



Speakers:

Roger M. Lyons, MD, FACP
Virginia E. Aguilar, NP

Audrey Hassan: I'm sorry to interrupt and also if you want to get a second opinion it's not that you can't do it on your own, but you can always contact me and I can arrange... I can E-mail Dr. Lyons directly and arrange it for you or any Center of Excellence wherever you want to go. So, that's another thing that the Foundation will do. They'll arrange second... we'll get you a preferential appointment with one of our MDS Centers of Excellence.

Virginia E. Aguilar, NP: So, but one website that all the oncologists I've ever worked with use is called NCCN Guidelines, National... NCCN and it's National Comprehensive Cancer... I don't remember what it stands for... Network or something, but, anyway, NCCN. It's free for everyone and you're looking at the exact same thing that I'm looking at that Dr. Lyons is looking at. Now, where Dr. Lyons is above and beyond and that's why you go to a hematologist oncologist is that he knows the latest research. He's involved in the research and so... and he can interpret some of the data that we look at and go yeah, whatever, or how to get that data.

Q1: Dr. Lyons, he's an MD.

Q2: He's a (inaudible 2:51) oncologist.

Virginia E. Aguilar, NP: Yes.

Q2: He normally does all the research and he's got (inaudible) on the horizon (inaudible).

Q3: Well, they're doing next generation sequencing here.

Virginia E. Aguilar, NP: We send out for it, but yes. It's done. Yes.

Q3: (inaudible 3:06) done. I was wondering (inaudible)

Q4: .org here?

Virginia E. Aguilar, NP: Just if you get in Google and put NCCN it'll come up National Cancer and it will be one of the first second link and you'll have to register with your E-mail and a password, but it's so much information and then you just pick disease type and any time you know somebody, oh, I've got a friend that's got breast cancer, now there's different types, but you can go and see why they're getting this treatment as opposed to that one. It'll tell you.

Q4: The National Cancer... which...

Virginia E. Aguilar, NP: Every kind of cancer. Every kind of cancer you've ever heard of.

Q4: I mean, what's the site on the Internet?

Virginia E. Aguilar, NP: NCCN. National Cancer...

Q4: Before that. What was the top number?

Virginia E. Aguilar, NP: Oh, www...

Q4: No. Is it National Cancer or Cancer...?

Q5: (inaudible 3:56)

Virginia E. Aguilar, NP: It says cancer.

Q5: (inaudible 3:59) in and (inaudible) come up.

Q4: Okay. That's what (inaudible)

Virginia E. Aguilar, NP: Yeah. It's Google it first. Google's my best friend.

Q4: Thought I had to go some other place first.

Virginia E. Aguilar, NP: Nope. You can Google it.

Q5: He wants to know what kind (inaudible 4:11)

Virginia E. Aguilar, NP: Yeah and I mean... It's pretty... I mean, it says breast. It says myelodysplastic. It says... and then there's... Yeah. Exactly and that's why you have those Building Blocks that great book because it helps you so that you can figure out exactly what types you have and you can write down what types you have and then you can go back and see oh, okay. Well, Dr. Lyons is treating me with this because this is what the guidelines say or he's not treating me with this, but he must know something that the guidelines haven't put in yet. Yeah.

Q5: (inaudible 4:44) a lot of time on the support groups that I work with that got MDS diagnosis (inaudible 4:50) all the time and they are bowled over when they find out that there's really only just the top of the (inaudible 5:02) couple of categories that it's going to be a problem. What if it went back (inaudible 5:06)

Virginia E. Aguilar, NP: NCCN.

Q5: NCCN.

Virginia E. Aguilar, NP: Uh-huh. Nancy-Cat-Cat... Yeah. Charlie-Charlie and then N again, Nancy. Or November for the military. And I bet you I haven't looked, but I bet you all have a link to that, too.

Audrey Hassan: It's in there. I wanted to say I would definitely utilize that there'll be (inaudible 5:34) literally nothing missing (inaudible)

Virginia E. Aguilar, NP: Unbelievable. It is a phenomenal website.

Audrey Hassan: I want get turned off by the volume of it. Everyone's different. I mean, I know patients that will be different (inaudible 5:46) but if you're not that type of person go to the section that you're interested on any given day and use it as a daily resource. Go to the section on what's new on the horizon to learn about what's currently being researched, what's in the pipeline for MDS. On another day you might want to go to nutrition. On another day you might want to go what is MDS, but I really urge you to use it because it's all up to date and it's the work done by all the top doctors in the field of MDS.

Q6: I think it would be good for your relatives that don't understand what you're going through.

Audrey Hassan: Believe it or not the university teaching hospitals, the academic cancer hospitals that are teaching med students are requesting that book for their medical library.

Q6: Good.

Audrey Hassan: So, it's a great teaching tool and I just urge you because I know (inaudible 6:40) and I (inaudible) but it's so important that when you had (inaudible) corner and forget about it. I still urge you to use it.

Virginia E. Aguilar, NP: Yeah. It's a phenomenal website. I'm not a big website person and I really thought that was a great website.

Q4: Thank you. I need that.

Virginia E. Aguilar, NP: So, another thing with MDS, I mean, I don't have it, so I don't know what quality of life issues people have. We've heard some of yours, but...

Q7: It all varies.

Virginia E. Aguilar, NP: It all varies. Exactly.

