

Speakers:

Rebekah Sibert RN

Tricia Mignott-Neal RN

Audrey Hassan

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Tricia Mignott-Neal: ... for symptom management. My name is Tricia. I am one of the leukemia coordinators at Northside. I work with Rebekah Barr as well Dr. Solh. So if you don't mind, I am going to sit.

In your binder, you should have each section as far I understand has the book three and a book five. I'm going to briefly talk about book five. Book five is the Building Blocks of Hope and it seems to be your MDS plan and it looks like a lot of good information that you can capture for yourself that if you were seeing an oncologist and then going to for a second opinion or to a transplant center for a consultation this might be some information you can reflect back on and just kind of see what your journey has been. It looks like a lot of vital information can be captured in here.

In book three, it's the Quick Tips. We're going to just talk about symptom management. So, we'll talk about anemia first. That's on page three. So, how do you guys manage anemia? I know you have your blood counts and if your hematocrit or hemoglobin depend on what your oncologist use as a guideline, you'll need red blood cell transfusions, but what else or other ways of managing anemia that you do at home?

Rebekah Sibert: What are some of the symptoms you're feeling when your blood counts are dropping?

Q1: Drink a lot.

Q2: Aspirate.

Q3: Short of breath.

Tricia Mignott-Neal: So, how do you manage...?

Q4: Breathing exercising and more recently I've been trying some circulation exercises to see if I can't get all the therapy at once.

Tricia Mignott-Neal: So when you're extremely fatigued because when you counts are low you are going to be tired a lot. So, one of the things that I've always spoken to the patients about and my patients about is listening to your body and resting when it tells you to because if you overexert yourself, you're going to pay for it the next day. You're going to not be motivated to

do anything not that you don't want to. It's just that physically you don't feel well enough to do anything. So, set goals for yourself for that day. If it's not a good day then know what your limitations are and rest when your body tells you to. In the between time, you will need red blood cell transfusions and there'll be days you feel really well and you want to conquer more and do more, but just don't overdo it because, of course, the next day you'll either pay for it or you're just going to be on the couch for that day. Do you have anything to add?

Rebekah Sibert: For some of the patients have not required transfusions maybe some people who have had a lot of experience with transfusions if you kind of share what going through that is like and how that effects your lifestyle.

Q5: Say it again.

Rebekah Sibert: I know some of the people here have not actually required transfusion support yet, so maybe some people who have more experience with that can share with them a little bit about how that impacts your lifestyle, what the experience is like.

Q6: I will mention the first time my husband had to have an infusion. He thought he thought he was going to go in for just four or five hours and be out. So, don't start at three o'clock in the afternoon. Start at 8:00 a.m. in the morning. So if you haven't had one, be prepared to spend 12 hours at the hospital and he was... couldn't understand while his second infusion why he couldn't... why he had to go through the crossmatching and it was like, "They've got it from six or eight weeks ago. Why do they got to do this again?" and talking with the family here from my hometown, I realized then that your blood can change a little bit after you've had an infusion and that's something I'm going to share with him. So, start at three o'clock... I mean, like I said 8:00 in the morning, you'll be out 8:00 at night. We started the first transfusion in the 3:00 in the afternoon and left at 2:00 a.m. the next morning. So, just a forewarn if you have not have had transfusions before.

Q7: That's good to know. Does it make him sick?

Q8: (inaudible 4:52) I would assume most doctors (inaudible 5:01) because if you (inaudible 5:05) another couple of hours.

Tricia Mignott-Neal: Depending on if you're symptomatic or not and if it's later in the evening, some centers will allow you to get your crossmatch that day and come back the next day early in the morning to start your transfusion so that your day starts off early and you can finish early afternoon rather than starting at 2:00 and then staying late in the evening, but it really just depends on what your trends have been and if you're symptomatic with it.

Q9: Sometimes you don't have the energy to go two times.

Tricia Mignott-Neal: I understand that. I understand that.

Q10: She goes all the time is they've got the (inaudible 5:46). We... hour and a half (inaudible 5:50) about two hours per unit and then the hour to observe (inaudible 5:59) seven – eight hours.

