



Valerie Ironside, CRNP

Lisa Barbarotta, APRN

Lisa Barbarotta: ... you all today. I really love hearing from patients and their families, hearing what the questions that you all have really helps me to be a better provider when I go back to take care of my patients. What Valerie and I are going to spend some time talking about some of it will overlap with what Dr. DeZern talked about. She did an excellent job of talking about treatment strategies for MDS, but we also really want to talk about living with MDS, quality of life concerns and most of all we want to hear from all of you and what concerns you have and the things that you all want to talk about. So, we're happy to keep it very informal and open. We have a short number of slides to go through and then we can do questions and answers, but feel free to interrupt either of us at any time during our slide presentation.

Many of you may have picked up the *Building Blocks of Hope* when you checked in. The MDS Foundation website has a number of resources one of them being this *Building Blocks of Hope* handout which contains a very useful information from the basics of what MDS is to treatment strategies as well side effects. This is the MDS Foundation International Nurse Leadership Board. The people on this slide here helps to develop the content in the *Building Blocks of Hope*. So, these are really experts worldwide in the treatment of MDS.

So, Dr. DeZern talked about this quite a bit, but the treatment of MDS is really individualized based on many different things. Some of the triggers that we use to decide when to initiate treatment with patients. Some of the things are listed here with transfusion dependence being one of them. So, coming in at varying frequencies for transfusions can be very burdensome to patients who spend hours in an infusion chair at maybe once a week, for some of my patients it's as frequently as three times a week. So, those are really the patients that we start to talk about. If there's something that we can do to decrease the frequency of their transfusions is that something that you want to do. Something that I should say from the beginning the first thing we really talk to our patients about is what your own goals are for your life and how you want to approach the treatment of your MDS because that will also help us tailor the discussion of what the options are.

Progressive or symptomatic cytopenias. So, cytopenias means that one or more of your blood counts are low. So, it may be your white blood cells and your neutrophils are the most important type of white blood cells. So, we say neutropenia is one of those cytopenias and neutropenia may be a trigger for treatment because when you're neutropenic you're at much higher risk for developing infections even if you're not exposed to a particular infection. Thrombocytopenia is another type of cytopenia which means low platelet count which increases your risk for bleeding and anemia is the third type of cytopenia. You may only have one of those or you may have all three.

Increasing blasts is another consideration for starting treatment. Do you all of you know what your blast count is? Do you know what risk category you fit into? So, the percentage of blasts is important. Patients with a low percentage of blasts are less than five percent may fall into the low risk category and as that blast count rises, you may fall into a higher risk category. A cutoff of about 20 percent is where we distinguish between MDS and acute leukemia. So, it's important to know your blast count and that information is contained on your bone marrow biopsy report.

High risk disease is also considered a trigger for treatment and Dr. DeZern talked about the things that are considered high risk focused on primarily your blast count and cytogenetic abnormalities.

Other things that we might consider when thinking about what types of treatments to talk to patients about. Performance status is one of the most important and that's really just a fancy way of saying how fit or how active are you and your provider may spend actually quite a lot of time understanding how active you are and what your performance status is. Most if not all clinical trials have a cutoff for performance status as an inclusion criteria. So if your provider is asking you how much time are you spending in bed, how much time are you resting or sitting down during your day, that's why they really want to get an idea of can you tolerate this treatment that we're going to talk about or that we're going to consider for you because the goals of these treatments are to improve your quality of life ultimately and we don't want to give you a treatment that you may not be able to tolerate or that may make your quality of life worse.

Comorbidities are certainly another important consideration. That just means other medical problems that you may have. Hypertension, diabetes, do you have a history of a heart attack? The reason that these things are important is because they may put you at risk for other complications of treatment and we really want to understand you as an individual and how these treatments may affect you.

Your risk category, we talked... Dr. DeZern talked quite a bit about that with the goals being different based on low risk disease and high risk. Low risk, the goals of treatment are really to improve hematopoiesis or improve how well your bone marrow is working, help decrease your transfusion requirement, help improve your quality of life. That's any kind of stark contrast to the higher risk patients where we're really focusing on survival and decreasing your risk of transforming to acute leukemia.

Do you have primary versus secondary MDS. This means was your MDS caused by previous cancer treatments. Some of you have mentioned that. So patients that have secondary MDS meaning their MDS was caused by chemotherapy getting for other types of cancer or radiation, those patients we think have higher risk disease and they tend to have higher risk cytogenetic abnormalities.

Cytogenetic status we also touched on. Certain cytogenetic abnormalities may predict better response to certain treatments with the most specific one being that deletion 5Q in which Revlimid is a very specific therapy for those patients and then lifestyle and I touched on that and that just means what is your current level of activity and what's important to you and that's especially in my first meeting with patients that's something I really try hard to understand - who's your support system, who's your family and what's most important to you.

So unfortunately, allogeneic stem cell transplant remains the only cure for this disease and Dr. DeZern did talk a bit about this. Sometimes this may not be an option. Age alone is not necessarily a cutoff. You'll hear different things from center to center. Some transplant centers do have absolute age cutoffs. Others focus their decision more on how active or how fit you are based on a number alone as well as your comorbidities. Age alone should never exclude any active therapy. Again, the focus should really be on performance status and comorbidities.

All active therapies for MDS take time to work. I think we've talked a bit about that and the next several slides will explain why that's the case. So, four to six months or cycles of continued treatment really until we decide whether it's working or not. Blood counts may get worse before they get better and proactive management of side effects especially in the first couple of cycles of treatment is really key to obtaining the best response. I would also say setting up realistic expectations for the patient is also very important. So, upfront making sure they understand what will happen with the blood counts so that they're not disappointed when the counts get worse before they get better.

So, why is time required for these treatments to work and we're talking mostly about Azacitidine or Decitabine but this may also happen with Revlimid as well. So, the problem with MDS is in the marrow. That's the factory where all the cells in the blood come from. So, if we want to fix the problem in the blood, we have to fix where the problem is starting inside the factory. So typically for a patient with MDS, the marrow is full of abnormal cells, full of MDS cells and the marrow is usually described as hypercellular. That means there's more cells in the marrow than we would expect and all those abnormal cells are really getting in the way of normal cell production, normal platelet production, normal red blood cell production, normal neutrophil and white blood cell production. So, the blood counts that we can measure by checking your blood may drop as those abnormal cells in the marrow increase and they're crowded out by the abnormal cells in the bone marrow.

