



Managing impact of stress while living with myeloma with MLB Coach Don Baylor

On this show we host Myeloma Survivor and Baseball Coach Don Baylor (Arizona Diamondbacks) and eminent myeloma specialist Dr. James R. Berenson from IMBCR to discuss: Impact of stress and managing stress while living with myeloma.

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Priya : Hello, everyone, and welcome to the Cure Panel Talk Show on multiple myeloma. I am Priya Menon, Scientific Media Editor at Cure Talk, and along with the Cure Talk team of Sharib Khan and Chintan Patel, I welcome all of you this afternoon to a discussion on multiple myeloma. As always, we will be moderating the call and bringing people live on the show. Cure Panel Talk Show is organized by Cure Talk, the blog of trialx.com, an online platform to connect patients to clinical trials of new treatments. For information on clinical trials for all conditions, please visit trialx.com/ask; and for information about clinical trials on myeloma, please visit MMRF site, myelomatrials.org. This is the 16th episode of the Cure Panel Talk Show and the 10th time we are discussing multiple myeloma on this platform. Our panel discussion broadcasts have received over 97,000 replays, and today's show has been selected to be featured on Blog Talk Radio. Before we begin today's show, I would like to remind everyone that our live, on-air myeloma support group meeting for the month of June is scheduled for Thursday, the 27th, and the next Cure Panel discussion of myeloma will feature Dr. Shaji Kumar from Mayo Clinic and is scheduled for July, the 25th. Today's panel is co-hosted by myeloma survivor and blogger, Matt Goldman. Matt was diagnosed with multiple myeloma in May 2011 and is currently undergoing treatment under Dr. James Berenson. Matt documents his myeloma journey on his blog, mattversusmyeloma.com. Welcome to the show, Matt. It is with immense pleasure, honor, and awe that I welcome Don Baylor to the Cure Panel Talk Show.

Matt Goldman : Did we lose... Did we lose, Priya?

Gary Petersen : I lost Priya.

Matt Goldman : Okay, well, as long as we are here, this is Matt Goldman. Hi, everybody! As long as we are here, why don't we get going until Priya can get back on? As Priya said, I am Matt Goldman. I was diagnosed May 2nd, 2011. Dr. Berenson is my doctor and yesterday, in fact, I had maintenance chemo, so my voice is a little bit hoarse, I apologize for that. Anyhow, I am not sure excited is the right word here, but I have been looking forward to this panel discussion for a while. Thanks, everybody, for joining us. We have a really great group of people on today. The panel today what we are going to talk about is kind of a continuation of a subject that we discussed a few months ago on Cure Talk about balancing myeloma and managing your health and careers and during that panel we discussed stress and got in to the impact of it



and managing it. Pat Killingsworth, he is also a blogger and an author (excuse me) and a myeloma survivor who is on that panel and he has some interesting thoughts about how he thought we can pass the stress, so we invited him back today. We also have Dr. Berenson, Dr. James Berenson, he is a myeloma specialist here in Los Angeles and he is Founder of The Institute Of Myeloma And Blood Cancer Research and then last but not least, as Priya mentioned it, we have Don Baylor who is a myeloma survivor, current hitting coach for the Arizona Diamondbacks in 1979 American League MVP for the Angels in 1995 National League Manager for the Rockies. So, like I said, we have a great panel. Thanks to everybody for joining us. Our goal today is to talk with the panelists and, you know, I will be asking questions to the panelists maybe for about 45 minutes and then we will try to spend about 15 minutes on listener questions and hopefully we can fit it all in. So, before we get started on the real questions, why don't we just... I mean to say each of the panelists can introduce themselves. Don, why don't you lead off maybe?

Don Baylor : Okay. Don Baylor here. I am an author. I am not a blogger, but I am an author of baseball book, but I was diagnosed in 2003 and I have had treatment at Sloan-Kettering, New York, currently at the City of Hope in Duarte in California. So, my doctor out there is Dr. Forman in which I have really stayed on top of it, with the travel thing, so, you know, I... Every trip we go in to Los Angeles, always making appointment there so I definitely stay on top of taking care of it, especially because of the travel that we do have late nights and things like that, so.. We can talk about that a little bit more later.