Tricia Mignott-Neal: It makes for a long day.

Q11: And most of the time I've gone to the doctor before that (inaudible 6:07) been there a good hour, hour and a half. (Inaudible)

Q12: (inaudible 6:15) because if you can do what you did (inaudible 6:19) start the day out early.

Rebekah Sibert: And for people who haven't had transfusions before, the crossmatch is where they take a bit of your blood and they mix it with the blood they want to transfuse and make sure there's not going to be a reaction and so that extra step does add a bit of time and for people speaking, if you could speak into the microphone that'll help us out a little bit to be heard.

Q12: I don't need a mic.

Tricia Mignott-Neal: Most crossmatch are good for 72 hours and so if they know what your trends are then when you hit that after 72 hours even 96, they might proactively go ahead and crossmatch you and knowing that's good for three days.

Q13: (inaudible 7:12) I mean, I was just (inaudible 7:15) for a few days because we had a type and crossmatch and we couldn't get an appointment for the transfusion because on the fourth day we didn't know... but they called us again for (inaudible 7:25) crossmatch.

Tricia Mignott-Neal: Yeah and it usually expires one minute before midnight.

Let's talk about a neutropenia. So for you at other centers, are there multiple restrictions while you're neutropenic which means that your white count is really low and you're susceptible to infections? Are you able to travel? Are you able to go grocery shopping? Are there any restrictions with the low white count? Yes, ma'am.

Q14: I have dealt with that a lot and I wear a mask which when I go to places like Walmart, church, anywhere like that and I really don't enjoy wearing a mask. My personality is such that I'm not so terribly self-conscious about it, but I really didn't like the idea of people thinking that I might have something that would bother them. Just like I have cooties and stand back and also I've really found that children are sort of concerned. One child said to his parent, "Is she a doctor?" Well, that didn't bother me too much. The parent wouldn't have known how to answer necessarily. So, I have... if you don't mind me, can I tell you something about it?

Tricia Mignott-Neal: Yes, ma'am.

Q14: I was at a CVS drugstore trying to find masks. Just like where in the store are those masks? On the bottom shelf this lady helped me find them and then she said, "My father-in-law had to wear a mask and we found a button for him that said 'I'm on chemo' and it was through CVS." Well, we looked and she said, "Well, maybe you can find one online." So, I went online and I couldn't find one. Well, my sister and friend and I that have been... they've just been both of them like sisters had a button machine and she made a button for me that said 'I'm on chemo.' Well, a month after I was diagnosed, I online had found the AAMDS International Foundation meeting in New Orleans and my daughter and I flew down for that and two nurses came up to me while I was waiting at baggage and said, "We saw you get on the plane. We think your button is the best idea," and so I have really benefited by wearing it because like when a child said one time to the mother, "Mom, why is that lady wearing a mask?" The mother said, "She wants to get well." She was able to come up with her answer in her own way and so I wore my button today. I am on a break from chemo right now. So, it's not really telling the truth that I'm chemo and I don't usually wear it unless I am wearing a mask. So, I'm really wearing it sort of weirdly today, but I knew I was coming to something that was a safe environment and I hope to have an opportunity during this time to share with you. I have a friend whose husband and she have an engraving business in their home. It's ideal because he has been in a wheelchair from polio since age seven and they do beautiful engraving and she visited me recently and I showed her my button and she said, "Oh, Tom can make those magnet ones on his new machine." So, she happened to send in what I call GPT, God's Perfect Timing. She sent me six of these the other day and I'm not here to try to sell them. If anybody should want them I've given two away, one person was leaving and somebody else was sitting at my table, but I would share these with you only by giving them to you if you should want one at any point and he's not going to be in a business to sell 'I'm on chemo' buttons that I know of now, but at any rate this is the strongest magnet you'd see. When I got it, I kept trying to pull it off and my friend said, "You could hurt your nails doing it." Well, she said, "We forgot to send you instructions with it," but... and I'm not very creative in figuring out things, but I figured that if you turned it, it comes off easily because it's got three strong magnets. It'd go through a jacket or a sweater, not the thickest jacket, I'm sure, but and I just feel better when I'm wearing the button when I'm wearing a mask. So, I'm a teacher. You can see me after class if you would like... (Laughter) and also I will give you my card. I assume most if not all of you deal with the computer and I'll give you my E-mail address that you can communicate with me. I had the privilege of facilitating the caregiver support group for 10 years as a volunteer. Something that just happened is somebody else invited me to go to breakfast and we talked about our caregiving the next month we had 10. I hated to leave those people in Florida come back to Atlanta, but there's a time and place you can help other people wherever you are and I'm happy to be here today. I'm just so glad that I found out about this and I really feel like the doctors could know and share more about the opportunities available it'd be a blessing, but a lot of hematologists maybe like mine taking care of lots of people with other illnesses and not know enough. So, the best thing we can do is let them know in case there's somebody else in their patient load that it might be helpful.

