn't even know about that. It is a national thing?

Q28: They're regional. I know they've got places throughout California and (inaudible 37:12) if you're in Nevada. Yes?

Q29: I'm (Attendee). I'm 64 and I was just diagnosed with I have high risk MDS on the last day of the year December 31, 2015. I do want to say I'm an RN, but I can't believe I'm overwhelmed and I even know the medical terms. So, people who aren't, I would think that would be so difficult to learn all this stuff, but anyway what I wanted to say was since I'm starting I believe treatment on Dacogen this week and the hematologist I've... I finally got a good one. I went to two terrible ones and they were basically saying no treatment. Go home and die sort of... I mean, they didn't use those words, but that was the message, but anyway I am finally now starting treatment at Norris (sp? 38:25) with a very good hematologist hopefully this week, but one thing I wanted to say is in my adult life I've had a pretty good life, but I've also had to suffer a lot from a chronic neurological condition and when I got this I was just really angry, I guess angry at God. It's like now why do I have this? My children are having my grandchildren and then I would look in those rating charts. One year to survive and I thought oh wow. This is not good, but anyway since then I've gotten a lot of hope that... but it's a tremendous job taking care of yourself and your caregivers and I know now I'm going to have to get a lot of help and anyway I really appreciate having this forum and meeting people. So, I hope we can do it some more. Dysplastic anemia and MDS International Foundation also has additional support groups.

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Q30: By state. So, California got about 10, 10 of them by name so you can...

Q31: Do you live around here?

Q29: Oh, I live in Pasadena.

Q31: Well, check out We Spark because it's been really, really helpful for us and we also went through looking at the chart. According to the charts, you should be dead by now.

Q29: Yeah.

Q31: Don't look at that.

Q29: I started reading all that material and the doctors chart and I was scaring myself so I stopped reading.

Q31: No, no. You can't do that. Even the doctor...

Q29: What was it called?

Q32: We Spark.

Q29: Oh, you wrote that down. Thank you.

Q31: (Attendee)'s been going to group there for...

Q32: Five years.

Q29: Oh, wow. Alright. Great. Thank you.

Q32: You get to learn about all kinds of other cancers.

Q29: That's alright.

Q32: You know what? I'm going to tell you. I feel lucky I have MDS because when you get people who come in with brain tumors and they have colo-rectal cancer or prostate or breast cancer and what they go through. It's okay that I've got MDS because I've been living pretty well, a normal life. I get blood, but I'm not going through the pain, the torture of having something removed or having to cut me open to pull something out. So, we have that as a plus by the way.

Q29: That's true. Thank you.

Q33: You're a wealth of information.

Q34: When I was first diagnosed my original diagnosis was aplastic anemia which is just bone marrow failure, bone was empty. My hemoglobin was four and (inaudible 41:55) and when we had to learn about the disease and learn about the relationship between aplastic anemia and MDS we looked at each other and thought thank goodness it isn't MDS because that would have just been...

Q35: It was preleukemia.

Q34: It was preleukemia but it meant chromosome involvement and so forth. So, we went about two years in that world where I was treated for aplastic anemia and gradually as I improved they were able to get better sample of my bone marrow and then we discovered it was really MDS and we looked at each other and thought now we're really in for it.

Q36: I've got a question. Are they doing anything...? Like I've got Q5 deletion which means my fifth chromosome, the short antenna is giving bad instructions to my bone marrow. Is there any kind of research being done right now which is going into the chromosomes to affect the change?

Erin Demakos: Well, that was Lenalidomide. You were on Lenalidomide, so we knew that was effective so in working that. So, Dr. Schiller touched upon just a little bit of the different medications and we talk about targeted therapy he was talking about targeting the 5Q.

Q36: And that worked for a year and a half and then it stopped working.

Erin Demakos: But there's lots of other drugs. If you go onto the clinicaltrials.gov website you'll see... you can just Google 5Q and see what clinical trials because there's a lot of other... they might add Lenalidomide back to the recipe in combination with something else for you.