Matt Goldman : Okay. Thanks. Pat, how about you? Just a little brief summary of your diagnosis date and your treatment.

Pat Killingsworth : Sure, sure, and thanks, Matt. I was diagnosed in 2007 and working backwards matter of fact, stuck in traffic, I was just seeing my myeloma specialist, (laughter) Dr. Alsina, Melissa Alsina, at Moffitt Cancer Center, and she was running an hour late, so its stressful, you know, you know you are going on air and you are stuck in, you know, stuck in traffic, but the news was great. My myeloma was stable for the third cycle, the third three-month cycle in a row. So, I was really pleased about that and I had a stem cell transplant and everything's feeling great. I look forward to the next hour.

Matt Goldman : Good! Congratulations on the positive report. Dr. Berenson!

Priya : Matt, thank you so much. Matt, thank you so very much for stepping in. I apologize. I got.. I dropped my call. I am calling in from India, so... I think I am back now. Matt, thank you so very much for taking over just in time. I would like to actually welcome Dr. James Berenson once again on to the Cure Panel Talk Show. Dr. Berenson, thank you so much for taking time out and being here with us. Dr. Berenson is Founder-Director of Institute of Myeloma and Bone Cancer Research located in West Hollywood. He specializes in research related to myeloma and metastatic bone diseases. Welcome to the show, Dr. Berenson and Pat... Pat has been with us throughout the Cure Panel Talk Show, supporting us. Pat is a myeloma blogger and survivor and a noted myeloma author. Hi, Pat, and welcome to the show. Matt, thank you so very much for taking over. Now you may please continue.

Matt Goldman : Oh, no problem. Thanks, Priya. Umm...Already Don, Don and Pat have already introduced themselves and I thought Dr. Berenson could just give a quick introduction of yourself and kind of your philosophy for treatment even.

Dr. Berenson : Yeah, I think the... This is Dr. Berenson. I have been working on myeloma for about three decades, both in the laboratory and clinically. I was actually inspired to work on it by a cousin who developed it back in the mid 80s and I have been trying to get therapy into patients that, as I like to say, allows them to live a complete life, not necessarily a complete remission which in myeloma patients isn't always meaning the disease is gone and our philosophy is really that to give patients a long as life possible with the least impact from the treatment, not only the disease and I think we often forget about that. All right. I guess I will have to leave it at that for now.

Matt Goldman : All right. Thanks, doctor. Let's get to the real part of the matter here. Don, again going to



you, you mentioned that with what you do, your job to be stressful, lot of travel, busy schedules, composition, all that. How and you mentioned that you whenever you are in LA, you visit with your doctors and make sure everything's good. When you are on the road or even when you are at home for games, how do you handle... How do you handle the stress with your job in relation to staying on top of your myeloma?

Dr. Berenson : Well, stress has been a part of my life for being in sports is for ever, you know, you can imagine playing to deal with it when you have myeloma, I mean its... Its still stress but not where it was as a player, put it that way, or if you are managing the club, just the stress dealing with the writers and things or your stomach is tied up in knots from time to time. I don't have that kind of stress, that really is no different, I mean its... That part of it is just okay. The travel part is a little bit different because, you know, we get in late at night a lot of times or early mornings in some places, so the travel... I have done that kind of all my life. So, the difference is, I felt is the anemia part. Earlier, you know, I would just say, you know what is causing it until I discovered that I had myeloma, you know multiple myeloma, so I get my monthly labs and get checked all the time, so I am on a drug called Revlimid. I just like that the Revlimid, so..., and I do the dexamethasone once a week, but that's... So far, that's really kind of kept me stable.

Matt Goldman : Uhhh... Okay. Do you think your attitude towards the stress in the job has changed a little bit since your diagnosis?

Dr. Berenson : I have two granddaughters, 5 and 2, so that's pretty much been my attitude as far as, you know, you know, just your diet and things like that and, you know, looking ahead. I just kind of look, you know, at their lives. I would like to be around, you know, be healthy and be around them, so you know, that's kind of... So, my workout regimen is, you know... Sometimes you don't want to work out if you are biking or you are walking in and things like that. So, I do stay active even though I am not a player any longer.