Q15: I got a suggestion for when you wear the mask. Have a T-shirt made up that says (inaudible 14:16).

(Laughter)

Tricia Mignott-Neal: I just wanted to make mention that after today, we're not leaving you alone. After this meeting today, we're going to share with your permission everyone's address, contact information so that you can keep in touch with one another and it is our hope that from this patient forum that we create a self-sustaining patient support group. So if anyone's interested, contact me afterwards. You'll have my contact information as well and through the Foundation we do this and we've done it very successfully in different states, in other countries and we can support it whether we're giving you monies for refreshments or materials to hand out. We've even arranged for guest speakers to come to the different support group meetings. We also have and created coping and caring groups. Living with this new normal of MDS can create a lot of anxiety and so from time to time I'll arrange... I've arranged from yoga instructors to holistic nurses attending doing prayer circles, whatever will help patients and their caregivers living with this. So, I don't want you to think you're alone. After this, we'll keep in touch.

Rebekah Sibert: One other thing I wanted to speak on with neutropenia if you're in a chronic low white count state, you are very susceptible to infections. So one of the major things and you hear it all the time is handwashing. When you have people come to visit you you want... don't be embarrassed or afraid to say, "Can you go wash your hands?" If it's easier for you to have hand sanitizer, have it available. I know we're going to start changing seasons soon, so your family might be getting the flu shot. They do not need to get the live flu vaccine which is the mist. They should get the injection and so you want to be careful. Kids are going back to school and they will come home with sniffles. So if they're not feeling well, they shouldn't be around you because a cold for them is okay. They have the immune system to fight off a cold. A cold for you could land you in the hospital. You should have a working thermometer at home that you're monitoring your temperature and try to keep all your appointments with your physician. If you're not well enough to keep your appointment then you should have on call number for your physician where you can call regardless of the hour and let them know what your symptoms are even if it's a temperature. You might be directed to go straight to the hospital. It might be you need to come to your appointment earlier than later in the day.

Q16: Can I ask a question about the mask and I did have experience with (inaudible 17:22) low count and a bad cold (inaudible 17:23), but one thing that I read about the mask was for the first time a person a few hours wear them they filter. After that they start to accumulate bacteria. Is that right and what's the public guidelines for the mask?

Tricia Mignott-Neal: I would say to have multiple masks and to change them out because they do as you...

Q16: How often do you change them is my question.

Tricia Mignott-Neal: That's a hard question.

Rebekah Sibert: I don't think there's specific data on that.

Tricia Mignott-Neal: Right. I do know like for the treatment center at Northside with the blood and marrow transplant program our office is a HEPA filtered office which means that when you're in the office, you do not need to wear a mask. When you're in the parking lot and when you're walking around the hospital you want to. As you know with your talking with a mask on they probably get wet or moist in about 10 minutes. So, I would just say have multiple... The N95 masks are a little better however they're kind of hard to talk and wear them around all the time and they're... it's a much thicker. The surgical masks are probably the thin ones that you're talking about.