The patient may start one of those treatments that we've talked about and the goal or the job of that treatment is to really get rid of those abnormal cells that are inside the marrow causing the problem. Unfortunately, those treatments kind of wipe everything out and they're not necessarily selective to the abnormal cells. So, all those counts in the blood may initially go down especially as Dr. DeZern mentioned kind of in a cyclical way usually about a week to 10 days after the initiation of that first treatment and then we hope by the time the second cycle comes your counts are kind of at least back to the baseline of where they started and we hope that with each cycle

that baseline starts to become better and better so that ultimately we get back to normal counts. So, the graph here depicts somebody's neutrophil count. So, I mentioned the neutrophil count is important because it's the most important type of white blood cell to help prevent infection. So when this person started, their neutrophil count actually wasn't in a terrible place, but after treatment started that neutrophil dropped quite low close to 700 which anything less than 1,000 increases the risk for infection and we see that it took till about week 11 before that neutrophil count really started to come up and recover to this kind of new normal of around 1.7 which is a normal neutrophil count. So, it took, let's see, from about week three or four to week 11 for that neutrophil count to improve. So, it's really during this time that the neutrophil count and the other counts may similarly drop during that time. That's the timeframe where the patients may need the most support 1) getting back to expectations what this means. This doesn't mean that the treatment is not working. It may actually mean that the treatment is doing what we thought it would do and that we just need to hang in there and wait and give the treatment enough time to work and focus on things that we may be able to do to keep you feeling okay during this time. So, preventing infections, transfusing your to parameters that keep you feeling well. So, the bone marrow may begin to recover around that 11 week period. Remember with drugs Azacitidine it can take from four to six cycles or four to six months to see an effect. So, that may vary from patient to patient, but once the response starts, the blood cell count should start to rise and we hope in conjunction with that that some of the symptoms should also improve. Ideally, the supportive measures like blood transfusions, platelet transfusions should be able to be weaned off or at least decreased as the response to treatment really sets in.

As I mentioned, it's really the early toxicities that can be difficult and discouraging. So, my approach is always to make sure expectations are clear in the beginning and then when the counts do drop, I say remember we discussed this. This is expected and I expect that as the treatment starts to work that this will get better.

I'm going to hand it over to Valerie.

Valerie Ironside: So, I'm Valerie. I'm blessed to work at Hopkins with Dr. DeZern, Dr. Gore who's here, a great pioneer in MDS and, of course, to work at Hopkins and have many patients with MDS who at our center many of them go onto transplant as well. So, very familiar with the lifecycle of MDS from the diagnosis which, of course, is frightening as all cancer diagnoses are, but maybe the blood cancer diagnoses are harder to take because they're in your blood and so it's everywhere. Whereas you might have a lung cancer with one nodule in your lung, but when you have a bone marrow disorder, you're starting with your life blood being affected by cancer. So, we talk about the therapy and we talk about teaching our patients how to deal with the various therapies which are complicated and which don't have a magic fix right away which is very hard because this is in America, right, and there must be a pill to take to fix my condition, but there isn't. There's a process and the treatment takes its toll on people. As Lisa was saying, time is required for the best response - a minimum of four to six months and most of our patients get worse before they get better and there's troubles during... and you know that and there's troubles

during each week a new side effect can occur. Each day. Absolutely. And you think you're ready because you've been told, but are we ever really ready for... to lose our energy, to lose our ability to get to work, to lose appetite, to lose brain cells. You know...

Q1: (inaudible 16:16)

Lisa Barbarotta: Yes. People that whole concept of chemo brain which is maybe a nonscientific nomenclature for a condition. That is true and these toxic chemicals are running through your body all the time. Your brain is not as sharp especially during the treatment and maybe for the next week. Reflexes might get lower. So, it's hard to work through that stuff. So, we as nurses try to be there with our patients during those moments and help say this is sort of normal even though it sucks. It's sort of normal and we hope to get through this to a time when you're brighter and more energetic again. So, you can see that we're working together to get the best response. There are dose modifications that happen with Vidaza. Sometimes people's blood counts go too low. We've been known to lower the dose. Some of our doctors lower the length of time. We have gone from the seven day treatment of Vidaza to five days. If peoples' counts dip too low after the first four cycles then we try the next two cycles to just give five days a week and see if we can keep patients at a better equilibrium which is the change.

So, here you can see what the response is like following four cycles of Azacitidine which the hemoglobin, see, is going like this and then after the fourth cycle, it's in a better a range perhaps up to 11 or 12 which is exciting and you just feel so alive and your hemoglobin is 12 versus when its eight and that's the point if a patient is going onto stem cell transplant that we at Hopkins do another bone marrow test to see what's going on inside the bone marrow and determine if they just have the minimal residual disease, patients if they're eligible can move onto to stem cell transplant. So, is that what occurred in your situation?

Q2: (inaudible 18:37).

Lisa Barbarotta: But you had stem cell transplant.

Q2: I'm sorry. Yes. Yes, I had a stem cell transplant and usual for Hopkins they decided not to use my daughter's... I had a haplo... not to use my daughter's marrow, but instead peripheral blood and I was kind of wondering about that, but the guy I had a for a doctor, I knew he knew what he was doing and I started Thursday and he explained that he did that because there's more GDHD with the peripheral and I was so high risk he wanted to give me some and that's why I'm on Pred.

Lisa Barbarotta: And did you get GVH?

Q2: Oh, did I ever.

Lisa Barbarotta: Okay. So, that's a...

Q2: About a month ago.

Lisa Barbarotta: Okay, but you're doing... you're living with your GVH which is great.

Q2: Absolutely. Even the Pred.

Lisa Barbarotta: She's talking about Prednisone. Steroids are one of the treatments for graft versus host disease which is one of the complications that can occur after a successful stem cell transplant.

Q2: And it can be good because it cuts your risk of relapse which is why he was kind of eager to have me get it.

Lisa Barbarotta: Right. So, that's what our hematologists are like. They make people sicker before they get better, but it's all part of the plan.

So for Revlimid, there's also a patient response and some patients have been on Revlimid for up to 10 years. Now, the most that I have seen a patient is about six or seven, but it is wonderful when that hemoglobin here started at eight or nine and then taking Revlimid every day or 21 days out of a 28 day period gives you this kind of response for your hemoglobin is again up to 11 or 12. Revlimid, if you're taking it, you know it can cause a dip in the platelet count. So, we have to watch you counts very carefully when you're on that, but then the platelet count can be bound as well and we also watch hemoglobin and hematocrit as well as white blood cells, obviously.