Matt Goldman : Uhhh.... Thanks. Pat, how about you? Your comments on a recent call kind of prompted this panel discussion from your thoughts on stress and it seemed like you thought stress can necessarily have a negative impact on your health and actually unless I interpreted what you said wrong, it sounded like you thought it might even, in your case, sort of be helpful having the stress of doing what you do, that it keeps you active and keeps your mind shut. Can you just explain that a little bit more?

Pat Killingsworth : Sure, of course, and you know you read that you are not supposed to... You know that stress is bad if you have cancer and then you get stressed. You are trying not to be stressed and instead of worrying all of that, I found that it actually helps me... You know, it helps you get out of bed in the morning. It helps you... If you are not feeling good, if you are sore, if you are tired, if you are fatigued, it helps keep you going. So, I think its... You know, I think there are advantages to at least living an active engaged life and if you do that, of course there are going to be times that you are under stress. I have been dying to ask Don about how he managed, you know, flying from city to city to deal with ongoing treatment, of course, you know, if he's fortunate enough to be taking Revlimid which is an oral chemotherapy, I can see how he could do that. Don, have you been... Have you been on Revlimid the entire time from when you were diagnosed back in 2003?

Don Baylor : No. It was... I have my other half of my existence is my wife is my number one caregiver. She is sitting right here next to me, so she has both file of things that I was on, so I am staying with my wife.

Becky : (Laughter) Yeah, if you all don't mind, I might jump in from time to time just to help him with the details of this.

Matt Goldman : Yeah. No problem. Thanks.

Becky : Thank you. My name is Becky.

Matt Goldman : Okay. Thanks, Becky.



Becky : Yeah. He really started the Revlimid post transplant. So, he had an autologous stem cell transplant in 2004 and two to three years after that went on the regimen of Revlimid and dexamethasone. Also had Aredia infusions intermittently for a number of years after that, but he is no longer on the Aredia or any of the infusions. Its simply, strictly the pill form, oral chemo and, you know, we sort of tinkered a little bit with the dosage on that, but that's where we are right now, which has maintained him very well, kept him pretty stable.

Matt Goldman : Glad to hear it. Dr. Berenson, as someone who treats myeloma patients everyday, what's your position or thoughts on stress, the stress from everyday life, stress from your patients trying to work. What's your feelings on that in terms of managing myeloma and sort of managing cancer in general?

Dr. Berenson : Well, I don't think we have really good studies about the effect of stress on myeloma and other cancers unfortunately. I am certainly a big believer that these things contribute to poor outcome, but to tell you we have objective studies to say that case is really not true and unfortunately many of the drugs we use only heighten the stress. Drugs such as steroids certainly have profound effects on mood. Drugs such as thalidomide and the [00:16:57] Imritz and certainly Velcade to some extent, maybe Kyprolis as well or carfilzomib do affect mental function and its clear that we as oncologists have done a very..., done a very good job of dealing with that. So, you know, I think we all live a stressful life, but I must confess that we don't have good studies either showing that or causes it, makes the disease get worse. We just don't have the data.

Matt Goldman : Uhhh... Okay. Yeah. I know about the steroids and the dex, I am feeling it today.

Dr. Berenson : On certain days, you know, as with the dexamethasone, I know earlier when I was taking it, you know, I could sleep for a couple hours. It keeps me up late at night, then next day, you know, you want to... Next morning you want to wash your cars [00:17:54] _____ 2 to 3 in the morning and that kind of wears of and maybe the third day you are kind of punky, you don't like... but I have gotten through that part of it, that's when I was taking it once a month. Now its once a week. I kind of know what to expect and I get a good night's sleep on top of that. So...

Matt Goldman : Yeah. It seems like from my experience, we sort of learned how to deal with the ups and the downs that come with the energy or lack of energy from the steroids. I am speaking with you, Don, when you were first diagnosed or even during your initial treatment or your transplant, was there ever a time that you considered not returning to baseball because you just thought it wouldn't be good for you or did that thought never even cross your mind?

Don Baylor : It never crossed my mind because I had Mel Stottlemyre, the ex major league player also. At that time, he was a pitching coach for New York Yankees and he was the one that really talked me through it. You know, I had somebody I could call who actually had multiple myeloma and, you know, he talked me through it. You know, he did a world series with myeloma and things and so I really had that positive feedback from him, just kind of, you know, just deal with it and see what happens and Mel is living up in the north, northwest. Right now, he is back to many things. So, he has had it probably... I think he was diagnosed like 1999 or so, you know, that far back. So, he is doing okay.