Q16: I don't wear them and I just read that article said there's some crossover when they start... working against you rather than helping you.

Tricia Mignott-Neal: The reality is is sick people don't stay home. So if someone has the flu or has a cold they're going to go to Walmart, they're going to go to CVS and if they cough on you you're going to pick up whatever they have as a virus. So, it would be better even if they did have that accumulation and you were running into Walgreens to get something to have a mask on and that would be a barrier for you.

Rebekah Sibert: And it's accumulating germs because you've been wearing it for a little while those are going to be your own germs. It's still going to give you some protection from someone else.

Q17: I have a question. Is the neutropenia, could that be the cause of sores in your mouth, on your tongue, gums and your little canker type sores?

Tricia Mignott-Neal: It can because you don't have the white cells to fight that off and the bacteria in your mouth, but also it can be sometimes from the treatment.

Q17: Im not getting any kind of treatment. Is anybody else experiencing getting sores on their tongue or gums at all?

Tricia Mignott-Neal: Is it like a canker sore type?

Q17: Yeah. It's very painful and I might get two at a time or three.

Tricia Mignott-Neal: Your doctor should be able to give you a kind of mouthwash or oral rise.

Q17: Yes. It's a rinse, but it stains your teeth. You got to make sure you brush your teeth afterwards, but I was just curious because they're really painful and they last longer than you're used to when you got canker sores.

Rebekah Sibert: And your body just not heal as well.

Q18: (inaudible 20:18) supplements that he can take for those that treat for canker sores? (inaudible 20:25). You know, something like that?

Q19: Vizine.

Tricia Mignott-Neal: Lizine. That one I'm not familiar with to be honest.

Q18: There is a canker sore medicine you can buy at CVS that you can dip on it and it works.

Rebekah Sibert: That I think is primarily an anesthetic, so it'll help with the pain.

Q17: There's Anbesol and then there's actually my dentist gave me some little stuff that's a little more stiff or a gel that stays on firmer to help heal, but I'm just curious.

Q20: I'm not sure what you all are covering, but I was curious as to what kind of research might be out there about nutrition and very proactive naturopathic things because cancers are free radicals for one thing and your body exists at a cellular level. So, the nutrition you're putting in your system is extremely important and I hadn't really other than seen a little chart in the book that shows you food groups, I've not heard anything said today by a formal presenter about nutrition.

Rebekah Sibert: The problem with nutritional research is that the results tend to be very mixed.

Q20: Very what?

Rebekah Sibert: Mixed from study to study.

Q20: Have you all had any done in MDS with nutritional people looking at nutrition that are specifically for MDS people?

Tricia Mignott-Neal: I recently had an oncology dietitian and she did give me a lot of notes from her talk and I can share that with you. If anybody wants it I can share it with them via E-mail and I'll do that after the meeting. I think it'll be helpful. She's actually writing a more extensive

piece for our next printed newsletter, but I have her notes and her PowerPoint presentation which I can share and I think that will be helpful specifically for MDS patients.

Q21: I know my doctor sent me to a nutritionist and they told me a high protein diet was very good. I had a lot of nausea and vomiting and stuff and wasn't doing well with food, so they told me to make the high protein shakes with the powder and the fruit stuff.

Tricia Mignott-Neal: So, you'll get the caloric intake and the protein are good for healing.

I kind of touched on fever a little bit when I was talking about the neutropenia. Your physician will probably give you what he thinks is acceptable for a temperature and what you need to call him. You probably if you run in a low white count state most of the time, you're probably on prophylactic antibiotics or antifungals or antivirals and if you're on a break from the treatment you might not very well be on that, but during active times of treatment you might very well be on those and that's just to kind of help you mount an immune response.

Q22: Can you tell me about like the shots that I've had (inaudible 23:45).

Tricia Mignott-Neal: That one helps stimulate your body to make white cells to help increase it. Now, whenever you have a fever... you can have a fever and there's not really a source for your fever and it's not a bacterial source or viral source or a fungal source. It very well can be that you're having a fever because you're in a low white count state.