Q36: I know somebody's trying to do that in Florida with the Revlimid and the Vidaza.

Erin Demakos: And the Vidaza. That's what I'm saying. It's like Vidaza is just like think of it as like vanilla ice cream and now you want to add a little strawberry to it or a little chocolate or a little rocky road. It is about combination therapy because the disease is so complex and we don't know all the pathways necessarily and what is making you different than somebody else and that's where that whole world of mutations which is different from your chromosomes. Dr. Schiller didn't present specific stuff, but when we're talking about you're going to hear mutations on TP53 and all these other mutations that are inherently known in a lot of MDS now, but what does it mean and what drugs are going to be targeted to affect those mutations and down the road. We don't know and we don't want to... Now like I said three years ago when they started figuring this out like what you talking about put the BRCA1 gene in breast cancer, TP53 in MDS. It's not a good mutation to have. What drugs are going to target specifically TP53? Several years ago it was only three mutations. Now, we're studying 40 and there's a lot more but coming from the meeting in December which is the American Society of Hematology. It's called ASH and that's with 30 something thousand members are there. We're all there listening to the scientist the lab people, the clinical trial people. What's the future not just in MDS and the leukemia? We're all trying to figure out about these

mutations and drug targeted therapies and we're all going to have mutations as we get older. We're living... my kids being young are going to live with knowing about diet and environmental things and how we improve our exposure to certain things are going to live well into their 90s, over 100 and God willing, but as we get older we're going to acquire mutations. So, we're studying that all the time in New York and a lot of these big cancer centers are looking at the time that they do a bone marrow biopsy on you besides our chromosomes what mutations do or do you not have and then what we do in New York and a lot of other places when they're repeating your bone marrow if it's just at a routine standard time if you're responding to a treatment or if you're not responding to a treatment... say you're responding to a treatment. Did that mutation go away? Did you acquire any new mutations if you're progressing and what does it mean? So, we're still trying to analyze things because it is like a moving target. What does it mean and what does it matter and so we don't know, but we... unfortunately we are moving the field forward in a very fast way on a molecular science lab base. We need to get these drugs off the shelf and approved by the FDA in a quicker way, but they want... It took forever for the Azacitidine and Vidaza to get approved. It took forever, but now at least... like I said these clinical trials you have 200 centers across the world. MDS is not unique to the United States. You have the top doctors in France, the top doctors in Germany that are seeing all these patients there as well and want to have the same kind of answers. It's a disease it's just culturally things are different. They don't have access to what we have access to in the United States, but they're participating in these trials so we can figure this out. So, more and more work is being done and like I said we have rechallenged patients that have been in remission and we've given them Azacitidine again and they have gotten their response back. It might not been as good as before, but then they become transfusion independent again and they're kind of holding steady.

Q36: My doc said... I said, "Well, can I participate or would I go to some of these trials?" and he said he looked at me and he said, "Why? You're doing very well on just transfusions." He said, "If we knew that something was working for sure and that you wouldn't be participating in a trial that perhaps harm you why would we put you at risk if we know that you're okay with just the blood," and I can't argue with his logic, but I'm so proactive I want to get involved in doing something because it's my life and he just says, "Well, wait. Stay where you are right now and we'll just play it out." So, play it out.

Erin Demakos: You've been with the same physician through the whole course...

Q36: Yeah, but I've got to City of Hope. I've gone to SC. I've gone to Cedars and now my exposure to UCLA and I went up to San Francisco and I've talked to as many people. I've gotten as much information as I possibly can and then Audrey, of course, has been fantastic in guiding me to different places and I've talked to Moffitt, whatever and I know exactly where I am and I want to do more because I'd love to do more.

Erin Demakos: Well, you are doing more. You shared with this group a great site that no one knew about and, I mean, you've said it several times. You have to be your own advocate. It's as overwhelming as it is with the information you do need to seek trying to get to a center of excellence and unfortunately it's very said. There are many patients that don't have access to a center of excellence and they're just getting suboptimal care or whatever that physician... but if they're not

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well read because the field is constantly changing. They don't have the finger on the pulse. What's different? It's a different look. Sometimes you don't even have to do a blood test. We'll say to the patient... You're not feeling well, what's going on? And of course, "I don't know. I've been doing so well."

