



Diet and Myeloma

What not to do if you are a myeloma patient, what not to eat, what supplements not to use? Ever since Dr. Durie, the head of the IMF, came out and conceded or made a pronouncement that myeloma and diet were not exclusive and there is relationship and they are interconnected, diet and myeloma is much discussed.

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Tune into Danny Parker and CurePanelists discussing myeloma and diet.

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Full Transcript:

Priya Menon : Good evening, everyone! Hello and welcome to the Cure Panel Talk Show. I am Priya Menon, Scientific Media Editor of the Cure Talk blog and I welcome all of you this evening to a discussion on diet and myeloma in our talk series on cancer and nutrition. Cure Panel Talk Show is now a featured host on Blog Talk Radio and our shows have recorded over 114 listens. This is the 29th episode of Cure Panel Talk Show and the second time we are discussing cancer and nutrition on this platform. It is with immense pleasure that I welcome today's expert, Danny S. Parker, to the show. Danny Parker is a research scientist with the University of Central Florida where he studies low-energy homes under contract to the US Department of Energy. He is also an author and has varied interests in many areas. He underwent a stem cell transplant in January 2011 and has been in remission since. Given a lifelong dedication to research, Danny now studies myeloma and seeks to find ways to help himself and others to a happy and productive life. Danny, thank you so much for being with us here on the show today.

Danny Parker : Priya, I am honored to be able to speak to you today about this supportive topic.

Priya Menon : Thank you so much, Danny. The co-host of today's show is Pat Killingsworth and Pat I don't think needs any introduction among the myeloma community. Pat has authored four books on myeloma and has two popular blogs where he writes about myeloma and cancer. Welcome to the show, Pat. We have an international panel of experts and patients joining us. Nancy Shamanna is joining us from Canada. Nancy is a four-year myeloma survivor and is currently in remission. She writes a column about her experiences for the Myeloma Beacon. We have Gary Petersen, co-host of our Cure Panel shows on myeloma, editor of myelomasurvival.com, joining us from Florida. We have Dr. Smriti Parikh, a nutritionist and dietitian at NutritionRank.com, who will be joining us from India very shortly. I welcome all the panelists to the show today. I would like to remind our audience that we will be taking in live questions at the end of the discussion; and if you like to ask a question, please press 1 on your keypad and we will bring you live on air to ask your question. I will now bring Pat on air to introduce the topic of today's discussion. Pat, you are live.

Pat Killingsworth : Hello, Priya. Hi, Danny and...

Danny Parker : Hi, Pat.



Pat Killingsworth : Hello, panelists.

Nancy Shamanna : Hi, there, Pat.

Gary Petersen : Hi, Pat. How are you?

Pat Killingsworth : Good. I am excited to be doing this, you know, here in the United States on a holiday, Labor Day. This is a very important topic. I just completed a four-part series, a lot of it based on Danny's work about just on what not to do if you are a myeloma patient, what not to eat, what supplements not to use. So, its a very broad topic and I have read some of your questions ahead of time and I think this is going to be a valuable experience. Diet and myeloma is a hot topic. Ever since Dr. Durie, the head of the IMF, came out and conceded or made a pronouncement that myeloma and diet were not exclusive and there is relationship and they are interconnected up until recently and a lot of physicians, if you speak to them now, myeloma experts, they will say eat whatever you want, it doesn't really make a difference, it doesn't affect how your myeloma will react or how well that you will do and I think we are learning that that just isn't the case, so this should be a valuable hour and I don't want to take any more time, so, Danny, why don't you give us an overview, I don't know, maybe 5 or 10 minutes, about some of the things that you have researched and some of the conclusions that you have come to.

Danny Parker : Thanks, Pat. You know, so I am not a nutritionist, I should say that first, and nor am I a myeloma expert, although having studied the disease now for several years, I know a lot about it and having looked at nutrition and myeloma for a couple of years now, I have learned a lot about that too, but since I do work in the sciences, I am just a researcher by training, and so I think whatever I am doing, I am interested in learning about it in the sense, you know, this is a very important topic in terms of whether we can improve our chances to stick around longer through diet. Then, I have been researching this just the way I would research something else and it turns out that there actually is a good amount of information on this topic and, of course, you have been generous enough to vow me to publish these various things in your column over the last couple of years, but yes, it turns out that researchers at the National Cancer Institute and other places have studied relationships between what people eat and their likelihood of developing myeloma and that has provided some information on what looks like might be helpful and some things that look like they might not be helpful and so within my work, I have tried to find out, you know, what are the things that in one study after another, and I am talking about studies done by reputable medical organizations where you actually have important statistics attached to the investigation, but what can we learn from this? It turns out that you can learn quite a bit.

Priya Menon : Danny, can you hear me?

Danny Parker : Yes. I can hear you.

Priya Menon : Danny, I think we lost you for some time there.

Danny Parker : Oh, ok. We will try again. So, are you hearing me now?

Priya Menon : Yes, yes. I can hear you. I would like to just remind, I mean just tell all the panelists and the expert, I think Blog Talk Radio has been experiencing some audio difficulties of this kind where we go off air sometimes and I have been reading about this issue with them for last one week. So, in case that happens, I will just let you know.

Danny Parker : Okay. Oh. Thank you.