Q8: I had a discussion with my doctor this week coming up because he had an appointment with him. Okay what are my restrictions now because they're not the same as they were a year ago or six months ago. One of my doctors over there said awhile back probably the best thing I've heard from any of them. He said, "What's the point of me of saving your life if you don't have a life?"

Virginia E. Aguilar, NP: A hundred percent agree.

Q8: You know right (inaudible 7:35) go back to drinking scotch. Just don't do too much (inaudible)

Virginia E. Aguilar, NP: Just don't get crazy. Exactly.

Q9: Like why am I saving it?

Virginia E. Aguilar, NP: Exactly.

Q10: He also wants to go back to riding his motorcycle.

Q8: Oh, that's before Christmas that's going to happen.

Virginia E. Aguilar, NP: With the blood pressure, be careful.

Q10: If he can just get his platelets into triple digits that would be wonderful.

Virginia E. Aguilar, NP: I'm not sure that'd make a big difference on a motorcycle. Just saying.

Q10: (inaudible 8:06) machines.

Q11: I'll tell you my experience. So, I've only had... was diagnosed about a year and a half ago and prior to that I definitely had symptoms but I'm never sick. So, it was inconceivable to me. I didn't think I was sick, so I'm blaming everything on getting older. So, I was getting. I'm normally very high energy and I was tired so much. So, I thought well, you know, you're getting older and at the same time my doctor sent me to the hematologist oncologist. I also had to go the hepatologist. I had really high iron overload. I have this terrible bloodwork and I had Graves' Disease and which so I had to see an endocrinologist. So, all of my doctors assured me that these are not linked together. In my mind I can't believe they're that kind of coincidence. A person whose been healthy for years, but whatever it is it was, but so I lost a tremendous amount of weight with the Graves' Disease and I knew that wasn't just getting older because I wasn't trying to, but my color got really bad and my energy level and I was just thinking well, you're getting

older and it didn't occur to me, but I went for my routine annual and all of these things popped up on the blood. So, since then because the Aranesp injections that I get anytime my hemoglobin is below 11, I get a blood draw every three weeks and it's always low are helping me, but I feel that I never will and I certainly don't have the very high energy I had before and I did have to modify my... because of my decreased energy and... that I can't even sometimes get through like a whole... maybe by five o'clock I'm just... so two of my passions in life... I'm 78, but I still work, but I work part-time because I couldn't stand retirement and so work is one of my passions and it's a sedentary work and I work at home. So, if I'm having a (inaudible 10:12) day I can pick it up the next day, but my other passion was my hobbies of wildlife rehabilitation. That's 24/7. That is and I had to give that up and that truly... So, that was a major lifestyle change for me and that really broke my heart, but I couldn't make a commitment like with work if I can't finish my day and I'm just part-time, so I... you know, I can say oh-oh work on Saturday and make it up, but I couldn't say to a baby animal of which I get 50 to 100 a year of four different species, gee, I'm too tired to feed you ten o'clock at night. I'll feed you twice tomorrow. So, that was a modification in my life I had to give up which was very hurtful for me and other than that I think the tiredness and sometimes I seemed to be a little foggy brained and I think am I getting early dementia or is it the MDS or doc, no just that. So...

Virginia E. Aguilar, NP: Gotcha. I went to a lecture a long, long time ago with a lady that was a breast cancer survivor, but she was also a breast cancer oncologist and she said that the fatigue that you get is completely different than any fatigue you'll feel before you ever have any kind of treatment, chemotherapy or disease. I mean, she said there's no comparison in the world. So, providers don't have a clue really of what the fatigue is really like. We try our best, but we don't know.

Q11: Very draining. Very draining.

Virginia E. Aguilar, NP: That's what they say.

Q10: It's hard on men, too.

Virginia E. Aguilar, NP: Yes, because...

Q10: Who have been in positions of some importance in their working life especially the younger ones and there's so many younger ones.

Virginia E. Aguilar, NP: And it's a loss of control because now we're dictating everything. We're dictating you come and get your blood draw three time... every three weeks. We're dictating your whole life. It's a complete loss of control.

Q10: I'm only one (inaudible 12:05) because...

Q8: Just as along as she (inaudible 12:08)

Q10: I was getting so sad.

Virginia E. Aguilar, NP: I think it happens to (inaudible 12:13)

Q12: (inaudible 12:12)

Q13: I feel that applies to the women also because you're used to doing things that you may not be able to do anymore and you have to clip it. Just ask the good Lord to get you through it.

Virginia E. Aguilar, NP: That's okay I can hear you.

Q14: One of the hardest periods when I was going through all that chemo was thinking that I was losing myself and my mind and that I wouldn't be able to do anything and this body even though it was getting really bad that it wasn't... I wasn't even going to know and I wasn't going to know anybody I loved around me because I couldn't think straight and like you said being foggy and then I picked up a magazine at the clinic and the magazine is *Cure* and the reason I picked it up because when I saw it I thought ah and I thought I got to get up quick (inaudible 13:22) the magazine. It said chemo brain and that's the first time I ever heard about that because it was... the cancer was robbing my body of its life, but for me it was robbing me mentally and I thought this must be just terrible. That's why Alzheimer's is just the worst because you lose that person. So...

Q8: I used chemo brain is an excuse for along and she made me quit using it.

Q14: But that magazine, I'd recommend that magazine, a *Cure*...

Q8: Well, I do, too.

Q14: And that article made me feel better.