Q36: (inaudible 49:09) eye to see if it's white.

Erin Demakos: You got to continue that course and seek out on your own this information and make sure that they're doing the right thing.

Q37: Are they doing more DNA things?

Erin Demakos: Well, it's the whole mutations. It's about your chromosomes and about mutations and looking at if they're doing that that's something you'd have to ask your physician. Have you done a mutation analysis on my bone marrow or my blood? Right now we can do it by blood. So when he was mentioning, Dr. Schiller mentioned that sending it out to this particular lab there's a couple of labs that do it but to see what your profile is separate from your chromosomes, but it's all part of the plan.

Q37: (inaudible 49:54)

Erin Demakos: You have to see. Got to see if they've done it. Maybe they've done it and haven't said anything, but they should... It's kind of like standard in the MDS world that this is the new thing. There's a question in the back and then I'll get right to it.

Q38: Actually, the MDS Anderson website has a lot of good information.

Erin Demakos: Which one?

Q39: MDS Anderson.

Erin Demakos: The MD Anderson website.

Q39: Because they're doing that moon shot right now.

Erin Demakos: (inaudible 50:16) It's another big...

Q40: (inaudible)

Erin Demakos: Yes.

Q39: They're coming out with things every day so it's to keep up with things.

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Q41: (inaudible 50:28) this might be more politically inclined, are there organizations that are working with the FDA to try to release some of those (inaudible 50:37) on getting these drugs approved because there's so many subcategories, are they somehow working with them to explain to them what the situation is so that they can ease up on some of the restrictions?

Erin Demakos: Well, Dr. Silverman actually, the physician that I work with, has gone to the FDA, was at the FDA just for Vidaza, for Azacitidine. He sat in front of that panel multiple times and educated and mentored these physicians on the other side. This is a rare disease because the drug was an orphan drug then it was acquired by a company then that company sold it to another company, but you want to get it approved. So for a lot of these drugs that are in development, these pharmaceutical companies will go to these experts like Garcia Manero from MD Anderson or Contagion (sp? 51:31) that have worked on the clinical trials when they get to the next stage for the FDA to look at the data. Like Dr. Schiller was saying it's about survival. Well, survival is a big thing. They want to make sure patients are benefitting from the treatment and living longer because of the treatment, but that shouldn't be the sole criteria to get a drug approved. So, all of these physicians are sitting amongst the panel of the FDA experts going there's more to this then, but still allow us to ease up on it because it is a subset of a subset of patients with MDS now. It's different categories of the disease as we know. So, some of these drugs... There's another drug that is called Rigosertib. It's by a company... it's a small company, Onconova, and we're doing a lot of the trials. We've done a lot of work with this, but it's for patients that have failed Vidaza or Dacogen. So, it's an HMA failure and they're launching yet another trial because the FDA goes and launch another trial. We see benefit. Patients do respond, but they respond also in combination with Azacitidine. So, Azacitidine seems to be the kind of like still the drug that you're able to because of profile for the side effects is very manageable. Your counts can be managed, but you can add other things to that drug and still be able to handle it. So...

Q42: But is there a public advocacy component to the FDA's work? It's all the FDA asking for evidence from doctors, but this...

Erin Demakos: Yes, it's science.

Q42: ... any can we as patients.

Erin Demakos: You can. You can try, but they sit there with the experts that were showing the data because they always want to see the science and so the physicians sit there. I've never seen a patient advocate in front of the FDA at all. You need the Robin Roberts. Robin Roberts puts... You need somebody famous that's going to say this... here you go. This is what I went through as a donor and this is what my sister was going through and be the match. People need to be out there so donors have options. People don't have matches. So, she's driving that moving forward. So, unfortunately it does. It takes somebody famous to put a face on what is MDS. MDS is young and old. Right now in our practice, unfortunately, we have a lot of young 20 year olds with this disease.