So, the thing... the part that we're getting into now is what can you do as patients and caregivers to stay healthy when you're getting these treatments or when you're getting supportive care and these are all such obvious things you think we wouldn't even be talking about them, but sometimes we forget if we're on this... patients are on a sexy, new clinical trial and it might be magical and make them all well again, but in order to get well, they still have to take care of their own bodies. They have to keep the rhythm of your life, the rhythm of eating and sleeping and exercising which is just as important as your treatment plan. Are there any things that any of you have found that has helped you through a treatment, length of time or a supportive care? Has anyone found something?

Q3: I just have one comment about that and it's having gone through a lot of this. At the beginning, you always take the view that you're not as sick as you think you are or they say you are and in my case I tried to tough out a lot of things – don't really need a blood transfusion today, that sort of thing. With hindsight, I would actually go with the program especially for an institution like Hopkins who is deep and broad experience with a lot of different patient bases. They really have a good sense of when it's time to do something.

Lisa Barbarotta: So, your intervention was listening to your team and or would be... could you do it again. Thank you.

Q2: And I want to second that because once I found the doctor in Boston when I consulted there said just find one good doctor, stick with what he says and I just had put myself totally in his hands and I think that he will do what's best for me and it's very anxiety relieving. Do your research and find the best one.

Lisa Barbarotta: Thank you. Great. So, the things that we recommend are the obvious things like diet and exercise, avoiding infection. I'm sure many of you or your family members have had a time when their white count has been exceedingly low and they've been told to practice neutropenic precautions where they've been told they should avoid crowds, wear masks, not eat certain fresh foods from a salad bar perhaps and these are very important things to listen to your team about because a life threatening infection in the middle of your treatment will slow down your treatment because you'll have to go in the hospital for IV antibiotics. We also watch over our people for bleeding because when your platelets get low you all know that there's a danger of that bleeding. We don't like people to run their marathons when their platelets are low or maybe even run the power mower. So, we don't want accidents. Getting enough rest and also keeping goals in your life is very, very important. I honor what a person I met today said who's been newly diagnosed and she said so far she has no symptoms, if I may say this, but... except for anxiety about what is going to happen next and she is taken a modality of going to a practitioner to do acupuncture to help with that anxiety, to take proactive charge of her own life with the symptom that she's having now. Did you have a thought, (Attendee)?

Q5: I'd like to share another thing. I'm sorry. Although I didn't need it all through the two cancers and the B&T and all that, this Pred got to me and my nurse practitioner at my local doctor here said she's... you know, it is possible to bring yourself down just a little bit with medication or something like that and I want to recommend there is an app for iPad and for iPhone called Calm and, man, you do that you feel like you smoked dope. It turns you into putty. It's wonderful. This woman's beautiful voice. There's no hocus pocus, religion, smocus, it's just wonderful. Highly recommend it.

Lisa Barbarotta: Thank you and that's taking advantage of available resources. Yes, (Attendee)?

Q6: If I may, I'm the (inaudible) for acupuncture and it's very interesting because acupuncture is not going to diagnose you, but it's going to help you on a different side. It gives you a different perspective, a different type of approach to disease because that's the Chinese way. It's more than 1,000 years of experience. So, it's helping you because you can also tell what your fears are. So, it's very, very helpful and going through meditation or deep breathing is also very important and it helps because when I was diagnosed I started to take Valium. It was a catastrophe because I was just thinking about when I'm going to take this next pill and so acupuncture, deep

breathing, I got rid of the Valium and I'm doing fine. So, it's a very complimentary help (inaudible 26:44) from what your doctor is doing.

Q7: I apologize again. I have to say one more thing about how right you are about acupuncture. I had a stroke about two years ago and I'm a former journalist and all of my thoughts come out on a keyboard and I had neuropathy in these three fingers and I could barely type. So, I went to an acupuncturist and after two treatments they had been trying in PT to get me go... After two treatments, couldn't do it. I said, "Please hand me that clipboard,"

Q8: Can I ask a question or should I wait? The question is related to exercises. I said my mom, she's 81, has MDS, lives in New York, coming down was too hard, but she wanted me to find out everything and thank you for this presentation and my heart goes out to everyone with MDS. I think it's a really horrible disease and I know there's not a cure in particular, but anyway just... but my question is about exercise. So in my mom's case, she didn't start out particularly fit in the first place and then with the disease, she's very weak. I mean, going half block to her corner is a massive undertaking, but I feel like it's a slippery slope because if you get more and more out of shape, you're getting more and more and less and less fit and the question is how to sort of stay healthy in terms of exercise specifically when she's already so weak and as the time lapses since her last transfusion which is about every two weeks, she's just so weak and yet I think you're trying to maintain a certain level. So, I'm curious from any of you or either of you expert nurses what you can recommend in sort of a realistic way to at least not get in worse shape. She'll be 82 this month, but again she didn't start out as really fit as a fiddle in which kind of makes me realize I have to stay as fit as a fiddle because it really hurts you to not start even healthy. So, I welcome anyone's comment.

Valerie Ironside: I'll answer first and then I defer to Lisa for her thoughts, too. One of our doctors is a great cheerleader for initial diagnosis and planning and he talks about all the things that Dr. DeZern talked about. He talks about the diagnosis, how we got there, the treatment plan, the prognosis and then he talks about the patient's contribution to this team effort of walking through a treatment plan for MDS and he advises his people to keep a journal especially about exercise especially if they have not been exercising or they have... because they've been so sick they have lost their functioning with exercise and he tells them, "I want you to walk for five minutes every single day this week before I see you next week. Just five minutes and I want you to put it in your journal and I want you to tell me how you felt after that," and then he remembers that he gave them that homework and he says, "Now, you're doing great. I want you to go 10 minutes next week," and we recommend walking or gentler exercise than high endurance marathon running, but setting the goals on paper really helps patients with their homework and when my husband had a kidney transplant two years ago, I gave him the speech of my Dr. Smith beforehand because I said, "This is not my advice because you know, a wife could never tell a husband to keep a journal or, you know, to do 10 minutes," but I would come home from work and he'd be doing laps around the dining room table because it was midwinter because he really likes Dr. Smith and he thought, "If Dr. Smith says to take laps," and he kept a journal which

that's not like him. So, I think specific, gentle goals that you can even write down are helpful for patients. Lisa, do you want to...?