Q15: The last issue's got MDS (inaudible 14:05)

Q14: And it did get better when the medicine (inaudible 14:11)

Virginia E. Aguilar, NP: I think... I don't know if you've had treatment, but I know chemo brain exists, but I think that there's other aspects that we don't understand that contribute because a hemoglobin of 11, 10...

Q14: No oxygen...

Virginia E. Aguilar, NP: You know, it's less oxygen, but...

Q11: (inaudible 14:28) it was in the 9 something.

Virginia E. Aguilar, NP: Right and that's contribute. We just don't know everything about the human body and then, again, everybody's different.

Q10: He was fine. He was still working and collapse unresponsive in an elevator and we happened to be at (inaudible 14:44) Medical Center when it happened. They called me from the ER. (inaudible 14:49) what? He's never sick. What do you mean he's in the ER and then a week later they said yeah, he has high risk Myelodysplastic Syndrome, 1.6 years to live. No treatment. No cure. What? How can that possibly be? So, it's not always a progressive kind of thing or if it is you just attribute it to other things until it smacks you in the face, but his hemoglobin was 6.0. So, he had been working and functioning I'm not sure.

Virginia E. Aguilar, NP: Well, that just tells you your body has gotten used to it and it's been like that for quite some time.

Q10: Yeah.

Virginia E. Aguilar, NP: If we see somebody that's pretty not symptomatic with a hemoglobin that low we know that it's been low for a while because their body's compensated.

Q8: The other discretion I've had with some of my doctors is there is no resolution to this or answer is what I'm feeling, doing, thinking, can't remember is part of my disease, my chemo, my whatever, part of is the fact that I turned 70 this year and things change as you get older. So, we kind of threw it up in the air and said all of the above.

Q16: I think for us you were talking about quality of life we kind of... he's on the Revlimid for three weeks and he's off for a week is what his cycle is and we know that the week he's off he feels good and we also know the first week he's back on it he feels awful. So, we kind of do a schedule around... like he's starting back on it tonight, so we won't plan anything for this week. We've learned to adjust, but before he was diagnosed he was always tired and I'd get so aggravated that you just woke up and you're taking a nap?

Q10: And a couple hours later you're taking another nap.

Q16: It was good for me to finally get a diagnosis and know why he's so tired and to be able to accept that. I know I was ugly to him but I don't tell him.

Q8: Before we found that there's no telling what the cause for all the different tests that they put me through. They check your heart, they check your circulatory, they check your lungs, they check everything and...

Virginia E. Aguilar, NP: Well, you're just mildly anemic? Was that it?

Q8: Pretty much anemic, but it was dropping so severely it kept getting worse and worse and that's finally decided to send me...

Q11: And they did the bone marrow.

Q8: To (inaudible 17:23) hematology oncologist or whatever.

Q11: MD Anderson put an article on Facebook recently that said fully 25 percent of the patients that are returned to them for a second opinion were misdiagnosed. I was shocked at that. Twenty five percent. Now, they, obviously, treat all kind of cancers.

Q8: And there's a lot of people that she's met and talked to that come from small towns in the middle of no place. They got one doctor there. He's a GP.

Virginia E. Aguilar, NP: Or better yet, I had a patient... just, I mean, not three weeks ago came in and he just gets... he has overproduction of his red blood cells so he gets drained every so often and he came in and I was going through his med list he had no idea what his meds were for. He was taking as needed diabetes med and he didn't even know it was a diabetes med. He didn't check his sugars and it was a pediatrician filling his prescriptions. He was 67.

Q8: Well, (inaudible 18:34) doctors are doing the best they can do, but...

Virginia E. Aguilar, NP: I know and just... the care in the outlying areas is...

Q8: I'm going to MD Anderson there's an entire department over there that does nothing but leukemia. That tells you how specialized that stuff is.

Virginia E. Aguilar, NP: Oh, yeah, but you don't want that person treating your diabetes either and you hear and I know it's so frustrating every single day I get a patient that says oh, by the way, can you just refill this real quick or can you refill that? In addition to the fact that where I came from, Parkland Hospital, they didn't have insurance. So, I could get whatever I wanted. It was very easy, but apparently the insurances will deny if an oncologist asks for like a hemoglobin A1C or... for diabetes or some tests that's not really related to the cancer unless I can justify it and so a lot of times I can't refill because I can't monitor your labs and that's why you get referred back to your primary care doctor and the whole purpose is that ideal world. The whole purpose of the primary care doctor is to make sure that all your treatments and everything

going into your body and everything being done to you is all coordinated. That's the whole purpose. I know that's not what's really happening most of the time, but that's the ideal world.

Q8: (inaudible 19:50) is an internal medicine doc because that's what they do.

Virginia E. Aguilar, NP: Well, and that's assuming everybody talks to him or her, but I mean, I see so many instances where patients just have no idea what they're taking or why they're taking it and they don't even know who prescribed it and they've got 15 different people prescribing stuff including the pediatrician and they don't know what it's for.

Q8: (inaudible 20:11) but I don't need to she does. This is my medicine expert.

Virginia E. Aguilar, NP: Well, they don't even have medicine experts and it's...

Q17: It's scary.

Virginia E. Aguilar, NP: Yeah. So, it's... and that's why when you come and you come in every other week or every three weeks or whatever and we're checking your labs if I can draw the lab and get away with it I'm going to, but I can't... I might be able to give you a refill, but I can't prescribe because I'm not allowed to follow it. I want to, but I'm not allowed to.