Q43: I would think that if the FDA, the people in the approving (inaudible 54:01) knew what the specific...

Q44: (inaudible 54:07)

Q43: Yeah. If they knew how they can help best and I think the problem is getting that message through to them and having to explain and having the experts there to explain that this is what they're approving and not approving and this is why they don't have the population approved to do that and they...

Erin Demakos: We might be getting there. You know why we might be getting there? Vice President Biden's son dying of brain cancer. Why do you think the government now all of a sudden now wants this whole campaign on cancer and research and moving maybe the door will open up a little bit a little bit more and they need to look at the FDA. Why is the process so long? I absolutely agree with you and I see a glimmer of hope in that in happening because it's the first time you've heard anything from the government saying they want to spend more money on research and figure this out.

Q44: The more people that get it then...

Q45: (inaudible 54:58)

Q44: Yeah it probably is.

Erin Demakos: That's if you get diagnosed. It all starts with diagnosis and not everyone gets diagnosed. They die of other things before...

Q44: The more benzene and chemicals there are in the air the more people that will get it. So, that effect a cure faster. Fifty years from now.

Erin Demakos: Yes?

Q45: These bone marrow test reports that we get are impossible to understand for the lay person. Is there a good reference that a lay person can go to to understand these terms and what they mean?

Erin Demakos: Well, on the website don't we have a nice breakdown for patients to look at in terms of the bone marrow and the reports? I thought there was a link in there. Not even what it all means though. I thought we had like a little section on that.

Audrey Hassan: (inaudible 55:57)

Erin Demakos: Well, in the *Building Blocks of Hope* we do, but I don't think it goes into like everything like morphology and...

Audrey Hassan: (inaudible 56:05)

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Erin Demakos: We need to look at that further, but it is very complex. It's not always so easy, too, for... it depends on how the pathologist reads it. It's often... I shouldn't say often, but at least a couple times a month Dr. Silverman who is renowned in the field, is very experienced will go to the pathologist and go, "This doesn't make sense. I don't agree. I'm going to look... I want to look at this result. Let's sit down and look at the bone marrow together." He reads the aspirate and stuff like that. So, you can get an interpretation what does it mean because sometimes between your chromosomes and what's going on in your marrow, your chromosomes could be a whole lengthy list of things and it's just Xs, Ys, Ts, Ps, Qs. It's very complex, but I don't think between the aplastic anemia and the MDS Foundation you can really get...

Q46: They don't have anything for lab reports or biopsy.

Erin Demakos: Yeah. Maybe we should put that up so that...

Q46: We really have to start by asking your doctor what's important in this lab report and what does it mean?

Erin Demakos: Right. Circle it.

Q46: You go home and you see your...

Q47: Hemoglobin count. That's what's important.

Erin Demakos: Well, they'll say hemoglobin or they'll say the blast and they'll circle and they'll say...

Q46: A dictionary won't help?

Erin Demakos: We have a glossary of terms but in terms of the way the report they can visually look very different at every different place and how they come in, but they're looking at immature cells which is your blast. So, they'll always say your blast count. We'll say to patients, again, maybe your counts in your peripheral blood they're not reflective of what's happening in your bone marrow. I'm more interested because your bone marrow blasts were 18 percent when we started. Now, we've done even though you're still transfusion dependent, maybe your counts are still not great, but you went from 18 percent to 10 percent. You're seeing a reduction in that already in the bone marrow. That's something important a physician is going to focus on and say to you that's what I want you to focus on because it starts from the marrow and then the cells mature and go into your peripheral blood. So again like I said even though your hemoglobin is low, if they say to you, "Well, look. You know your last transfusion was three weeks ago. Before you could barely get through seven days. So, your transfusions requirements are lengthening, but still need them, but that means your body and your marrow is starting to produce normal functioning cells so that is eventually going to kind of go away. So, it is very complex. Yes?"