Lisa Barbarotta: So, that's a great suggestion and also for my elderly patients especially if there's any concern about safety on their feet, risk for falling, if their insurance will cover it, I will do a physical therapy referral and sometimes they can even come to the house if they have trouble getting out of the house. So especially... and not even just older, but anybody who's frail, at risk for falling, I try to optimize the resources that we have because physical therapists, obviously, are professionals who can guide an exercise plan and the only other thing I would mention, I don't know if they have these programs in this area, too, are some of the YMCAs have a Live Strong program funded by the Live Strong Foundation for Cancer Survivors which all of you are considered cancer survivors and those are also guided exercise programs by professionals who do an evaluation of your health starting out the program and guide the exercise based on your current level of fitness. So, physical therapy for sure if we can get it paid for would be something I would recommend.

Valerie Ironside: Yes?

Q9: I found that at least to begin with I was doing a lot, you know, I was a gym rat and went every day and so forth, but I think and even before diagnosis and going through treatment and all of that routine is a huge part of all this and I think you need to try to do what you can, but you also should have a daily routine and, of course, this will wreck your normal life. Your daily routine will be going to the doctor, sitting in the chair or doing whatever it is, but if you can build into that some piece of well, alright, fine I'll walk around the apartment for five minutes or whatever because I did find that having done the exercise and so forth it made things go better. The more you sit which is what you really want to do I think, you're tired, it's harder to get back into that routine of doing the exercise.

Valerie Ironside: Thank you. Yes.

Q10: I would like to mention also something else. Maybe some of you are familiar with the Feldenkrais method. It's a method which is used by dancers, actors, student to make your body more fluid. It's like your (inaudible 33:15) but less trainers and you can do those exercises in your chair. Generally, a Feldenkrais practitioner gets all the worst case. People who have been through everything trying to get better and it didn't work and it's absolutely without any danger of hurting yourself. So, it's written and it's spelled out F-E-L-D-E-N-K-R-I-I-S. That's the name of the guy who started with the letters.

Valerie Ironside: Is it Felden...?

Q9: Feldenkrais (inaudible 33:53). I can write it down. Here you can get it... We live in Arlington and through the county classes you can get those classes.

Valerie Ironside: Feldenkrais. Thank you. Thank you. (Attendee)?

Q10: Very different question and you can take the Fifth Amendment on this, but in DC you could grow your own cannabis. In Maryland, a law's been passed and they're in the process of drafting some regs which are actually liberally, the current draft, in terms of medically prescribed marijuana. They're calling it medical cannabis, by the way, to deliberately distinguish from recreation. I wondered whether places like Hopkins were actually thinking through protocols in terms of how to do that because, obviously, you don't want every doctor prescribing to every patient for everything, but and I wondered if you actually had a process to think it through in the oncology...?

Valerie Ironside: Yes, our pharmacy division does have a process and patients have asked me and I have asked the pharmacy can I prescribe because we nurse practitioners can prescribe and our pharmacist says, "No, we don't have a Hopkins protocol yet," but soon there will be a Hopkins protocol for that.

Q11: I can't resist. I put one of my crippled dogs on dog pot yesterday from Canapet. It doesn't have the intoxicant in it, however.

Valerie Ironside: Is this for a condition of your dog?

Q11: He's very old and lame and (inaudible 35:25) on special...

Valerie Ironside: You'll have to get back to us and tell us.

Q11: (inaudible 35:31) my own clinical trial.

Valerie Ironside: Lisa, is there anything at Yale?

Lisa Barbarotta: So medical marijuana has been legalized in Connecticut in the last year. Our institution is still working on policies as far as us prescribing it. I do have two patients who had it prescribed by primary care physicians in the community. They primarily are using it for symptom management – nausea, anxiety and pain with varying results. One is a 20 year old with leukemia who was using it prior to his medical use and he finds it helpful for those symptoms, but I think it's under a lot of study finally in a more scientific way and I think we'll have more information about how useful it is and to demonstrate 1) safety and usefulness. Whenever you inhale it there's risk for... we worry about fungus or mold and I know the newer medical formulations are supposed to be safer from that perspective, but that's always my one concern when patients tell me that they want to smoke pot to help their symptoms. I say please be aware your immune compromise and this may put you at risk for serious infections.

Q12: I had a very interesting discussion with a mental health provider that I used and she said that totally anecdotally she found that patients and she would take the drug history that patients with a depression history react very badly to marijuana whereas patients with an anxiety history react wonderfully. It's really a calming kind of thing and I don't know whether that's consistent with anything you're hearing, but I think for some people it's going to make a revolutionary difference for the nausea issues. Thank you, though. That's really great to know these... they're really... when leaders, intuitional leaders like that lead, everyone else will follow.

Lisa Barbarotta: I think it needs to be handled like any... it's not new, but handled like any new substance and it should be investigated similarly to other hopeful medication so that you're absolutely right for many people we hope that it's something that will be safe and helpful.

Valerie Ironside: Great. One of the things...

Q13: Actually going back to the exercise, one of my concerns with MDS is since I'm up and down, up and down kind of thing is what's the relationship between exercise and your hemoglobin? Are you using all that oxygen up with your exercise, so you're going to be going down again? What happens there?

Valerie Ironside: So, there's no science to say that exercise uses up your hemoglobin. You're using up the oxygen in your body and so you're going to use up what's available sooner when your hemoglobin is low, but I don't believe there's any science that says more exercise is going to break down hemoglobin. Lisa, do you know of any?

Lisa Barbarotta: No. I agree with what you said. I think that you may not be able to tolerate as much activity as you may have when your hemoglobin was higher. You may have to go slower or for shorter periods of time, but as it relates to fatigue, we know that inactivity can make fatigue worse and small amounts of activity whether it's 15 minutes, 20 minutes, 30 minutes can actually help fatigue. So, I would say even if you have to walk on a treadmill at a slow pace like a 20 minute mile that that may be better than not doing anything at all. You just may have to go slower and listen to your body if your heart is racing and you're having trouble breathing then obviously we would say you should either go slower or decrease your time. You have to kind of listen to how you're feeling and adjust the intensity of your activity accordingly.

Q13: Actually in my experience you can drop five points in three days and I think there's a big difference there.

Lisa Barbarotta: When you exercise?

Valerie Ironside: Just your disease is dropping five points and you feel it. I'm sure.

Lisa Barbarotta: So, I don't think that the exercise itself impacts the number, but I do think that you will feel the difference when you're exercising, so that's why I think it's so important to tailor whatever activity you're doing and listen to how you're feeling and how you're tolerating it.

Valerie Ironside: And keep doing it.

Lisa Barbarotta: And keep trying.

Valerie Ironside: Yes?

Q14: In your (inaudible 40:20) when you do deep breathing, breathing in, stopping everything for (inaudible 40:27) and then breathing out, it's supposed to increase your oxygen. So, is it something that people can do when they feel that they cannot walk, they cannot exercise. Does sit down a real effect?