Pat Killingsworth : And Priya, just to reassure you I heard him, I heard...

Priya Menon : Okay, okay, fine, fine. Then, maybe it was just me that I didn't hear him for some time, so..Thank you so much, Pat. Yeah.



Pat Killingsworth : Go ahead, Danny.

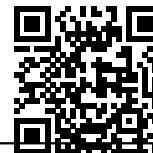
Danny Parker : I guess you end up within these studies, finding, you know, what things might look like that they are helpful related to myeloma and one of the things, I guess I tried to [00:07:40] _____ the very beginning is I think that its useful to find out what things look to be helpful and try to emphasize those within diet because often myeloma patients are older and their preferences for food are fairly set, but it would be useful to know what things would be really important to emphasize within the diet and there are things, it turns out, and they are quite wonderful things to eat and then the other aspect would be what can we learn from research that looks like things that look like they would be unhelpful relative to diet and there turns out be some evidence in that regard too and so, you know, I hope that we can cover a little bit of those over the hour and I also have sent Priya a kind of a distillation of the various columns I have written to Pat for his blog over the last couple of years as well. Its a summary and the summary is pretty important because that has all the information that I have in one place except for perhaps one thing and then in the other columns, it provides why will I believe this is true and why does it appear that this is so, that is the medical evidence for these things and so, anyway, that's really what I have done and so, within my own diet, what I have done is I have adapted so that the things that look beneficial relative to diet and myeloma, I emphasize those things in my diet and I try to eat something beneficial in each field and then the things that are not good, I don't completely eliminate them because some of them are things I love, but I do limit them. I mix it so that they are not emphasized or in some cases I might eliminate them entirely. For instance, I have stopped having asparagus any more. I try to limit ice cream and heavy cream products and so forth. But, I also emphasize berries, raspberries, try to eat more fish and so forth and then also the cruciferous vegetables, they are very important for cancer patients, not only myeloma patients, like broccoli, radishes, cabbage, cauliflower and one of my new favorites, water grass which is really quite marvelous in a lot of foods. So, I will turn it back over to see what Priya or Pat might want to ask me. You know, that gives you some ideas about the way I have looked at this and what I have been doing and, you know, and then the information is out there for those that are curious about it. You know, I can go over the specific items if that would seem to be appropriate.

Pat Killingsworth : Thanks, Danny. We have got a long list of questions here. And, this is good. We will exhaust all and get you out of spot a little bit and I think you are being modest by the way. I don't know anyone that knows more about how myeloma and diet, the relationship between myeloma and diet than Danny Parker. So, I am excited to have you here to help, Danny, and I will start it off and I just have a single question and obviously there are foods and then there are supplements. Looking at the supplement side, if you were to supplement your diet with one thing, what would that be?

Danny Parker : That would probably be curcumin because there is a fair amount of evidence that curcumin not only helps conventional myeloma therapies like the amino-suppressing drugs like thalidomide, Revlimid, and so forth but also the proteasome inhibitors like carfilzomib or bortezomib. So, curcumin looks to be a pretty good one, but you know, that said I think those fairly conventional things, the vitamin D3 is very important for myeloma patients and is also nutritious, so, but you know, if you had said, well, what is the single one that you least like to give up (laughter) I would probably say, that but certainly supplements are supplements. You know, a good diet provides you the foundation for your health, not only within myeloma but helps your body and, you know, each person takes in several pounds or kilograms of food everyday and this, you know, complex chemistry, you know, those things we eat, they are quite complicated chemical compounds and so. We know that a drug like lenalidomide-Revlimid is powerful, but you know also that's an angiogenic agent, that is it prevents the growth of new blood vessels, but something like curcumin actually is an antiangiogenic agent. To add is something like blueberries. So, blueberries, raspberries, grapes, soy, all these contain compounds that are antiangiogenic that are potentially, I mean I am not saying they are substitute for Revlimid, but you know, they can help solve your chance is the way I look at it.

Pat Killingsworth : Wonderful! Thank you. Let's go north to the border and bring Nancy in and Nancy, its a holiday in Canada, Tuesday, isn't it? Enlighten us.

Nancy Shamanna : Yes. Its also Labor Day here and we had a nice long weekend and I was gardening this



morning and now I am having the pleasure of being on this program. So, thanks for inviting me. Yeah.

Pat Killingsworth : Its nice to hear you, Nancy, after seeing your name and your writing for a long time. (Laughter) Really nice to hear your voice.

Nancy Shamanna : Yes, I think I am far too verbal sometimes. (Laughter) You know, I get off to writing, so I do, but I must say over the weekend I have a very good editor and she really, you know, she really edits what I write and so maybe its just half of what I write that shows up there. So, that's fine too. But, Danny, I just wanted to say my husband, Dilip, and I tried your seaweed miso soup last winter. It was a recipe from Pat's blog and it was very good. It took me a while to find the ingredients, so I did find them in a Japanese grocery store and I am still using up the dried shiitake mushrooms in cooking, they are very delicious. So, one set of generalized question I had was how have you changed your diet since your diagnosis and what are your favorite foods now and maybe you have already mentioned what your favorite foods are now, but if you have any more thoughts on that...