Q23: What did you say that they would give you for it?

Tricia Mignott-Neal: They could give you an antifungal or antibacterial, antibiotic or an antiviral and it really just depends on your physician and what your trends are and what he's been monitoring you for.

Q23: That's for neutropenia you're saying.

Tricia Mignott-Neal: That they very well could. Yes, ma'am.

So thrombocytopenia which is low platelet counts, does anyone have an experience with that and having to need transfusions for low platelets?

Q24: I had that.

Tricia Mignott-Neal: Some of the things you might want to consider is to make sure you use a soft toothbrush and avoid flossing if your platelet counts are around less than 50,000. Another thing is is when you are walking around your house, you want to make sure you wear house shoes. You don't want to walk around barefoot because you could very well stuff your toe and



get an ingrown nail and if your counts are low that's just another avenue for infections and bleeding.

Q25: I had (inaudible 25:37) actually (inaudible)

Tricia Mignott-Neal: No pedicures. No manicures. No tattoos or piercings.

Q26: I mean, I was surprised like I'm in... My son is going to be a donor for my wife and I was surprised when they did a checkup for him and the doctor has noted that he's in a less risk category because he doesn't have a piercing or a tattoo. I was very surprised by that.

Tricia Mignott-Neal: Did anyone have anything else to add?

So, we're going to talk about diarrhea. Dr. Solh made mention of it that the side effects that you can have with the Dacogen and Vidaza are not that which you would have with true chemotherapy. So, you shouldn't... you can have the diarrhea and if you do then there are ways to manage that diarrhea. You want to make sure that if you are having diarrhea you don't continue to eat foods that are high in fiber and stay away from things that are a stimulant such as caffeine. So, sodas and teas and coffees. Those are all stimulants. Chocolate is a stimulant because if you're having diarrhea and you're adding that on top of it you're just going to continue to have more diarrhea. If you're having more than one or two bouts of diarrhea a day you want to make sure you tell the doctor because you're not holding on to good calories and then what's happening is whatever you're putting you're also putting out.

Rebekah Sibert: Remember if you're having issues with diarrhea, vomiting, nausea, those sorts of symptoms that you're staying well hydrated.

Tricia Mignott-Neal: Which is a good balancing act as far as managing that with nausea and vomiting. Any issues with constipation?

Q27: I did, but because I get a pre-med before I get the IV. The pre-med is (inaudible 28:05) and then there's a steroid that goes in it that has it and if you look at Vidaza, the side effects it lists both constipation and diarrhea.

Tricia Mignott-Neal: So, it's a gamble which one you get.

Rebekah Sibert: The lucky patient can get both. One or the other.

Tricia Mignott-Neal: It's going to be clear. One or the other. If you are having experiencing constipation you want to eat fruits and vegetables. You want to increase your fluid intake. You want to try to walk and be active because that helps with the GI moving along so that you can actually pass the stool. If you're not having bowel movements, I'd say more than two or three

days you want to make sure you tell your doctor because then you'll start straining and if your platelet counts are low you can tear. You can have an infection there. It just leads to other things, so you want to just be... know what your normal habits are but then make sure you're talking to your doctor or your midlevel whoever you're seeing just as kind of give them a glance of what's going on in your day. Do you have anything more to add?

So on page 15, this is... Vidaza can be given in the tissue. So, there's a section here on injection site reactions and I was reading this and they were saying that you can use primrose oil at the injection site and that'll alleviate some of that. Make sure you rotate your sites which your healthcare provider should be doing. Make sure it's not in an area that's prone to friction or wear a belt nightly. Make sure it's not on inflamed skin where we're giving you the injections. Also, Neulasta as well as Neupogen is given in the subcu tissue as well and that's... the biggest I've seen on side effect I've seen with that is mostly from what patients tell me is bruising more so than actually a site injection reaction.

Q28: I'm glad to know that because I've had so many of those shots and I do bruise pretty easily.

Tricia Mignott-Neal: Are you rotating the sites?