Valerie Ironside: Absolutely. It has a real effect on endurance, indeed. I think Dr. Andrew Weil, is he from your institution from Yale? He's an oncologist who does a lot of writing on holistic and complementary modalities to help with people. He does not say don't take your traditional medical scientific therapies, but add to your therapies deep breathing and exercise and meditation and family and community. He's a wonderful scientific physician, but he adds these... what would we call them? Softer treatments which are just as important in a holistic view of any disease that we might be fighting or life. Yes?

Q15: I thought I would never live to set eyes on my grandson who was to be born and my best therapy is when he comes to visit almost every day. He's 10 ½ months.

Valerie Ironside: And that leads into the last participatory thing, on this little list anyway, is hope. We have a hope initiative at Hopkins that hope is an important part of cancer treatment. There's medicine and then there's your team, there's your health and lifestyle and nutrition and complementary medicine, but there's also hope and many of our doctors as we talk about the therapies that are ongoing and we talk about the side effects of each therapy what might could happen. We also encourage our patients to make goals. What are they hoping for? Maybe not in 10 years, but what are they hoping for in six months? What things are you keeping on your hope list in the next six months that will carry you through this yukky treatment where you're going to be tired and you're going to throw up and you're going to want to hide under the quilt? What is going to keep you hopeful as you go through this and keep revising those hopeful goals that we have. Yes?

Q16: Could I respond to that with a caution now? I mean, I always worry about the metaphor of cancer is fighting and the metaphor of defeat is blame and I think it's really particularly important for those who have something that unless we take the... make that risky decision about

stem cell... about the cell transplant, in the end we're going to get a moment of letting go and I think I'm not disagreeing that having things you look forward to and care about and that motivate you and you can get up thinking it's a terrible day or getting looking forward to something in the day and the second of those is better, but I think it's really important that our governing narrative not be one that ends in failure inevitably and that we feel like it's our fault, but for me personally, I pretty much made a decision I don't want to do the stem cell transplant, but I keep feeling guilty about it and...

Q17: (inaudible 43:59)

Q16: Yeah and I keep feeling guilty because I like I'm letting down the family and letting down... and (Attendee) been wonderful, but I guess I think it's really... and everybody makes their own decisions for their own reasons, but I just think it's very important that it's much less now but there used to be sort of combined with the medical systems denial of really being honest with people about how bad things were which has really gone away largely. Combined with that was this we must have hope, "Oh, I had one patient who lived 25 years after this diagnosis," and it's not just medical people who say that. Your friends say that about a different cancer, a different regimen, everything different and they think they're cheering you up, but I often hear it as... it's your fault if you don't, too, that kind of thing or at least that you're not obliged to fight every single inch rather than to accept that moment of letting go and while I deeply respect Nora Ephron, the writer, there's a thing about when she finally... she had this and when she finally realized that it hadn't worked, she was not just furious, but utterly unbelieving and uncomprehending and I guess not to judge that was her way of coping, but I chose a different one.

Valerie Ironside: Thank you, (Attendee). (Attendee)?

Q17: Sorry. Yet again. I don't think you should feel guilty in any way. My own oncologists here locally, we were talking and he was recommending I go to Hopkins and I'm to do this and I said, "Dr. Hier (sp? 45:45). Would you have a bone marrow transplant?" and his hand was on the doorknob and he stood there very still for the longest time and he turned and looked me in the eye and he says, "I don't know." Now, I had no choice. I had only a few months to live if I didn't do it. Either Dr. Jones said... a man asked him once why would you get on an airplane that had a 10 percent chance of crashing and Dr. Jones said, "If someone had a gun at your head and said if you didn't get that on airplane you would?" but don't feel guilty. That's a very personal and rational choice.

Q18: It's great to hear that from somebody made the other decision. That's very (inaudible 45:25).

Q17: Well, I had to. I had no other choice. You had one and don't feel guilty about making it.

Valerie Ironside: Thank you and I think there's a difference between true hope and false hope because our doctors as they're talking about hope may say, "You have four to six months to live, but let's make some goals about what we're going to do and how it's going to be the best time that you have."

Q18: I would like to share something. My sister died of melanoma in her 20s and this was in the 70s and she actually when the doctor told her right... a few weeks before the end what was going to happen which is another whole discussion, she basically asked would you help me kill myself and that was long before physician assisted suicide was called a level where people are talking about it seriously like they are now and his answer though was absolutely fascinating. What he said was, "If you asked me that it would mean that we had failed you," which is, again, back to this hope thing. In other words, I had not kept my promise to make your life as meaningful as possible for whatever it was and I think that's like a wonderful medical care philosophy which is what you're saying which is you're honest, but at the same time within that honesty you make it as good as possible.

Q19: You should ask something about hope. So as I said, it's my mother. So, I have a brother. I have two kids, so they're grandkids, etc. In her case, it's a little simpler in that she is not a stem cell candidate for various reasons, it doesn't matter, but so it's a supportive care level and there's not any drugs that she can take that will work particularly. So, it's really just managing the disease and so as her kids, grown kids, I'm just curious what you find helpful because she finds it's very... it's frustrating for her because there's not a cure, things seem to be going downhill. It's very up and down. I'm sure all of you are nodding your heads, you know and we watch this and live with it with her and so she gets depressed. So, I guess she shouldn't smoke pot, so that's great... easier answer, so we don't even have to ask the doctor now, but she considered herself a sort of venturesome, vibrant person. She's still mentally really with it except, you know, as she goes from transfusion she's a little more foggy. So, I guess I'm asking she gets... she doesn't feel like there's hope because this is the rest of her life and she doesn't know how long that will be even and so I guess I'm wondering from any of you and you expert nurses here what as her grown kids and grandkids we can do to... I don't know if it's giving her hope because what can she hope for? She feels like the quality of her life and to be colloquial sucks. My kids, her grandkids, have gone and visited her and stayed with her in her apartment in New York which she loves, of course, and that's been... I think something like that is great. We're each going to visit her for her birthday, but what do you feel as your family... she's divorced, so we're her main people, can give her hope and... not hope for a cure, but hope in general. So, I'm curious if anyone has recommendations because it's really hard... there's nothing I can do exactly. So, I'm just curious of what you find helpful from your loved ones. Thank you.

Valerie Ironside: I just want to say presence is huge for people when they're walking through a hard time, being there, even though we don't always know the right things to say, hanging out with your mom, bringing your kids, grandkids...

Q19: I'm long distance (inaudible 50:07) so I couldn't physically visit, but we would call (inaudible).