Danny Parker : Well, you know, that's really a great question, I think. I have changed the food that I emphasize in my diet and I have learned to really appreciate some that I had forgotten about and, like I eat a lot of apples now, I eat a lot of blueberries now. In fact, I just was making dinner before I came to the call, so, you know, what's for dinner, that's always a useful thing to have related to that, so I made some sandal cakes and I had some parsley, chopped parsley into the salmon, it was red sockeye salmon and it turns out that protein consumption is important for us and fish and repeated studies looks like special oily fish, like salmon or mackerel or sardines and so forth, they look to be useful for us, so I try to emphasize those, I mean to increase those. I have increased the amount of parsley I have in my diet. I have decreased some things that I love, like I do love ice creams, but that's not so good for me and I do love butter, but again it doesn't look so good for me. So, you know, I have decreased the amount of the stuffs that I have. One thing that I have done that I would like to share with others is at the meal try to make sure that you are starting with whatever you feel like is useful and then if you are going to have some of the things that you think aren't so good, then have less of them and have that later. That way you have got it covered really in, but its kind of like what you would expect, like I didn't drink diet soda so much before, but I gave up on those entirely, they looked to be..., you know, as you know, Nancy, there is accumulating evidence that they are not good for us. So, I think its basically... Its like the_____ that's what you didn't remember, which is accentuate the positive, you eliminate the negative. Don't mess with in between, that's what he said. I don't know what he meant by that, but anyway accentuate positive and you eliminate or limit the negative. That's pretty much what I have done.

Nancy Shamanna : Oh, that's great and I have to say sockeye salmon is about the best-tasting salmon, I think. You know, its just really great.

Danny Parker : Yeah. Take cheese and with that we are having a salad that's got a lot of water grass in it. I cut some grapes, so I have got grapes, chopped apples, and you know, and then there's like I said some parsley that's mixed in with the sandal cakes, so anyway that just shows an illustration of what I am doing and of course, each person I think needs to, patient needs to adapt within their own diet to find out, you know, what are the foods I love and how can I adapt them so that they would be helped by what I know now about diet and then maybe I can explore some new foods like you mentioned, the miso soup with kombu which is kelp essentially that grows in the ocean. It contains a compound called fucoidan that has pretty strong demonstrating antimyeloma properties and you know, I met a doctor yet who said, "Don't eat that." (Laughter) So, you know they will say, don't take the supplement. If you say I want to take supplement, they will say, "Oh, don't do that maybe," but, you know, if you are just saying, "I am going to eat miso soup," and no one is going to say, "Don't do that." So, anyway, yeah, I experimented with some new things, but I tried to accentuate positive related to certain things and yeah, on things that are not so good for me, I have gone back on those. Those include a lot of fried foods (laughter), a lot of baked goods, lot of sugar. It doesn't mean that I don't have cake, but it does mean that I am having less of it, but you know I sure enjoy it.



Pat Killingsworth : Thank you, Nancy. Thanks, Danny. Let's give everybody a shot, Nancy. What do you think? Hopefully, we'll be back and we will get to your last few questions if we can.

Danny Parker : I apologize, Nancy, for not being complete, so (laughter)

Pat Killingsworth : Gary, are you with us? (Pause) Maybe he is not. Is there everybody, anybody hear from Gary?

I don't think I heard Gary.

Pat Killingsworth : Oh, okay. While we are waiting for Gary, then...

Danny Parker : Yeah, so let's get back to your question, I didn't answer.

Pat Killingsworth : Okay, Priya.

Priya Menon : Gary... Gary is on air actually. Gary, you are live? Can you hear us?

Gary Petersen : Did you hear me now?

Pat Killingsworth : Yes, I can hear you.

Priya Menon : Yes. Yes, Gary. You are live on air.

Pat Killingsworth : Okay. You know what, when you push the mute button, you have got to push it again.

Gary Petersen : Oh! Is that how that works?

Pat Killingsworth : appears so, now I can hear you.

Gary Petersen : Sorry about that. I always thought I was so enamored with Nancy and her Canadian accent, I guess.

(Laughter)

Pat Killingsworth : But you put on pretty good too.

Gary Petersen : Nice of you. (Laughter) Well, that's my northern Wisconsin accent, I think. Yeah. Anyway, Danny, I grew to love you as soon as you said that asparagus wasn't good for me. As I was growing up as a kid, I kept on telling my mother, "I hate this junk." (Laughter) Not that you are one of those guys who said Brussels sprouts are terrible too. Well, that, you know, I think I could deal with Brussels sprouts, I think.

Danny Parker : Well, those are actually good for us. They are part of the cruciferous vegetable family and I actually really like asparagus, but it contains L-asparagine, which there are some studies showing that it helps myeloma cells proliferate and survive and basically my look at myeloma is like toss it an anchor. You know, anything that is helping it survive, I am not interested in providing, so I have pretty much given up on asparagus in my diet and it's kind of sad, I like it, but anyway go ahead.

Gary Petersen : I grew to like it over time, but when I was a kid, I thought it tasted terrible. (Umm...) One of the things I was wondering is I understand that refined sugar is like a huge no-no for myeloma patients, but then I was wondering there is this thing like Turbinado sugar and of course honey and a new thing, I think that you see on the grocery stores is called Agave nectar...and I was wondering if those are okay or better and if they are not, you know, is there any sugar substitute that is okay?