Q28: I tend to have it in my stomach because they always gave them in my arm and I thought of how my dad in assisted living he was (inaudible 30:56) in his stomach and my sisters had those Fortado (sp? 30:58) shots and the nurse told me that actually fat makes things absorb better. Is that true?

Tricia Mignott-Neal: Yes. Then you want to give it in that soft tissue because it's in the fatty area.

Q28: Don't feel it all if it's in your stomach. It's amazing. I don't think so. I mean, it makes a difference. (inaudible 31:20)

Q29: Do you get the Dacogen in your stomach?

Q28: Oh, no, no. It's IV.

Tricia Mignott-Neal: It's only IV.

Q28: Versus Vidaza.

Tricia Mignott-Neal: Vidaza you can give it in the IV form or the subcu tissue. It's called a subcutaneous shot.

Q30: Vidaza is given in the stomach (inaudible 31:42)

Tricia Mignott-Neal: It can be, yes.

Let's talk about fatigue and managing that. Anyone have any suggestions or any experience with managing fatigue?

Q31: Take power naps.

Tricia Mignott-Neal: Power naps. They're important.

Q31: The time of them then you'll be able to sleep at night.

Q32: I wanted to ask about the nausea and the vomiting.

Tricia Mignott-Neal: Okay. Let's go back to that.

Q32: We kind of skipped over that and went into the diarrhea and constipation. I have a lot of problems with that and I just wondered if the other people did too with the nausea and the vomiting. Is it common for MDS patients to have it?

Q33: Are you taking Vidaza or Dacogen?

Q32: No, I take Aranesp.

Rebekah Sibert: Our experience with it comes through people who are getting chemotherapy because that's what we see more commonly. You can get some antiemetics from your doctor. So sometimes it can help to take those before meals. Like take maybe half an hour before you eat and sometimes that can help you tolerate the meal a little bit better. We suggest patients have more frequent smaller meals. So, spread it out through the day instead of sitting down to a larger meal. Sometimes that's tolerated a little bit better.

Q32: I wake up in the middle of the night, middle of the morning and it hits me before breakfast, before anything.

Tricia Mignott-Neal: Are you taking the anti-nausea as soon as you wake up?

Q32: I wake up throwing up. The only time I take (inaudible) medicine when I first wake up in the morning, but later in the day I take (inaudible 33:44)

Rebekah Sibert: So, it's been several hours since you've had a dose because you've been sleeping. Have you tried something longer lasting like scopolamine patch?

Q32: No. They haven't put me on that. I have the Phenergan suppositories and the Phenergan cream that I put on my wrist.

Rebekah Sibert: And those are quick acting.

Q32: Yes, but the side effect is it makes you sleepy.

Rebekah Sibert: And that's common with all the antiemetics. There are little patches you can put behind your ear.

Q32: Little patches.

Rebekah Sibert: Patches that last for three days. So for some people who have persistent nausea something that's a little more long acting like that can be helpful.

Q34: What was the name of that? The patches.

Rebekah Sibert: Scopolamine. It's a prescription so it's not (inaudible 34:29)

Tricia Mignott-Neal: The biggest side effect of it is it will cause you to have dry mouth, so but I think that kind of outweighs if you're having ongoing nausea or waking up throughout the night and then you're interrupting your sleep, but you should ask them about that.

Rebekah Sibert: Something a little more longer lasting.

Q32: Okay. Thank you.

Rebekah Sibert: You're welcome.

Tricia Mignott-Neal: Anxiety and depression. So, this diagnosis is life changing, life altering, but you can still have quality of life with this diagnosis. So, you have to have an outlet whatever that outlet is whether it's a friend, whether it's journaling, whether it's just trying to incorporate yourself into your life as you had as closely as possible to it but still being safe towards your health. So, are there any experiences that anyone wants to speak about of dealing with whether it's just...? I mean, it's life changing from your diagnosis or dealing with anxiety or depression?

Rebekah Sibert: What your outlets are for your stress.

Q35: I like going fishing just to get away from everything, just get out of there.