Q8: I'm on so many medications that (inaudible 20:24) that are down to 24 or 12 that she finally... In fact, it's in the computer and we just print it out and we say whatever new doctor we see we go, "Here. This is it. You take a look a look at it and see what you think. If you see anything interesting..."

Virginia E. Aguilar, NP: And that's... by the way, that is super, super important taking that med list because I cannot tell you how many times yeah, I think... Yeah. Yeah. I don't know. So, and there's so many interactions and there's so many things that we really have to consider before we can prescribe something else that having an accurate list with dosages is really important. So, I mean, you just handwrite that stuff out legibly, but if you just handwrite it out that's fine. Put it on the computer in a list that's fine, too. I don't care how I get it, but as long as I know I can compare and make sure everything matches.

Q8: I think it's good to not just to do it when you're going to a doctor, but to carry it all the time in your wallet. I mean, God forbid if something happens to me out in the supermarket or something at least the EMS people should be able to see...

Virginia E. Aguilar, NP: Right. Exactly.

Q13: And also I do it on the computer for both of us and I have one we've had like major tests done, too, so that he can say well, I just had, you know, whatever, stress EKG two months ago and they'll say, oh, well, I'll just get the results from (inaudible 22:01) to do it again.

Virginia E. Aguilar, NP: And see that is phenomenal because, again, I worked at Parkland and I had a lot of homeless indigent population that had no primary care and so they would come in and they would have medications. They couldn't tell me if they were taking them or not. So, pretty much guessing they weren't, but you do all this workup and then you find out they had it worked up somewhere else and you know the whole computer thing is so that all the computers could talk and it'd be easier to manage care. Everyplace I've ever been has a different program. So, they don't talk. They don't talk at all. So, it's... I mean...

Q10: Sometimes even at the same hospital. We found out at Brick Army Medical Center that the ER records couldn't be accessed. The doctor himself could go in and do it, but the staff...

Virginia E. Aguilar, NP: Nobody else could and luckily the doctor could do it and probably just because he floated down there occasionally. At Texas Oncology, we have our computer system we type in and then we do our orders, but like the labs don't communicate with the... our computer doesn't communicate with the lab computer. So, they've got two people sitting in an office typing in the orders. What's the room for error there?

Q10: Oh, my gosh and errors happen.

Virginia E. Aguilar, NP: They do and so if you come and we didn't get the right lab draw that's why. So, I'm gentle. If you have a port I'm going to get it out of the port if you're getting treatment if I can. I'm a pretty good beggar.

Q8: (inaudible 23:27)

Q18: (inaudible 23:31) a new theory. I'm beginning to believe that my anemia is caused by blood tests.

(Laughter)

Virginia E. Aguilar, NP: You know what? You wouldn't be wrong.

Q10: I think (inaudible 23:53) is important. Some sort of outside caregiver support is crucial.

Virginia E. Aguilar, NP: It is absolutely. There's this handout that these nice ladies put together about like the MDS Foundation support groups and I think they handed them out? Maybe not. Nope.

Audrey Hassan: I think they're in everyone's package. It should be in there.

Virginia E. Aguilar, NP: So, it talks about if there's not a support group, forming one and how to go about doing it and planning the meeting and things you'd want to do just so that you could have the support there and talk about things that have worked for you all.

Q10: And Facebook's got an excellent one. Fight Myelodysplastic Syndrome. There's two MDS (inaudible 24:36)

Virginia E. Aguilar, NP: How many are Facebook users? Alright. My husband is not. I am, but he's not.

Q10: It's excellent.

Q8: And he doesn't like football. How come you need him around again?

Virginia E. Aguilar, NP: You know, he's special. He can kill rattlesnakes.

Q8: (inaudible 24:58) walked up and (inaudible) how he'd look at you funny or at least (inaudible) you don't say that.

Virginia E. Aguilar, NP: He would think that I was an alien invader because I would never say that.

Q10: Well, I know personally I have benefitted so much my caregiver support that comes in lots of different ways.

Virginia E. Aguilar, NP: And you... was it you that gave me this website? No, somebody gave me a... I talked about the calendar. So, there's another one. It's mypinkplanner.com where you can set up the calendars or somebody can set it up for you and then just send it out via E-mail to all your friends and then they can sign up like if you need a ride to an appointment you're not able to drive. Lots of people will be willing to help. I mean, if I were off I would take people. I don't mind. Cook dinner or mow your grass.

Q8: (inaudible 25:47) that you need help. We've talked about it. She's a breast cancer survivor. She was on all these websites and just it breaks your heart to read some of the stories you're hearing, these young women that got little kids and they're not married. They're single moms and they have to do all this stuff and I just know what I gave to her and I go how do they do this. I don't know how they do this. They've got to have help from somebody and like you said don't be afraid to ask.

Virginia E. Aguilar, NP: And like for instance, your fatigue. I mean, are you too tired to clean your house one week? That's reasonable because let me assure you if I'm going to live I'm not going to worry about my house. I mean, you have to to a point, but if I'm going to choose between that and doing something I want to do I'm going to do what I want to do.

Q8: One of my favorite saying is good housekeeping (inaudible 26:36) house inspectors aren't coming in and we said don't worry about it.

Q10: You have to lower your standards that's for sure.

Virginia E. Aguilar, NP: Well, somebody put on Facebook a thing where... I just put a bunch of get well cards so that when people come over and see how nasty it is they think you've been sick and you all actually are sick, but you can do that and get away with it.