Danny Parker : Well, this is kind of an unfortunate subject. I so like sweet things and, you know, that's been hard. Its not that sugar is really terrible for us, its bad, but when we are on dex, we are taking dexamethasone or prednisone or steroids, it is really bad for us then because we can end up with, you know, high glucose that can lead to type 2 diabetes and we don't want to go there, but everyone likes to talk about how glucose is a growth factor for cancer, but its also glucose is used for body functions to improve everything and so its where we create energy for our muscles and for all activities, but that said, you know, what a myeloma patient would really like would be have a very stable blood sugar so that doesn't change a whole lot for the day. So, what does that mean? That means probably doughnuts in the morning would probably be the biggest disaster you could imagine because it will send your glucose skyrocketing and then problem is, you know, you would probably get some insulin shots from all the sugar and so basically its probably if you are going to have sugar, my recommendation is that you have it towards the end of the meal or after a lot of protein loading or other stuff like that that's already in your gut so that it digests slowly. In terms of the type of sugar, the more complex the sugar the better. That means that for instance, like I have breakfast cereal now and often I will rather than add sugar to it, I generally won't do that. I will add blueberries to it. I might have a little honey or something like that, but I will just try to reduce the amount of sugar that I am using in general. Now if I am going to add something that's really sweet, then, you know, I might have some of it, but I won't have a lot of it and there are certain types of it that I just give up on entirely and that is we friends as we went out the other night and the kids wanted sushi, which is fine because, you know, sushi is good for me, but at the end of the meal, the waitress had showed up with cotton candy and said, "Would you like one?" I said, "Absolutely not." (Laughter) So, this is not good for us. So, yeah, the more complex the sugar, the better I would say. Probably the turbinados or the Agave might be better, but sugar, you know, its all kind of the same thing. It should help.

Danny Parker : Its, you know, if you don't have it on an empty stomach, have it at the end of a bigger meal, you know, like if you are in the... The difficult time for me is in the afternoon when I want a pick-me-up or something like that, then I want sugar. So, then, I will try to have like an apple with peanut butter or, you know, a slice of apple or maybe some nuts with raisins, something like that. So, anyway, that was my advice for you.

Gary Petersen : So, myeloma patients shouldn't cheer now that Twinkie's are back?

Danny Parker : Well, they could cheer about them. I don't recommend that they eat them very often though and, you know, I think I am relative to all these things and on the call people must think that I am really quite prudent in terms of my eating, but I eat just about anything and I do eat even some of the stuff that I say is probably not good to have, but I don't have very much of it and you know, so I think my eating is important so you are aware of like, "Okay, I am going to eat this piece of doughnut which would be a really terrible thing, but I am having a piece. I am not having a doughnut" or "if I am doing this, I am not doing it every morning" or you know, this sort of thing. So, you are actually thinking more about what am I putting in my mouth, you know, this sort of thing and how does that fit related to what I know might be helpful with myeloma.

Gary Petersen : I guess it all makes sense, I guess I am far, far more cognizant of the things that I put in my mouth, you know, like processed foods, you know, I will look at a label and it has, you know, 55 different things on it, pop each one because you are a chemist, you know, each one and as we know just like dex, Revlimid, like each one probably has some kind of interaction, no telling what you are doing to yourself.

Danny Parker : We can't know. I mean its way too complicated that doctors can't know. Its really complicated, so you know, Dr. Durie has one really great piece of advice and I think it comes from Michael Pollan's book "Food Rules," but anyway it is when you go shopping at the grocery store, shop at the edges and that's where you are getting real food, that is like it was green, it was harvested where it is rather than in the middle where there is all the stuff with labels like you are mentioning where, you know, there are 20 ingredients and Durie also says "don't eat things that your grandmother wouldn't know." I think that's pretty good advice too. Now, if your grandmother would say, "What the heck is that?" That might be a good clue that kind of removes from real food, you know, so anyway, but yeah, you are right.



Gary Petersen : All right, Pat.

Pat Killingsworth : Thanks, Gary.

Gary Petersen : Move on. Yeah. Thank you, Pat.

Pat Killingsworth : Thank you, Gary. Priya, is that special guest here?

Priya Menon : Yes, Pat. She will be in with us right now and she is live on air. Smriti is a nutritionist and dietitian with NutritionRank.com and Smriti, you can ask your questions to our expert Danny.

Smriti Parikh : Thank you, Priya. Thank you, Pat. Enlightening hearing from you. And I loved your writeups and I can't wait to share them.

Danny Parker : Good. This is a case where an expert is asking someone who may not be an expert. Anyway, go ahead. (Laughter)

Smriti Parekh : Anybody who knows food is an expert. There are so many things that you learn every single day. And food changes every single day. All these processed products coming up, you really do not know. And I love your quote on don't eat what your grandmother doesn't know." That's like fantastic! That sums it all up.

Danny Parker : And, you know it and also too but at the same time look at the evidence in terms of what the evidence suggests. For instance, the rate at which people develop myeloma is approximately the same in Great Britain and slightly less in Germany than it is in the United States, but in India, its half what it is in the US and China, its about a third. So, this is, you know, you could say well, that the genetic socket of the people are different, but we are all human beings and we share more genetic material than not and so the very likely difference is that it has something to do with our diet and for instance, you know, so we need to, you know, take that into account too in terms of considering grandmother's advice, you know, so anyway, yeah, I would say that's true.