Q36: Not on the support groups, just to develop one locally, what's the best way to go about doing that? I mean, I know we've got this group now that's starting, but how about in your own

more geographical area? Like a Facebook thing if you want to share that with everybody or is that probably sharing information (inaudible 36:35)

Tricia Mignott-Neal: There are support groups. I'll speak with Deborah and Audrey to see which ones there are, but there are support groups here around... I'll have to check with Northside to see if they actually have one.

Q36: (inaudible 36:53)

Rebekah Sibert: There may be some more general oncology related ones that might be helpful in addition to things that are MDS specific depending on what you're looking for.

Q37: Your local doctor (inaudible 37:06)

Q36: They weren't any help at all.

Q37: They weren't?

Q36: No. In fact, this group is going online (inaudible 37:13) you know you don't have any support groups you can start with the Cancer Society and basic ones like that.

Q37: Online is the best way to find anything I promise you. Just MDS support and you'll find...

Audrey Hassan: I also want to mention if you go on our website... Are you all familiar with our website? We have a very active message board. So, you can sign up very easily and you can speak with others on the message board, ask questions. Someone will respond to you whether it's an expert or another patient. So, I would recommend that you do that and, of course, you can always call me. I can always find another patient for you to speak to who's similar to you who's in your shoes. We kind of have a peer support group that will do that, a network.

Q37: Do we have your name and information in this book?

Audrey Hassan: Yes. I know that I'm in the newsletter and did (inaudible 38:24)... In *The Building Blocks of Hope*, I think, our information is in there for sure.

Q37: This? The very (inaudible 38:41) on right hand content.

Audrey Hassan: Right on the back of it. If you turn it over it has our contact information, website, telephone number.

Q37: And what is your name?

Audrey Hassan: Audrey. We're only five people in the office. I can literally call across the office and ask for Dee. She'll hear me. So, if you call that number, you can get me.

Q37: Is on the website the Centers for Excellence for Treatment of MDS? Is that on your website? I see a findahematologist.org, but also see a reference in here about Centers for Excellence for the Treatment of MDS.

Audrey Hassan: Yes. I'm sorry. I couldn't hear you. Did you just ask me if the listing for MDS Centers of Excellence are in (inaudible 39:40)

Q37: Well, I see reference to a website, findahematologist.org then I also see a reference for Centers of Excellence for the Treatment of MDS and I'm wondering if you can Google that up and come up with what's being referred to in this book. This is on page 140 of this 100 question/answers.

Audrey Hassan: I'll take a look at it. Let me see. I'm not sure.

Q37: He said mentioned one doctor she got additional opinion from was on the staff of one of the Centers of Excellence for the Treatment of MDS and I didn't know if that was a way of just describing but it is capitalized, so it makes me think it's specific thing she's referencing.

Rebekah Sibert: In *The Building Blocks of Hope*, there is a list of Centers of Excellence.

Q37: Okay. What number is it?

Rebekah Sibert: I'm not sure off the top of my head.

Tricia Mignott-Neal: I think it's in book number five is a list of the all the MDS Centers of Excellence. They're also listed in the newsletter. The newsletter has them listed by state in the US and by country.

The authors of the *100 Question and Answer* book that you have are from Stanford University and Len who is the nurse is on our nurse leadership board and Dr. Gottlieb is actually her husband. They are the authors of the *100 Question and Answer* book, but the list of our MDS Centers of Excellence worldwide are in *The Building Blocks of Hope*, on our website, in the newsletter that you have.

Dee Murray: And if everyone can fill out their survey and just hand it to me before you leave please.

Tricia Mignott-Neal: So, it's in book six and then it's on page eight.

Rebekah Sibert: So does anyone want to share any last thoughts or tips or helpful thoughts for their fellow patients?

(General chat)

Q38: You were talking about support groups. Out there in the support (inaudible 432:12) that there were actually two support groups through my church. I go to a fairly large church and found out that there was a caregiver support group as well as a cancer support group. So if there's any large churches close to you, you might just call and check. They don't really advertise, but the church office would know. That's another support group.

(General chat)