Valerie Ironside: That's a presence. Any presence is a great thing. Other thoughts?

Q20: I find friends and family to be the most important thing. I know she's older and maybe a lot of her friends are no longer living that reach out to the neighbors in her apartment building, to the doorman, to anybody she still knows in New York who gets out and around to make plans with her, to... on Tuesday, let's meet for coffee or on Tuesday could I bring a bagel over for us to share. Try to get her more connected with people.

Q19: She has a lot of friends and what she finds also frustrating she keeps cancelling on them because she's physically not up for it that day and she wants to go and so she does have a lot of friends, but half the time she cancels. She'll make theater tickets and then she cancels and so and then she gets more depressed about that. So, she's trying but her body is saying no, I'm not up for it today.

Q21: I could have two thoughts. The first is I have a psychiatrist who specializes in death and dying patients or in issues and she was actually referred by the Hopkins social worker. Her name is Lauren Hodas and she's in Bethesda and I have found it hugely helpful not only having a professional's assistance, but actually having a psychiatrist who...

Q22: Can you repeat the name?

Q21: Yeah. Lauren Hodas. And because so much of this is at the interface of mental and physical and in fact the discussion... I was talking to her about stem cell and feeling guilty and said maybe 50 percent chance of being back to where I started, maybe that's not so bad and she said, "But you won't be back to where you started," and I said, "You mean because of the treatments," and she said, "Yes." I said actually, I said, "Are you talking as a doctor here," and she said, "Yes," and that was so liberating along that because it's a different calculus and so I would strongly... and again somebody who's used to working with dying, patients threatening death... facing death and dying, again is going to be less than this just deal with your problem, confront your parent, get it over. For me, my wife's just given me her number.

Q22: My mom's not local, but for anyone else here, yes.

Q21: (301) 530-1127. Hodas.

Q22: My mom actually happily Memorial Sloan Kettering where she gets treatment is really great and they have a whole therapy... or mental health. So, she sees a psychiatrist at Memorial Sloan Kettering which is great because that person, all the see are people with various cancers.

Q21: Okay. So, you're saying the same thing.

Q22: And she'll say... she wasn't a person who thought she needed to go to... she's said I'm going to go get shrunk today and she's taking a mild antidepressant which she also never thought she needed, but Memorial Sloan Kettering has that and she's been going and she'll say, "I want to make an appointment. Like I realize I need this that will help boost." So, I encourage... Also I think you're totally right and also someone who specializes in this versus stiff upper lip. I mean, someone who's used to people dying and cancer and MDS and these are really challenging horrible things.

Q21: And I guess the sort of archetypal conversation with her was, "You know, I sleep a lot." She said, "Sleep is good." I spend a lot of time on the sofa. She said, "Sofas are good," and I think that's just so different from what I would have wanted 15 years ago. I guess the other thing is we live in a retirement community and we've actually informally formed what we call the Death and Dying Group and not all of us have terminal diagnoses, but often one in the couple does and I think we've been quite astonished at how much progress people have made in the group through talking and sharing and this was not led... created by a social worker. We were at a gathering of a network, The Quaker Network of Retirement Communities, and so I mentioned this in one of the gatherings. Within that... and immediately afterwards two people came up to me and said, "Can we join?" So...

Q22: Not everyone had MDS in the group.

Q21: No, no, but that's... again I think the issues really are ultimately similar. So, I guess the other thing I would say and I think individuals are very different, but for me I hate the feeling of being scheduled because of that energy. So when I look... at night I look at my schedule for tomorrow and there's nothing on it. Even not meeting anyone for dinner in the dining room. I am so happy because for me it's the sense of pressure and that sounds like what your mom is doing. So, thinking about the informal let me call you when because if she gets depressed when she has to say no and of course it's classically New York. You go out to do everything in New York.

Q22: Right and she just said what she said expressly she doesn't know how she'll feel from day to day. So, she tries to make... so she could make no plans and be depressed or make plans and cancel. So, but you're saying be more informal.

Q21: Everybody is different but I have to say for me that when I let myself stay in bed until 11:30 in the morning I have more energy in the rest of the day. Totally obviously.

Q23: This is really my last comment. As we're winding down, I started around a note which is very non-HIPAA so do not show it to those two ladies. It's a note inviting all of us who care to put our E-mails down there. I will start out a BCC chain if you have any interest. The young

woman next to me said there's no MDS support group here. Well, sure there is. So if you so choose, I don't know what happened to it, probably got stalled somewhere. Who was the last person who filled it out? I'll try to find it.

Valerie Ironside: Thank you and I think this all speaks to the whole concept of being a partner in your care and making your own plan, making a plan not to schedule a day. I think that's wonderful and considering your lifestyle, considering transportation maybe you used to walk everywhere and now you have to get rides from friends to take some ownership for your own illness at whatever stage of that illness you're in is very freeing and to ask for help. I have to confess that I am new to the *Building Blocks of Hope* and I've been a cancer nurse for almost 20 years. So, I just saw them last week when I felt them through the E-mail and I think they're wonderful for this particular disease because you start with a diagnosis. It starts with the scoring and then it goes through the various stages of treatment and the quick tips for what to do, how to conserve energy, how to maintain exercise, what to do about iron overload, the things that Dr. DeZern talked about and making your own MDS plan. So, I think at the end you're all going to get one of those notebooks there and you're going to be able to... If you're that kind of person who likes to write things down that's good. If you're that kind of person that just keeps them in your head and is creative that way, but it's so good to have all this information. We don't have this binder at Hopkins. So, I'm very eager to bring it back and put it in our patient teaching library and to bring a bunch back to start with the nurses who take care of the MDS patients because it's wonderfully informative and that was really the goal of this little session here was for those of us who are taking care of MDS and you who are experiencing MDS either in your own life or with your families is that you have a tool and you have more community that you're building yourselves and sometime in Baltimore we have a whole institution called Hopewell that is a center for people with cancer and they have different support groups for different illnesses and they also have complimentary therapies like yoga and stretching specifically tailored for people with cancer and it's all free.

Q24: They have massage.

Valerie Ironside: Right and it's free. It's called the Hopewell Institute. It's in Townsend, Maryland right outside of Baltimore.

Q24: No, in your hospital you have massage.

Valerie Ironside: Oh, we have massage in our hospital.

Q24: Got a grant from someone provided that free massage therapy. It's wonderful.

Valerie Ironside: It is. Yeah. Sometimes she gives it to the nurses, too. So, it's really great and you know there's people that... people who are looking for community if you can't find it in your neighborhood, in the documentation you get today there is people online or people by

phone that you can get help from and what we've been doing all along is we're talking about each other. Yes?