Smriti Parekh : Definitely. I think majorly it accounts for a low prevalence in India is because curcumin is a very integral part of Indian diet. We cannot cook food without it.

Danny Parker : Good idea and, you know, and people that say I am not going to take curcumin, you know, I recommend to them, well, you know, please embrace Indian food, but the curcumin has natural anti-inflammatory influences beyond even just its influence on myeloma, so like for instance something just came out recently showing osteoarthritis was possibly affected by it, so, you know, we can learn from this and we can learn from, for instance, like what might make the Chinese diet. Why is that better? Well, there is less meat, but, you know, the studies we have gotten. The best study in the US was done of Connecticut women, but meat wasn't the big factor, but they did find that there are some differences in the Chinese diet, for instance they don't have a lot of the dairy and butter products that we have in the western diet and, you know, so maybe we can learn something from that too.

Smriti Parekh : So, I would love to know your thoughts on probiotics and prebiotics in diet and myeloma.

Danny Parker : I think probiotics, especially yogurt, like I think that lot of dairy products are probably we should try to throttle back on them because they are quite prevalent in our diet, but yogurt is a case where I make pretty important exception because it contains a lot of helpful probiotic properties and that's strictly important for myeloma patients for other reasons because for instance, because we often have infections and can end up with antibiotics that plays havoc with our digestive system and probiotics are very helpful for that and then also you are probably aware there is evidence that probiotics actually for some reason in human beings appear to reduce stress. Now, we don't know exactly why that is, but you know, its kind of the scientist in me doesn't care. It just says, oh, okay. If there is an association, then people that are eating



yogurt seem to be less stressed, then I want to be one of those people (laughter), so I think that so often, something I will have in the morning for breakfast would be, I may have some simple cereal with some blueberries or raspberries with yogurt with just a couple of adult yogurt and that's a good way to start the day in terms of getting these probiotics as well as pterostilbene which is in the blueberries and ellagic acid which is in the raspberries and these things have demonstrated any myeloma properties and then you get, you know, basically some good quality protein in your belly too from the yogurt. So, I think, yeah, its important part of diet also too and there is a French study showing that having it is associated with appetite suppression and weight loss and that's a chronic problem in the United States, you know, is obesity and for myeloma patients we know that body mass index is, you know, we know that that's a factor. We know the fatter we are, the worse it is. You know, that sounds a crass way to put it, but its true. So, I think its important to do what we can to control our weight and so the yogurt may be an important part of it.

Pat Killingsworth : Well, Danny, hold on to that thought and, Smriti, thank you very much. We will continue rotating here and I have a long list of questions, emailed questions that listeners have submitted and so I am not going to ask a question per se, but I am just going to go through a couple of these. Lorraine asks several questions that I think we have at least started to cover about certain foods or herbs that she should be including in her diet and then she asks should I be taking certain vitamins or supplements. We seem to be getting to that a little bit already. Michael from the Netherlands... Oh, I am sorry. Go ahead, I was just...

Danny Parker : Yes, quickly for her. Basil, parsley, sage, rosemary, these are important for you and then in terms of vitamin, yes D3 is, I think, very important for myeloma patients and maybe a fish oil supplement, particularly if fish consumption is there. Go ahead, though.

Pat Killingsworth : No, no. Awesome! Michael from the Netherlands wrote a rather long question list. It was great to hear from him, but he touches on exercise at the end about after a late meal, the importance of going out for a long walk in the evening and he writes as soon as you believe it makes a difference, but is there any evidence? (Laughter) So, you were talking about the obesity thing. I thought _____ is there any evidence that exercising helps?

Danny Parker : As you know, we have eight-part series on exercise and myeloma, already I have blogged. So, please recommend to our friend in the Netherlands that maybe he could take a look at that, but the evidence is so overwhelming that Dr. Thomas Martin at University of California, San Francisco, where I was treated for my stem cell transplant, he said that it would be unconscionable not to recommend that myeloma patients seek increased ambulation, which is, this is the way of saying they need to walk. You need to walk and move around. We need to exercise. So, this is really an important thing and yeah, absolutely so, you know, and I have written a lot on it and I don't want to take too much time away from the diet topic, but no question and there's lots of medical evidence that even if you are in the middle of the stem cell transplant, you know, the used-to-be thought was don't exercise, you have been hurt so badly, you should just rest. That's turned out not to be true and some interesting research was done in Germany, but anyway exercise is really important for myeloma patients. So, it must be right, what he said.

Pat Killingsworth : Thank you. Thank you very much. Let's circle back around to Nancy. Nancy, another question for Danny.

Nancy Shamanna : Okay. I am fortunate I went through all of my treatments and I haven't had any for a couple of years now, but I remember at the time I had all kinds of dietary issues and concerns and, you know, I had to deal with nausea from chemotherapy. I had to deal with food cravings due to having dexamethasone and I had to deal with anemia a little bit, not clinical anemia but just low red blood cell count and all these things. So, at the time I was trained to focus on what to eat, you know, to help me with the nausea, the food cravings, the low red blood cells, so that, you know, there are many people listening, probably who are going through these things right now.