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Q48: I have a question people ask me a lot and I ask myself what causes MDS and they don't really have anything except either we don't know or toxins. Is it just our toxic environment and radiation? I mean, have they ever done any studies about like are there certain heavy metals in our blood for people who have MDS? It's frustrating for me because I've always tried to take good care of myself and so far I don't have any other medical diseases. So, has there been anything about that looking into a cause?

Erin Demakos: Yeah. I mean unfortunately...

Q49: I think I can help her. In the February issue of *Life Extension* magazine they have two issues, one at the health food stores which is a bimonthly issue, January and February, and the other one is at the newsstands which is the February issue. They have a beautiful article on toxins and the environment and the effect on all of the different functions of the body and I think at *Life Extension* magazine in February would be a great help.

Erin Demakos: Thank you for sharing that. We know that benzene chemicals is definitely a contributing factor. Smoking. What we know at least from the history that's one of the things that physicians and nurses want to collect information. What possibly could have been your exposure? For years we were treating patients in New York that were stripping furniture with chemicals never wearing a mask and so you wonder those chemicals and breathing in those chemicals for so many years because back then they just didn't wear masks was an issue. Farmers that were using lots of pesticides and just dusting their crops without wearing a mask and they were inhaling that stuff. Over time something is going to possibly get altered. At Mt. Sinai we have the World Trade Center program. So, anybody that was willing and wanting to be monitored and followed after the 9/11 attacks on the buildings and police officers and first responders and nurses and doctors that were exposed we were watching them over time and unfortunately some of the 20 year olds, a bunch of the 20 year olds were literally 10 years old and 9 years old at the time are now coming in and they have MDS or they have AML and they're New York City dwellers and have always been New York City dwellers.

Q50: How about living in LA in the '70s and '80s? It was orange air.

Erin Demakos: When you think about our environment, yes, we are exposed to lots of different toxins and why does it wreak havoc in my immune system and not somebody else's? What activates it? That's what they're trying to figure out. So, I'm a big... GMO. What is that? Is it going to impact on us when we're having genetically modified food over a period of time? You don't have that data. People are going to be looking at that. So, we have high dose chemotherapy and high dose radiation therapy will affect the bone marrow. That was Robin Roberts. She was a breast cancer survivor. She had high dose chemotherapy. Now, she has MDS. So, we've known that's unfortunately you're treated for one cancer and given drugs that were curative and working well back then, but now people are living longer and you have that 20 years post for chemotherapy. It's impacted on your bone marrow and it's altered things. So, that we know. Unfortunately 90 percent of the time you sit there and you go I don't have answer and that's the most frustrating thing. That was the same thing with my grandfather. Now when I sit here and I go... We call my grandfather PePa, because my

sister couldn't say Grandpa when she was little, so he was PePa and I was... and then for short we'll call Peeps and I'd go, "Peeps, let's think about it. When you're saying you're working for the American Chiclet Factory which is gum making think about all the stuff and the powders that were put on the gum and he was working the factory and doing plant stuff. He was exposed to certain chemicals. Could that have attributed to his MDS? No one else in my family has MDS. None of his children had MDS. Nobody else. We do see familial MDS. There's some... a couple people we're following, but who knows what that is. Is there some kind of genetic link there? It's not been reported that way, but you're still going to see it potentially. So, that's what's frustrating. You want answers. You want to know cause and effect and you want to know all the radiation that we're exposed to, our environment. I believe there's certain combinations there but they're looking at it in different epidemiology studies and things like that we're looking at and as a nurse you're probably saying was I exposed to anything in my profession and I don't... That's just something even as oncology nurses for years we were mixing up chemotherapy ourselves without even a hood and then or even if we were wearing a hood were we exposed to anything. Those are things that people sit and just kind of wonder about, but you can't drive yourself crazy because you will drive yourself crazy trying to think, but we don't have exact...

Yes?