Q11: Because my fatigue is not consistent. So, I can't say that I mean, I have less energy every day than I had two or three years ago or pre MDS. I am like (inaudible 27:08) I am getting older so I recognize that, but it just changed so suddenly that I'm not... I think that is MDS related...

Virginia E. Aguilar, NP: I agree.

Q11: ... but it's not the same degree of fatigue as you get (inaudible 27:17). So, what I find on my days that I'm really fatigued, I don't know worry so much about what's not done, but I don't ask for help either and I just do... because I know the next day or two days or three days that I'm going to have a really good day and I'm just (inaudible 27:34)

Virginia E. Aguilar, NP: So, why would you spend that good day doing your housework? Go spend the day doing something fun that you want to do.

Q11: I get very... it's very hard for me... it's easier for me to help people and even though I'm sick I have a very close friend that has MS and I'm helping her all the time and I find and I really feel bad because now I can't help her as much. Well, she's got other people to help her, too. She needs a community to help her. She's almost no longer mobile that it's progressive, but... and I have an elderly woman at my church that I drive her and take her to doctor appointments. It's much easier for me to do for others. It's very hard for me to let people do for me.

Virginia E. Aguilar, NP: And you're the person that probably would benefit...

Q11: Yeah.

Virginia E. Aguilar, NP: But you won't ask.

Q10: People want to help.

Virginia E. Aguilar, NP: People do want to help. They do want to help.

Q10: When he got diagnosed and then we found out that the bone marrow transplant was imminent I had to get the house ready because you can't just bring him home from the hospital. (Inaudible 28:36) So, I took the dining room that was hardly ever used. Somebody came in, they built walls, we put HEPA filters in there, I took out the carpet, I got the popcorn ceilings down. Everything was done. I had people everywhere come in to help with that. We had some friends... I walked out and there was a ramp. I said, "Well, that's going to be hard for you to get him in the house without this ramp." So...

Virginia E. Aguilar, NP: And see that makes... You know how good you feel helping people? That's how people feel when you ask for help. They feel like oh, my gosh I can contribute and you're actually helping them by letting them help you.

Q10: If you're like me sometimes you have to get yourself to that point.

Virginia E. Aguilar, NP: I know.

Q10: (inaudible 29:22) as well because you're overwhelmed and you have to because I can't bring him home unless I can (inaudible 29:29)

Q8: (inaudible) is something that we all struggle with.

Q10: Yeah.

Q8: I've gotten over that.

(Laughter)

Q8: It took a while but I've gotten over what I (inaudible 29:43) I cry and I pray about it, but I still haven't (inaudible 29:48)

Q10: A problem that we noticed not just him and I want to support groups is typical - keeping things from your caregiver, keeping secrets and he would not tell me something because he didn't want me to tell the doctor because if I told the doctor that would mean he'll put him back hospital or somebody (inaudible 30:15) then I found out it's very common.

Virginia E. Aguilar, NP: Oh, yeah. So when I'm actually seeing a patient especially the first couple of times I ask them the question and I look at the caregiver. So, what's really going on because they know him.



Q8: (inaudible 30:27) being in a room with my doctor with me. That didn't work.

Virginia E. Aguilar, NP: No, it's not going to work.

Q10: Maybe if you don't tell (inaudible 30;34) okay. Alright.

Q8: The first thing she said in the door was what I didn't want the doctor to know.

Q10: But he's over it now.

Q8: But I got over that. If I sneeze twice, I tell the doctor next time I see him.

Q10: He has to go to the ER if his temp is 100.4, not 104.

Q8: That's from my transplant doctors.

Virginia E. Aguilar, NP: That's true for every one of you guys, by the way. Okay? It's true for every one of you because none of you have a normal immune system.

Q8: That's the one I will not (inaudible 31:03) on. I'll go in a heartbeat when it's 100.4.

Q11: Is 100.4 you go to your doctor?

Virginia E. Aguilar, NP: Well, you should call our ER. Yeah. But you should... I mean, it depends. His is a little more severe, but every one of you should be monitoring if you get a temperature we need to know immediately because you're probably going to need antibiotics and if you wait any length of time with no immune system...

Q8: (inaudible 31:25) probably kill more people with what we're (inaudible)

Q10: With MDS.

Q8: (inaudible 31:27) anything else that MDS.

Virginia E. Aguilar, NP: Yeah and it's true.

Q10: (inaudible 31:30) from MDS is bleeding or infection.

Virginia E. Aguilar, NP: Exactly.

Q8: Since all my life mine has been low though like 97.6 or so or it might (inaudible 31:43) then when I get up to 99 I'm... ask her. I got a fan blowing on me and I'm like oh, man. I'm taking Tylenol and stuff.

Virginia E. Aguilar, NP: But you should be calling. Even if you're just having chills. We want to know.

Q10: Got to take Tylenol.

Virginia E. Aguilar, NP: Okay because I don't...

Q10: (inaudible 31:59) do not lower that fan because you're covering up what will help them diagnose what's going on.

Virginia E. Aguilar, NP: So, actually I don't care if you take Tylenol because you feel miserable (inaudible)

Q10: They tell us do not take (inaudible 32:11) call, you come into the ER and let us give it to you because (inaudible)

Virginia E. Aguilar, NP: It's six one way, half a dozen another.

Q8: The ER, a lot of the ERs I don't have faith that they're going to know what the hell is going on with me.

Virginia E. Aguilar, NP: I'm with you on that.