Danny Parker : Right. Well, you know, stem cell transplant is difficult, mine was. I won't paint it any other way and the worst of it was, as you mentioned, the nausea. I mean I had loved food all my life. I loved to



cook and my mother taught me to enjoy food at an early age and this was an absolute shocking thing to learn after my stem cell transplant that I no longer liked food and it went on for two or three months where I really didn't buy food, at first it was just kind of really disgusting and sounds like terrible to say, but I would look at food that I normally would consider to be something good to eat and I would say that's disgusting, I can't eat that and you know, and then finally when I was at the hospital, the work doctor came around one day and then he came to me and he whispered, he said, "You know, Mr. Parker, if you don't start eating, then I am going to get you out of here." (Laughter) So, (laughter) (yeah) I said okay, bring apples, (laughter) bring apples and fruit and I did say bring apples and fruits and some simple cereal like raisin bran, bring me raisin bran, apples and fruits and I was able to get that down. I could eat fruit. Now, this is a really personal matter though in terms of what you can like to eat after you have had a stem cell transplant because the nausea for me was so intense, its very difficult, but I found that fruit and some cereals, those were kind of the best I could do. I would try other things at different times, that just usually wouldn't work and some of the things that I really recommend for you now like broccoli or whatever, you know, if I could smell broccoli on floor where I was in the hospital, my stomach was churning. So, you know, picture is quite different but anyway fruit worked for me. You know, you would have to experiment what can work for you and be patient and the only thing that was good other than, you know, what we were aiming for in the stem cell transplant was I lost a lot of weight and I did say to the staff that that was a good thing and my sister who was my caregiver at home, she said, "Oh, this is not going to remain this way on my watch," so she was determined to get the weight back on me, which you know, it did happen, but anyway, its a challenge, its really a challenge, but thank you for your question. I don't have any super answer, you know, in terms of what is the magic thing that I am aware of.

Nancy Shamanna : No. Thank you.

Pat Killingsworth : Let's, now let's rotate back to our favorite standup comedian from Orlando, Florida. Gary!

Gary Petersen : Actually, its from Jacksonville, Florida. Yeah. One thing, Danny, I was trying to get back on line when you were talking about the benefits of exercise . I went to Little Rock, you know, I don't know if you did as well. Did you?

Danny Parker : No, I didn't. I didn't go to Little Rock, but...

Gary Petersen : Okay. Okay. But when I did, they told me that everyday I should get, you know, I got as much exercise as I could during my stem cell transplant and so I tried as best I could. Yeah. Yeah. Exactly. I did as much as I could, but later on I found there was an article that I found in my research that showed that people who got 30 minutes of exercise a day, you know, and had cancer, had I think it was 60%, 50% or 60% better chance of a non-reccurence of that same disease, which I thought was phenomenal.

Danny Parker : Yeah. And there is in the stuff I have written for Pat, you know, there is a really great article in the New York Times that basically shows that the people that are exercising live longer, I mean the title of it "The active ones live longer" and if that doesn't get you motivated as a cancer patient, I am not sure what will. Basically, your activity and food can be proactivity. So, you try to eat, you know, perhaps not really healthy meals so that you will want to go out on the walk as our friend from the Netherlands suggested. You know its something like that, its pretty important and plus free of mental outlook. I mean this is a difficult disease we know and we are faced with our mortality and often times its difficult within our families and its difficult for ourselves, for everybody, so you are getting out and walking some and just getting outside and moving around, it feels good and we will feel better and our mental outlook is important. In fact, there was an interesting study that was cited by Dr. Brian Durie, suggesting that reducing stress was more important than diet. So, this means that, you know, the question is though how do you stop, if you are really worried how do you stop from worrying and that's a good question, but exercise and...

Gary Petersen : Yeah, you are right, you know, how do you do that? You know somebody tells you you have got three years to live, you know?



Danny Parker : Right (laughter). So, one thing to do is... Yeah, let's do something. That's my idea and part of this is, you know, there are various people in this field who would say, well, the recognition they are making are nice and its nice they have done all this work and so forth, but really its just rearranging the deck chairs on the titanic and so forth, but as far as I am concerned, you know these chairs look really good or I think they will make a difference, so...

Gary Petersen : I bet they will. Start saving _____ and maybe we wouldn't be in the position we are in as we would have done some of this stuff upfront _____ which is my daughter's physician who is kind of a health food nut, kind of a vegetarian, kind of a don't put anything that has the diphosphamide and anything on the label, if it doesn't say what the food is, you know, don't eat it.

Danny Parker : I think we have to live too and you have to enjoy your food. I think that that's really important, so that's why I am not like a food _____ or anything more, I say like you know, you can't thou shalt not eat ice cream. You should never have butter. You should not have coffee because its got acrylamide. No! You know, every once in a while I am going to have a little ice cream. I am going to have coffee and I like coffee.

Gary Petersen : So, you are savage!

Danny Parker : I know but, you know, our life is to live. Its not, you know, I studied statistics on diet and myeloma, that doesn't mean, its your life! You know, we eat food and you should be enjoying your food so you can enjoy your life and I think that this is really a much more important issue, but that said, you know, probably we don't want to be eating a lot of wrong things that are going to, you know, make this likely have more trouble. So, and then, that brings me to another topic. I don't think its in the question, but I did want to get it out because I look at it as being a little controversial of late and that is alcohol consumption and repeated studies done by repeated investigators around the world, one after another and a very recent one, a pooled study of almost 9,000 individuals showed that alcohol consumption at least in moderation was inversely associated with the likelihood of developing myeloma. So, I think a glass of red wine...