Q25: Before we get off, speaking of listservs, what do people think is the best existing listserv for MDS and also what happened to the MDS Beacon?

Valerie Ironside: So, I don't know. Lisa, do you know?

Lisa Barbarotta: Do you mean the MDS Beacon website?

Q25: The MDS Beacon website.

Lisa Barbarotta: Is it down?

Q25: They haven't posted for years that I'm aware of.

Lisa Barbarotta: I'm unaware of what happened.

Valerie Ironside: I wonder if this organization has kind of taken over that role.

Q26: (inaudible 1:00:46)

Q25: But it is down. That's too bad. (inaudible 1:00:56).

Lisa Barbarotta: So, does anybody participate in listservs that could help him with useful listservs? No.

Q26: Oh, when I was first diagnosed with follicular lymphoma I went on the... I think it's the leukemia and lymphoma patient site and it is incredibly active, very, very active. I kind of haven't checked it since I got my next cancer, but I would look on there because they... the MDS people may be going there.

Q25: I did check it and I didn't find very much.

Q26: We're a rare breed.

Q25: I guess so.

Q27: That's where I find the first document explaining me MDS. It was not too complicated, but scientific enough. That's on that website, the leukemia website.

Q25: What is that?

Lisa Barbarotta: I think there's some kind of... A message board on the MDS Foundation website. It's not exactly a listserv, but you could ask things and people might answer. Have you looked there? So if you go to the MDS Foundation, it's something like patient forum or...

?: It's on the MDS website. (inaudible 1:02:27)

Q25: (inaudible 1:02:35)

Q28: I just went on the website, www.mdsbeacon.com. It does appear not to be up to date. At least the first entry which was probably the most recent is May 14, 2014. So, it suggests that it's not very active. It obviously isn't that...

Q25: (inaudible 1:03:11).

Lisa Barbarotta: So, there was a lot of productive conversation. Do people have other thoughts, concerns, questions, things they want to share?

Q29: When I got MDS, it was... they didn't give me much hope for living very long. So, I went to into a total different diet. I changed my diet. I read everything online and they said alkalinize your blood. So, I went into a total alkaline diet. So, I really... I mean, all I eat is vegetables and grains and fruit. That's it and now after six months of ASA, I don't have any of the problems. My blood and my bone marrow turned out to be normal. But I'm afraid to get off the diet. I'm afraid to eat anything that I think might...

Lisa Barbarotta: Live life, drink wine. Don't wait.

Q29: No, I'm sorry. I do drink beer and I once in a while will have a little bit of wine. So, it's not like my whole life, but I just fear... Like I was afraid to come to this conference because I thought I really have to eat every couple of hours, but I don't know what happens if I start to eat normal again?

Q30: Wouldn't that be wonderful?

Valerie Ironside: So, what does your doctor say?

Q29: Oh, he doesn't believe anything... He's just an oncologist and I also go to a Vinteg (sp? 1:05:16) and she thought I should be eating at least grass fed beef and pasture... I do eggs. I do do eggs and they are pasture eggs and fish, not too often, but once in a while, but I just am afraid to do anything. I mean, like this lunch was very difficult here because...

Valerie Ironside: Did they have any grains?

Q29: No, no grains. Just... Well, I don't do gluten either. I'm afraid because that is supposed to change the alkalinity of your blood and I had such positive, wonderful results, but it looks like I'm going to be on as a... for the rest of my life if I want to keep it that way and I do because I'm going to be a grandmother in the next couple of years. My daughter got married. My son got married this past year and I do want grandchildren, but I do fear living practically. I just worry about... Has anyone ever done anything on your diet? I mean, I know they say should eat vegetables and stuff, but then you've also included dairy and I've been off dairy entirely because apparently that's supposed to also... Yeah. I know. I don't weigh anything, but that wasn't it. I mean, I started at 100 and only dipped down a little bit and now I'm up to 102. So, but I just want some kind of confirmation from other people maybe. Is there any source of either do nurses keep track of that stuff? I know doctors do.

Valerie Ironside: So unfortunately, there's a lack of clinical trials on the effects of diet and cancer and that's a hardship because we all know as sensible people that what we put in our body makes a difference. It effects our immune system. It effects who we are, how we think, the energy we have and at Hopkins, of course, they would honor... the doctors would honor your choice to have tried that, but they would say there's no clinical trials backing that your diet had anything to do with your MDS and how well that you've done with that. So, I think there are a few private oncologists that if you go on the website that may be incorporating more diet with that, but I can't think of any right now, but it is a question that many people who are thoughtful about their health and their diet come up with this and most of the medical community isn't helpful as much as they'd like to be.

Q32: It's a lot better than Revlimid.

Valerie Ironside: You mean diet is better than Revlimid.

Q32: Yes.

Valerie Ironside: Yeah, for side effects. Certainly. Yes?

Q33: I'm so (inaudible 1:08:43) and all his courage and (inaudible 1:08:53). My comment to you is you have made (inaudible 1:09:00) your diet every day of the week trying (inaudible 1:09:11). That's just something that you really like and enjoy. It is (inaudible 1:09:27) just keep with your own diet introducing the before cancer diet.

Q29: The thing is it takes so long to diagnose MDS, but it's like when we started I had the bone marrow and then six months later, he said out of four months later, let's try my bone marrow. He said, "Oh, no, no, no," but he said six months. So at six months, I was like, "Okay, let's do the bone marrow," and he finally did the bone marrow and he didn't find anything and he actually questioned the guy who did the (inaudible 1:10:07). He said, "How is it possible that she had this

chromosome damage and now there's nothing and the blasts are zero and all these kind of things that were super high just six months ago?" and he said, "Could there have been a problem with contamination," and they guy said, "Oh, we don't do..." He really...

Q34: Have you had one since?

Q35: It was a couple weeks ago.

Q29: I was hoping that maybe you knew of some study using diet type things, but you don't.

Q33: I have to what to do with mom just (inaudible 1:11:00) So, I'm (inaudible 1:11:02). I am a gambler. Is your mother a gambler? Maybe she likes to go to the casino or online.

Q36: I don't think that's here thing, but thank you. I mean, I'm open to suggestions.

Q33: I know my children will take me there.

Q37: Canasta or something online or...

Q36: She used to be a bridge addict and now she can't get there. So, she plays online. Thank you.

Valerie Ironside: Thanks. We are so grateful as nurses to have heard so much from your about your story and it helps us as we go back to our places to think more deeply of this journey of MDS together and I think we've accomplished all of our goals today.