Q8: A lot of them never heard of this thing (inaudible 32:23) always got to take that into consideration. I got access to one of the best ERs in the state of Texas.

Q10: We're lucky there but still...

Q8: Brick Army Medical Center, but not everybody is going to get (inaudible 32:36). Some form of treatment or something, but I haven't heard anybody saying I want to be off treatment. I want to get rid of this Revlimid because I don't like the side effects at all and I want to get off of it which the doctors agree with and December after I see them if the counts are okay and he's going to let me get off it and then monitor me afterward. Is there any success stories when people with...

Virginia E. Aguilar, NP: So, for a time you'll...

Q8: Can't we get off of it?



Virginia E. Aguilar, NP: Not permanently. No. Again, the only way to be off treatment of any sort supportive or otherwise is a transplant and only if it's successful.

Q8: (inaudible 33:21)

Virginia E. Aguilar, NP: Right and so...

Q10: MDS is going to kill you sooner or later.

Virginia E. Aguilar, NP: Depending on your... it depends on the variety one of the seven categories if you're low risk or high risk. High risk it's probably going to get you, but low risk, I mean, you may die of a heart attack or a stroke or whatever because people are living quite a while. I mean, you saw that... and that's the average eight.

Q10: (inaudible 33:41) are down, you catch more.

Q8: When I was going through MDS and getting the Azacitidine once a month there was a gentleman over there that (inaudible 33:51) he had been going in there every once a month for a week for five years and (inaudible 33:58) he gets. He was never going to stop it, but it didn't get any worse. So, he just kept going and they did the same thing they did to me except after a year mine didn't work anymore. His kept working, so that happens, too.

Virginia E. Aguilar, NP: You don't.

Q8: So, I may get off of it for...

Virginia E. Aguilar, NP: A period of time.

Q8: A month or something and it'd just pop back up (inaudible 34:18)

Q10: (inaudible 34:19) alternative treatment.

Virginia E. Aguilar, NP: Yeah. Exactly. I mean, like Dr. Lyons said there's... and they developed so many in just the last two years. You just or you become part of a study drug or whatever like his.

Q8: MD Anderson right now they got one of the top doctors in the entire country runs that department because it is so big and so complex. It's so involved. There's trials they have going on. That's all she does is babysit those.

Q10: Putting a lot of people on Aza, Azacitidine that where they never used to and for a low risk category. That's something to look into.

Q8: What's it called again?

Q10: Azacitidine. (inaudible)

Virginia E. Aguilar, NP: I don't know who your doctor is and I don't know what your cytogenetics look like or your disease type but it's not unheard of to get a second opinion and if the side effects are uncomfortable. We're doing this so you can live. We may not cure it, but we want you to live and if this is so miserable that you're not living look at alternatives.

Q8: Well, I'm living, but...

Virginia E. Aguilar, NP: Yeah, but...

Q8: It's not like I like I like to (inaudible 35:25). You know, I come to grips with the fact that it's never going to be like it used to be, but it's just the way things are. I'm going to have to adjust and modify and reduce some things, but it's not going to be... Normal isn't old normal. It's new normal.

Q10: Yeah. It's true.

Virginia E. Aguilar, NP: But you still should enjoy life. If you're not enjoying life it's no...

Q10: (inaudible 35:44)

Q8: My doctor said I could just drink scotch just not too much of it.

Virginia E. Aguilar, NP: Exactly. Exactly. Exactly.

Q10: He tells me all the time, "You know for somebody with a fatal disease I'm doing pretty good."

Q8: I go I am the healthiest person you'll ever meet that's got a fatal disease.

Virginia E. Aguilar, NP: Right. So... Go ahead.

Audrey Hassan: Other joke. We met a psycho oncologist...

Q8: Psycho oncologist.

Audrey Hassan: A psycho oncologist and if I can get it correct now. She said, “Life itself is a fatally transmitted disorder... Sexually transmitted disorder.”

Virginia E. Aguilar, NP: There you go. It’s right.

Audrey Hassan: I just wanted to add that. We’re all not going to be here.

Virginia E. Aguilar, NP: That’s the one guarantee we have in life is we’re all going to die. It’s just how it is unfortunately, but we want to live while we’re here.

Q8: (inaudible 36:47) if I had motorcycle (inaudible)

Virginia E. Aguilar, NP: Be careful.

Q10: I told him before I got you through seven times that you were trying to die for the last two years. If you go out on that motorcycle and lay it down and die for... uhhh

Q8: I’m going to die of something.

Q10: Yeah just not that.

Q8: You better make sure you’re smiling when you lay it down.

Virginia E. Aguilar, NP: That’s right or hopefully not lay it down, but that is part of living. That’s what he...

Q9: When I’m my bike I’m always smiling.

Virginia E. Aguilar, NP: That’s awesome. So, another... I came from Dallas and I mean, obviously, I don’t know everything here, but we have... we had a... one of my very best friends up there is palliative care and so everyone here equates palliative care with hospice. It’s absolutely not the same unless I’m missing something, but palliative care sometimes it doesn’t seem except for the neuropathy that there’s too many painful situations, but it’s really good because they are so much better at controlling symptoms and issues, neuropathy, pain, nausea, vomiting, lack of appetite. They’re my go to. I’m still texting my friend, “Hey, I’ve got this situation. What do you think would work for her or him because they’re so much better at managing symptoms and they are not synonymous with hospice. They’re absolutely. She treats people... if they don’t want hospice, great. If they want hospice, okay. In fact, when they go on hospice they’re no longer hers. So... but she’s... I don’t know what the situation for palliative care here is, but if you ever hear of that and it’s a good organization it’s a great organization and is not hospice care. It’s care.