Gary Petersen : I saw that too. I like that study.

Danny Parker : Yeah. Well, you know, different... Some people that are teetotalers say, "No, I hate that study. You know, I really don't like that information. That's got to be wrong," but it appears like there is something to this. Now, this doesn't mean that you should decide, "Well, I am going to go on a drinking binge because he said it was okay." No, I didn't say that was okay. I said probably a glass or two of red wine probably is a good thing for you. In fact, the evidence suggests that it might be, also you get those healthy polyphenols in red wine. So, even Dr. Brian Durie is recommending this for a lot of patients, so I feel like that's...

Pat Killingsworth : ...a little. Are you justifying to yourself?

Gary Petersen : Yes, I am going to have red wine tonight. [00:46:50] Can I ask my question? Can I ask my question? I haven't asked my question. Danny, this was my question. Before we all got off on this bizarre tangent..Some multiple myeloma patients have kidney involved. For example, I was on dialysis, but now I am not, but my kidneys are still compromised and as you know, that many people do have, you know, kidney problems with multiple myeloma with life changes. So, do you have any recommended sources of information that kidney-involved MM patients can go to and frankly because I had gone through it with my wife and my sister-in-law and they damn near starved me to death. About all I could eat was Snickerdoodle cookies...

Danny Parker : I mean I looked at this seeing that you are interested in this topic, so I don't really know that much about it, but it looked like there were some things that I would normally recommend like things that are high in phosphorus, looks like they are not interested in you having a lot of that and that for instance would be broccoli which is really important for us, otherwise. So, but, yeah, there is a lot of information on the



internet in terms of what to do. What I would do is I would index those again, what I recommend for diet and see what looks like its excluded and it looked to me like you could still do most of the things that I was talking about. I don't know what your wife and daughter were trying to do to you... I am not sure what they are trying to do, but it looks to me like that for a dialysis type of diet that a lot of the things that I am recommending would be okay. Certain things, no, like for instance broccoli, as I mentioned, that wouldn't be okay. (Umm...) But, there is information already on the internet on diet for that and I would just look across the index and see.

Gary Petersen : Oh, well. Thanks.

Pat Killingsworth : My wife works as the office manager at the dialysis clinic and I am interested in it for obvious reasons. So, and I think, you know, speaking to one of their nutritionists, every one of these clinics has one, and you know, I would compare, I would put their list of the foods that are okay on one side and the foods that would be good for myeloma patients to consume on the other and just cross reference and I think somebody wouldn't take long. It would be nice to think that some of these staffers could help you with that and hopefully they can, but I find sometimes they are so one dimensional, but that's for another story.

Gary Petersen : Well, I lost 40 pounds on that diet, so it was good.

Pat Killingsworth : Do you realize the... I think they were just trying to pull up the insurance perhaps. Smriti, you had another question for Danny. Go ahead.

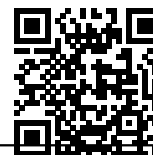
Smriti Parekh : Yes. Okay. So, I am a clinical nutritionist, so I know sodium is important, but wherever I hear high sodium levels, its like sense danger bells ringing all through. So, I wanted to know your take on the sodium intake for myeloma patients, for both someone who has normal kidney function and compromised kidney function.

Danny Parker : Yeah. I would say certainly with compromised kidney function, you would want to pay close attention to that and frankly, I think paying close attention to that anyway just within your diet. My big recommendation there is that you have fewer problems if you are avoiding processed foods because a lot of processed foods have salt being added and this does make for more work in terms of food preparation for you, but you end up with more healthy food and you end up with something where you can control the sodium level when you are dealing with foods that don't already have a lot of loaded sodium in them. So, you know, I would say, yeah, this is certainly something to pay attention to, but I think a lot of that is affected by the fact that with so many processed foods, then also awareness of what we are doing when we are eating, that is how much salt is being used in preparation of the food and also some substitutes, for instance if you are making ____ I could cut the salt down that's recommended for making something if its possible to add lime or lemon juice to that preparation. In the tongue, it actually increases your taste bud sensitivity to sodium and you can decrease the sodium level in the cooking with, for instance like with a salad dressing or in something where something is being saute'ed, you can use the lemon or lime to actually decrease the sodium level while preserving taste, so I am always after things like that. That's a great _____. Smriti, where are you from?

Smriti Parekh : I am from India.

Danny Parker : So, yeah, I think in Indian cooking, a good amount of salt is used at times, so you know, but also actually I think women would work quite well with a lot of preparations where this kind of food is being prepared, but you know, again, you have to be careful with things like chutney. If you are making your own chutney, then that's one thing, but if you are buying commercial chutney like Major Grey's or something, you have to watch what is the sodium level of that food and so that would affect, you know, your health.

Pat Killingsworth : Thanks, Danny. Seems like... Priya, did we have anyone listening in, wanted to ask a question like?



Priya Menon : I will just find out that. Our listeners, if you have a question for our panel, you may please press 1 on your keypad and we can bring you live on air to ask your question. I believe most of them have actually sent in their questions, Pat, so maybe we could quickly go through the questions. We have around eight minutes. Ah, yes, we have... Yeah, we have a person on line, Pat, who wants to ask a question. The person calling in from telephone number (415)531-6949, you may please ask your question. You are on air.