Q38: It's unfortunate there wasn't more of a turnout.

Q39: The question I have why there are not so many people. We are in Washington, DC. I mean, it's a large population and educated population. Why, why, why? Do you have any...? I mean, when those gathering in other cities. Do you have a large number of people that you get?

Lisa Barbarotta: Do you guys want to answer like what the average turnout is at these events?

?: The average turnout that people come to this (inaudible 1:12:37) in a big city like Washington or (inaudible) we normally have like 50. We had more people on the attendance list, but you know people get sick and (inaudible) and I'm surprised that this many (inaudible) but I was in Pittsburgh a couple weeks ago which is not like Washington, DC and we had about (inaudible). Then in San Diego, we had about 70. So, it depends on where it's at. We're having one at Hackensack which is (inaudible 1:13:14) areas. We'll probably get a turnout of 50 to (inaudible 1:13:22), but you'll be receiving invite (inaudible)

Q39: Question. If we organize a listserv here in the area, could we pass through the MDS Foundation, to extend it for people who were not able to come, for example?

?: (inaudible 1:13:40)

?: If you look inside of your booklet, it's a form about support groups guidelines. So, if you wanted to get a group together, we have some guidelines in there and if you call the office (inaudible 1:14:06) support which can be (inaudible)

Q36: I have more questions. I'm sorry since I'm not the patient, so if people want more patients talking just tell me to shut up which is fine. So, two questions. One, my mom wanted me to ask you one. I wanted to ask the one about she wanted me to ask is have people experienced loss of appetite because she has lost so much weight. We kind of joke she spent her whole life trying to lose weight and now she's trying to gain weight. She wanted to know if that's normal. The second question is she's been... she read some study I think from the MDS Foundation, the Building Blocks, about the benefits of wheat grass when you have low red blood cells and hemoglobin and so she's gotten very devoted about getting out which is a big deal to get to the local juice place to get her fresh wheat grass every day which is an entirely big challenge for her every day and the local juice bar closed because it's New York and things close, but anyway so she did that for months and months and months and at some point it seemed like it helped a little. Her hemoglobin became once in five years in the range of normal, but she also has low blood pressure and she had read also that it has the effect of lowering blood pressure. So, my question is if anyone here knows about anything further than this one study in India years ago about the benefits of wheat grass for MDS specifically and if any of you have done it and what have you found because she tried it and now she's a little nervous it's lowering her blood pressure even...

Q40: Just Google it.

Q36: Well, no, no. We've Googled extensively and brother can even get into like academic things. So, there's not much factual information. So, that's why I was wondering about anecdotal information from any of you including you.

Valerie Ironside: I don't.

Lisa Barbarotta: I don't have experience with that either.

Valerie Ironside: I do think that the wheat grass situation was good and that your mom had this goal that it's going to... I'm going to feel better. I'm going to get out. I'm going to find the wheat grass. I'm going to do the wheat grass and that's... Yeah. And I achieved getting the wheat grass and I feel better.

Q36: She stopped now and that was her like reason she actually pushed herself to get out every day...

Valerie Ironside: To get out of the house.

Q36: ... just to get her wheat grass.

Q41: On the appetite question, obviously everybody is different and so many of us are on drugs and if you find a drug that doesn't have nausea listed as a side effect, you should get a special prize, but and of course anxiety also contributes to it and it's very hard to separate that out, but my sense is yes and legalized cannabis, but I think for some of us it's become a daily battle that's associated with the disease whether, again, exactly what the path of association is I wouldn't know and I think that to be honest I think that the medical system doesn't... there's a tendency to... Well, make an appointment with the GI people and my experience with the GI people is that they are great at finding cancer in your intestinal track and cutting it out and preventing it from coming back but and understanding the kind of, the vague abnormalities of the GI system, they're actually... they don't know what they're doing and we know everybody's body chemistry is different and it gets out of whack. I had a very bizarre thing happen to me which was in November I had my gallbladder taken out, not anything to do with the MDS and for about three or four months, my stomach was so much better and then it just flipped back and I don't... Actually, it's better. Not only was my stomach better, but a lot of my other numbers got sufficiency better that they're retrying the... what was it that it failed? The Aranesp that had failed, they're trying it again and it seems to be working more. So, there's weird stuff going on and nobody really knows except our clinicians are all feeling their way and this is not like breast cancer where you go in and you get a series of genetic tests and they know what to do... or if it doesn't then there's a back out and they'll go back out and this is...

Valerie Ironside: Thanks. We are all individuals and our body chemistry is different for each of us.

Q41: I will say for me when I was on Prednisone in an attempt to try and reach my number, I felt more energetic by far and had much better appetite to the point where without getting into specifics one of my clinicians apparently said to the other, "See if you can find an excuse to put him back on Prednisone," but, again, you get into these questions of quality versus quantity.

Q42: So is it actually is it her appetite?

Q36: Yeah. She just doesn't feel like eating. Sometimes she said her left side hurts so thought maybe it was sort of... sometimes when your white blood cell's high, your spleen's enlarged and she thought may it was pushing on it, but GI determined that wasn't what was going on, but she just isn't hungry half the time and we're always saying like eat, eat, eat and I don't live with her but when she visited me basically just kept offering her great food the whole visit and she, her

energy was a lot better and I talked to her doctor after and she said, “She was great after I think it was because she visited family.” I said, “It’s because she visited family, but she also was eating more literally.” So, it’s a slippery slope because when you don’t eat you have low energy and so it exacerbates it, but she just says every time I get her on the phone I’ll just say... “I’m about to have dinner. Okay. I’m hanging up. Eat,” but she just says, “I’m not hungry. I’m like forcing myself to eat.” She’s like lost a lot of weight. She looks like a little bird now which is not healthy either. So, she’s just... Says she’s not hungry.

Q41: A lot of people find (inaudible 1:20:49) I found fluid stuff much easier than solid stuff. Soup broth is easier than stew, but smoothies are great. Yogurt (inaudible 1:21:01) great. The obvious...

Q42: It boosts your (inaudible 1:21:04)

Q36: She doesn’t like anything milk based and they have one Ensure that’s not milk... that’s another... because we said just drink that stuff. No, no, but it’s great suggestion.

Q43: There is a health food store that (inaudible 1:21:15) Grain or something like that it doesn’t have sugar and (inaudible)

Valerie Ironside: Well, we would like to softly end this meeting and then people can continue to gather individually and speak...

?: Thanks.

Valerie Ironside: You’re welcome.

(Applause)

Valerie Ironside: Thank you.

(No Audio 1:21:55 - 1:50:57)