Q51: Why don't the doctors do a toxin test on patients? In this type of environment, I'm sure the majority of the people have some kind of a toxin in their system.

Erin Demakos: No, I'm sure they do. It's very expensive tests. Where do you start? Where do you end? And what do people really want to know. I mean, it's the same thing that a lot of people don't want to know what their genetic profile is or what their abnormalities are because is it going to make a difference? Is this going to change things? This is the same thing with mutations. When we're doing the mutations what does it mean? Are we going to change therapy? Will that mutation always be there and are there certain good ones and bad ones? Like we learned about the chromosomes. Right? So, is having that mutation a good prognosis? Does it mean... because you're going to get them because you're exposed to something over time. We don't know. These are... lots of studies are being done on this though. I mean we are as a society looking into obviously much more better health, much more about air quality. Even after 9/11 they were testing the air constantly, but who knows what the particles and everything else that just flies all over the place and you're exposed to it.

Yes.

Q52: How can you measure? Is there a way to measure that the impact of low hemoglobin on the brain and how lower oxygen to the heart, lower oxygen to the brain and how it impacts those?

Erin Demakos: Well, it's very important. Like I said, it's very important. Everyone has their own threshold that they need to maintain, but you need oxygen, obviously, to your brain and your heart and decreased oxygen to your brain and your heart, I mean, they look at this with dementia. They look at this in Alzheimer's now. They're looking at is there that good profusion? You have to be careful. So, that's why your symptoms and how you're doing. My grandfather his little watch crew

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were the people that looked out their peepholes and said Mr. Murry's sitting on the second steps. He doesn't want to call Erin because I was working night shift. I'd get off the night shift, picked up my grandfather and bring him to a blood bank so he can get transfused and he didn't want to bother me, but it's like you have people that watch you and your friends and saying but when you're not feeling well, but you got to keep your hemoglobin up because it's important for your vital to all of your organs but definitely your brain.

Q52: I know, but what I'm asking is there a scientific way to measure it?

Erin Demakos: You're just getting your blood counts done.

Q52: No, but I mean the impact. Somebody told me that my hemoglobin reaches a certain point I got less oxygen to my hearts and less oxygen to my brain...

Erin Demakos: It's correct.

Q52: ... I'm going to have an impact on those...

Erin Demakos: That's what I'm saying. They're looking at that and how that's affecting dementia that you're chronically low and they're studying that. They're looking at other disease...

Q52: So, there's no way to do it now?

Erin Demakos: They're just looking at scans and looking at people that present to them with a diagnosis of dementia or Alzheimer's if they've had chronically low hemoglobins is this a big issue.

Q52: So, they're saying there's a link then between the two?

Erin Demakos: They're not saying there's a link. They're just saying that it's something that can make it be accelerated potentially more or basically more accelerated. It's going to just advance the disease because you're disturbing the brain. The more the active you can be and be more involved the better you're going to be overall. Please understand that. We see this with our patients all the time.

Q53: (inaudible 1:08:14) really tell you that you have enough oxygen in your body because like when you're getting blood test and so on they stick your finger in a little meter and shows 97, 98, and so on. What that is is the oxygen penetration in your body.

Q52: That's at the time the test is taken, but what about...

Q53: That's why you got (inaudible) You can't have the thing on your finger 24/7.

Q52: But I'm talking about if there's permanent damage created by these problems how do you measure it?



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Q53: Not unless your hemoglobin levels (inaudible 1:08:44)

Q52: From what I understand there's no scientific way to do it yet.

Erin Demakos: I think this...

Audrey Hassan: The binders (inaudible 1:08:54) we'd like to join that now.

Q54: Oh, it's already going on?

Audrey Hassan: It's going to be given (inaudible 1:09:02)

Erin Demakos: They're waiting. (Attendee) just has one question.

Audrey Hassan: I wanted to mention something. The patient who do the best are the ones who get involved with the doctor and learn about this disease and the fact that you guys are here and you're in that group. You're in the group that's going to be better.

(Applause)

Erin Demakos: Thank you, everybody.