Pat Killingsworth : Sounds like someone from the Bay Area. (Laughter)

Caller : Thank you. I have a question about asparagine which you mentioned in the context of asparagus not being good and I understand that asparagine is found in meat and fish and some things that seem like they would be good for us to eat, so how do you... Can you just say more about problems with asparagine?

Danny Parker : Well, asparagine levels in the other things is actually much, more lower than it is in asparagus. So, I don't worry because if I look at the concentrations that exist in some other foods, I don't worry about this too much, but the concentration in asparagus is quite high and so that's why I would be particularly concerned about that. This is also the reason the old joke about why urine has some strange smell after eating asparagus. It is caused by the asparagine, that's what is doing that, but most of the other foods that you are mentioning, I don't think in most cases the concentrations for the volume of what's contained in a typical serving would be such that you would be worried about that, but asparagus is a completely different picture and unfortunately, this is true of all asparagus. For instance, in overseas they have the white asparagus. They make this marvelous soup in Germany called Spargel, but I don't get to have it anymore because again it has the l-asparagine levels is pretty high and that's just a..., but yeah, I don't worry too much about other foods given the concentrations are not that high.

Caller : Right. Thank you so much.

Danny Parker : Welcome!

Pat Killingsworth : Shall I go on with these other questions, Priya? Do we have time?

Priya Menon : Yes, we have. We have. You can just quickly, maybe touch upon some of the important ones. Of course. We haven't discussed much on proteins...

Pat Killingsworth : Yeah, Danny. Danny, and there are a number of questions here. There is a question from Leah who asks any input on high-protein vegetarian diet with myeloma?

Danny Parker : Oh, okay. For vegetarian diet, soy products are really important for you and soy products actually contain anti-angiogenic compound called, if I pronounce it correct, Genestin and this is really beneficial for us because it looks like that its useful for not only providing a stable blood sugar, providing protein into the diet for vegetarian diet but also can be quite tasty, for instance, in the miso soup that I was talking about with Nancy, soy, tofu being cubed into that soup is quite tasty and then for instance, this is just another illustration. Yesterday was, you know, a big cookout here at my house and so people were going to have burgers and so forth and then I decided, well, even though I like those and occasionally I might be having hamburgers, no, I decided I would prepare a tempeh burger and that's what I had. So, I had a tempeh burger and I had it with, tempeh takes the form of soy and I had that with some sliced tomato and then big pieces of water crest on top rather than butter, so again I got that and so then I ended up with, then I actually because I like it, I added some cranberries to my burger, which is pretty unusual, to see what happened to that, it could be more classic but that's why that, for instance, you could get something that is considered to be a typical American diet but what seems like it except that you are getting two new helpful things, soy protein with Genestin which is helpful in the diet as well as you are getting something else like radishes too or something from the cruciferous vegetable family that's so helpful and you know, then for our salad, _____ shredded broccoli salad which was quite tasty too, so its possible also to achieve this within a vegetarian diet. Vitamin K2 which we haven't talked about looks to be helpful and you could buy vitamin K2 in _____, so those are other possibilities.



Pat Killingsworth : Boy, this hour has just flown by, everybody. Priya, we are going to have to do this again. What do you think?

Priya Menon : Definitely, Pat, definitely. I think this has been mostly a wonderful discussion actually and we have still questions that will need to be answered. I think one quick last question, Pat. Yeah. We have got just one last question from one of our listeners right now. She asks what recommendations do you have for medications that cause acid reflux?

Danny Parker : For medications that reduce acid reflux?

Priya Menon : Yes.

Danny Parker : So, so, this was a problem for me when I was taking dexamethasone and I think I ended up with Mylanta, which was what I was using because it was not causing constipation or what have you, but another thing that I find useful with acid reflux is actually mineral waters that are basic and so therefore tend to calm down stomach acid, especially when I was in induction and taking dexamethasone tablets. I always try to keep that around the house, but — water or something like that to help calm down my belly.

Priya Menon : Thank you so much, Danny. I think this was an absolutely wonderful discussion. I thank Danny and all the panelists for being with us today in spite of it being a holiday and Labor Day there in US and I thank Smriti for joining us from India at this time, its lovely 4:30 a.m. here. Thank you all the listeners for being with us on this holiday edition of Cure Panel Talk Show. Please, we look forward to having all of you join us for our next Cure Panel Talk Show that is scheduled for September 5th at 5 p.m. ET and we are discussing yoga for mid life and beyond and the expert on the show will be Dr. Larry Payne. Our monthly myeloma panel discussion for the month of September is scheduled for 26th of September at 6 p.m. eastern time and the expert on the show is Dr. Ajay Chari of Mount Sinai Hospital. Please mail me priya@trialx.com for registering for all the events. The broadcast link for today's show will be sent via email to all participants and I will be sharing all of Danny's work and a summary that he has sent me with all the participants. For more details of upcoming shows, please visit trialx.com/curetalk. Thank you.

Thank you, everybody.

Thanks.

Thanks much, Priya. Thank you, everybody.

Thank you.

Thank you, All.

Good night.

Yeah. Good night, everyone.