Q10: It's quality of life.

Virginia E. Aguilar, NP: It's to help you live a better life.

Q10: I don't know that they have a (inaudible 38:37)

Virginia E. Aguilar, NP: I know that they have an inpatient. At least I've seen some ads for in (inaudible) for inpatient, but I don't know if they have it like an outpatient like they do up in Dallas, but it's something to... I'm going to investigate it myself. I want to know, but I hadn't heard of it.

Q8: I have haven't heard either.

Virginia E. Aguilar, NP: Yeah, but they're phenomenal with symptom control. So, if you ever hear of that don't get oh, my gosh, because they used to call them the hospice team and they're like that is not what we do. In fact, we sign up you to hospice we're done. So, yeah. That contributes to quality of life.

Q17: (inaudible 39:18) good job.

Virginia E. Aguilar, NP: Well, I've worked with some of the oncologists and they don't do pain control very well and so it's very frustrating for me.

Q8: That's the other advantage of having doctors here and doctors in Houston. If one of them don't want to give you something I'll just ask the other one. It's like playing mom and dad off of your kid. I got the best of both worlds going on here.

Virginia E. Aguilar, NP: You do. You do. Luckily, this doesn't appear from the outside to be a real painful disease other than neuropathy.

Q8: And that's really not that painful.

Virginia E. Aguilar, NP: Good. It can be.

Q8: (inaudible 39:53) I've got some of that too.

Q10: It's painful when you're (inaudible 39:55)

Virginia E. Aguilar, NP: Yeah.

Q8: You know, I can't control...

Virginia E. Aguilar, NP: Your feet. Right.

Q8: You don't feel them as much or where they might catch on things.

Virginia E. Aguilar, NP: Right. Yeah. I saw that twice.

Q8: I just went to through a nerve reduction test about three weeks ago and the neurologist put me through that could say (inaudible 40:11) be sure. Yup, you got it. Yup. I said, well, it may never go away. It's gotten so much better in the last six months from what it was before (inaudible) the result of chemotherapy. It's gotten so much better (inaudible) I'm fine. He said (inaudible) you may get a little better. There's no silver bullet for it. You can't take this pill and it's going to get all better. It's not going to happen.

Q10: What he suggested if he feels (inaudible 40:35) walk up the ramps (inaudible) but there's so many ramps everywhere this way you don't really... you know, if you go in (inaudible) be able to catch him if he fell.

Q8: I still take a cane with me once in a while depending on where I'm going (inaudible 40:54). They make some really fancy ones with brass nobbs on them, too. I just bought myself one for Christmas.

Q18: (inaudible 41:06) the iron overload because at the time that everything was (inaudible) iron and so through the (inaudible) ruled out (inaudible) and the numbers were down without knowing why, but it's still very high and so I talked to my hematologist oncologist and I asked him and it was MDS related and I never get (inaudible 41:39) so I never had transfusions. So, he said to me unrelated. So, does anybody know anything about...?

Virginia E. Aguilar, NP: So, what I got from Dr. Lyons is they don't know, obviously, everything and they don't know why and there's some people that take the chelation therapy which has some side effects, but sometimes the iron levels don't drop, but their symptoms and survivability increases and they're not really sure why, but that... I don't know.

Q18: So, I have another question also that I'm confused that you or somebody here may or may not know, but I'm thinking and so vegans they all take B12 supplements. So, I take a B12 and I take a multivitamin that has B12 in it and... but I recently asked my doctor, the hematologist/oncologist, to have my B12 checked in my bloodwork which he refused to do. So, he said I don't need it. So, I mentioned about why I thought... and also I understand that sometimes the body doesn't... and this can be true with any vitamin or drug or anything won't absorb it. You take it in, but... and I've also unless I'm wrong I thought B12 was water soluble which means that if you didn't take enough you're... if you take too much in you're going to excrete it, but the reason he said I didn't need it is when I was first referred to him a year and a

half ago the blood work came in from my PCP and my B12 limits were within normal range. So, I said, “Yeah, but how ‘bout now?” and so he said that B12 is stored in the body and it takes years to deplete it. So, if it’s a water soluble vitamin and then I did my PCP did check it and it is good, but this is what I don’t understand if it’s a water soluble vitamin, but he says it stores... it takes year to deplete what’s in your body. Do you know anything about that? No. Does anybody know anything about this?

Virginia E. Aguilar, NP: You’re way out of mine, but she does.

Q8: Right here.

Virginia E. Aguilar, NP: I’m not going to lie. I’m not sure.

Q10: I give myself B12 injections. The oral doesn’t work. You’re right. Some people it works great.

Virginia E. Aguilar, NP: Some people... I do know that.

Q10: Some people don’t absorb it. I don’t absorb it. If I... When I switched from every two weeks to every week because my number was down into 300 and something. I don’t feel good when it’s at 3-something. I want it at 800, something like that because I feel better. Yes, 300’s within the normal range, but it’s...

Virginia E. Aguilar, NP: Some people actually get neuropathy with 300.

Q10: Yeah. I want it back up. So, they said, “Okay. Fine. Go from every other week to every week.” Got it to almost 500 in a month. So, this... it depletes.

Virginia E. Aguilar, NP: It may be stored in some people, but it... you’ve got... I mean, when we have a vitamin D or B12 deficient person we put them on the shots weekly for a month and then monthly and we check it pretty periodically and it may store, but they stay on those shots long term and we may take them off for a while, but we watch their counts.

Q10: And that can contribute to your fogginess. A lot of elderly patients in nursing homes that they are saying they have dementia. It’s not dementia. It’s a B12 deficiency.

Q18: I do understand it but my B12 numbers are good.

Q10: What are they?

Q18: I think actually 1,400.

Q10: Oh. That's good.

Q18: So, mine are very good. So, but I just had to like check again because I was concerned about it because last time they were checked was a year and a half ago when I had this bloodwork that showed everything else and so as you know when it was checked a year... they were 14 and when it was just checked again it was 1,400 (inaudible). So, there's no question but it's good. So, whatever I'm taking in either my oral supplement is working or I may not even need the supplement because it's stored in the body if it is, but I was just confused about that.

Q10: It can drop.

Q18: How can it be stored in the body if it's water...?

Virginia E. Aguilar, NP: It's going to drop.

Q10: I've gone from 800 to 300 in six months. So, this thing about years... I don't know about that.

Q18: I was just concerned and wanted it checked since I am vegan and... I just wanted it checked, but that conversation I had with the doctor when he refused to check it because he said you don't need it...

Virginia E. Aguilar, NP: Well, he may have been looking at something else because if your B12's really low there's indices on your CVC that will change. So, he may have looked at that and said no, no, no. That's normal, so your B12's normal. You can look at that, but I don't know about being stored in your body long term. You got some storage, but I don't know how much.

Q18: He said it takes year to deplete and I had... So, here's the thing. I had never heard that before and I talked to so many vegans that take the supplements and so I Googled it and I did find an article that agreed with... by another doctor with what my doctor said that it is stored. So, again, this guy says this and this guy says that. So, I just have to content myself with my numbers are good. So, I don't have to worry about it.

Q8: A lesson on that one is there are still people that think the earth is flat. So, be careful what you believe.

Q10: And the other thing is somebody had to graduate last in their class at medical school. Just because a doctor says something...

Q8: His name was Dr. He Gets to Write Things. It doesn't mean he's right.

Virginia E. Aguilar, NP: Right. That's why you get a second opinion.



Q10: That's right.

Virginia E. Aguilar, NP: If you can.

Q8: Yeah and if the second opinion is yeah, you're ugly, too, find another doctor.

Q10: There are some jerks out there, some real...

Q19: I trust NPs.

Virginia E. Aguilar, NP: There are.

Q8: I love most of my doctors, but every once in a while you run into one that you wonder what island did he graduate from medical school on.

Q10: One doctor at MD Anderson was awful. Everybody else was wonderful, but he's an inpatient. We have a mentally ill adult son that lives with us who was having a crisis. I had to leave and drive back here for two days and come back and this guy's when I finally saw him he's like, "Where have you been the last couple of days? I've been here every day. Why haven't you been here every day? You care so much about him why aren't you here?" What? Yeah. He was a pediatric oncologist doing I don't even know why he was got assigned to him for the... Yeah. Horrible.

Q8: I think everybody else was on vacation that day.

Q10: Just horrible and he went to the door and glared at me, started to go out and then turned around and went, "Do you know how long I've been a doctor?" I don't care.

Q8: Two weeks?

Q10: There are jerks out there.

Virginia E. Aguilar, NP: Not enough to learn customer service.

Q10: Horrible.

Q8: (inaudible 48:39) I got to stand up. If I sit down too long things hurt.

Virginia E. Aguilar, NP: You go right ahead.

Q8: That I know because I'm old.



Q10: Yeah, it is. You're great. You just don't have meat on bones like you used to.

Q8: I'm working on it. I gained 50 pounds in the last six months.

Q10: Yeah he has.

Q8: (inaudible 48:57)

(Laughter)

Virginia E. Aguilar, NP: Me, too.

Q8: Take another 20 or 30 (inaudible 49:05)

Q10: At least. Oh, yeah.

Virginia E. Aguilar, NP: Does anybody have anything else?

Q14: I would just like to say I think you all did an outstanding job on this. I was a little skeptical this morning. She's the expert in the family. I'm kind of like... most of this stuff goes over my head, but it was interesting and I liked it and you all did a great job.

Audrey Hassan: Well, I'm happy that you all came and I think we learned a lot. You can't paint everyone with MDS with the same paintbrush. It's never a good time to get MDS, but honestly I've been with the MDS Foundation for 16 years. We've come a long way and as Dr. Lyons said there's a lot in the pipeline. There are a lot of researchers dedicated solely to MDS. There are so many. I know at the MDS Foundation we give out Young Investigator Grants. So, we're encouraging young hematologists to continue the work of the older hematologists like Dr. Greenberg, Dr. Lyons, Dr. Silverman who created Vidaza who Dr. Lyons mentioned they laughed at him when he first created it. It was the very first drug approved by the FDA for the treatment of MDS. So, I hope you found it all enjoyable.

Q10: We did. Thank you.

Audrey Hassan: There is hope for MDS. Again, I want to thank Ginny. Ginny, you were great. Thank you so much for... She donated her time on a Saturday. She works very hard.

(Applause)

Audrey Hassan: And I want to thank you all for choosing to spend your day with us and we'll come back. I hope you want us to come back. We hope to see you again. Thank you.



Q8: If your MDS goes past that and gets into ALM, don't worry about it. Here I am.