Matt Goldman : Great! Thanks. Pat, even your sort of current view about getting up everyday and, you know, the stress and activity is good for you and keeps you active and your brain working. What's changed or have there been changes on your view on sort of destressing your life, if you will, from before your diagnosis to how you live your life now?

Pat Killingsworth : Sure and I do notice that I do become stressed more easily now and so I try to simplify it, doesn't always work, but things that I used to just brush off, get to me, seems to get to me now. So, I guess how you can do is try to stay organized, you know, keep a clean work space, follow tips that seem to be common sense, but, you know, if you are living a normal, crazy life like we all do, it may not matter, but if..., when every little thing seems to get to you, some of those small basic things, probably make a



difference. I will tell you that its inspirational to know that a baseball superstar goes through the exact same death cycle that you and I do, Matt. I am sorry you have got to, you got to go through that, Don, but... and I also want to share that I have a good friend named Richard who is a huge fan and he loved Mr. Stottlemire's blog and it mentioned that and you have both been inspirations to a lot of us in the myeloma community and I know, as I described and asked you about your treatment, I want to apologize. Some of us almost live and breathe multiple myeloma 24/7 for better or worse and your reaction or having to ask your wife or your caregiver about maybe a treatment five years ago and what you did or didn't do, that is something that I would expect. We are just myeloma geeks. How is that for us?

(Laughter)

Don Baylor : I am glad, I am glad. I am glad for that, you know...

Pat Killingsworth : I apologize if you felt like I was putting you on the spot.

Don Baylor : No, no, no. Not at all. Now she has kept me on the right track as far as, you know, appointments and things, you know, I... She says, okay, you are doing this. You are doing this blood draw, you know, because once you get, you know, wrapped up in the sport that we play, you know, my quote every year is, you know, we interrupt his marriage for the baseball season, so, you know, that's going to go sometimes. You just kind of think, but she is right there with me, doing my other things for me.

Pat Killingsworth : There you go, Matt. A good caregiver is a number one stress reducer.

Don Baylor : Yes, exactly.

Matt Goldmann : Exactly. I was thinking... I was just thinking that myself and Dr. Berenson would know very well about the role of my wife as caregiver. She keeps me organized and on target with what I need to eat, what I need to do physically, what I need to do mentally. She doesn't mess around, which is, I think, what we all need.

Don Baylor : Earlier when we were going through this, there was a bunch of myeloma patients there without a caregiver and I just said I wouldn't know where to go or who to talk to or whatever, you know, so that... She has been a tremendous asset, you know, that you don't have to have all that stress of running around and doing those things yourself, you know, all the time. Right. Even dealing with insurance, I don't even worry about that, I leave that in her hands.

Matt Goldmann : Back to you, Dr. Berenson, and you kind of touched on this a little bit. When you have a new patient and again you are my doctor and I experienced this and one of the reasons why I liked your approach is your philosophy about living a complete life, but if you could tell the listeners when you get a new patient and given your thoughts about that there is no real study on stress and the impact, what do you tell your new patients about how to handle everything, stress wise, career wise, activity wise, how to handle it all, while also and most importantly managing their health?

Dr. Berenson : Well, I think that my big thing is to maintain your life, not to get riled up in the fact that the disease overtakes your ability to function and you are not, as my good friend Jacob who I had dinner with last night, he was my mentor, now a lymphoma survivor for over 30 years, said its not about taking care of the myeloma or the cancer or lymphoma. Its not about taking care of the patient, its about taking care of the person and my favorite picture is down the hall of my patient, Jeff, who was in clinic today, when he was on a clinical trial at the top of Mount Kilimanjaro with his wife and orthopedic surgeon coincidentally and he is living his life. He is traveling. He is functioning. He has had myeloma for many years. He is trying to not let it get in his way. He is now on a trial with carfilzomib, so I mean, my job is to keep people functioning in terms of their lifestyle, their family style, their work style. You know, I think that this is key in terms of keeping people in the game and I think if you look at the data, people who can maintain their quality of life live longer. Now you could argue that's because they feel better, therefore they do more because they are



doing well or is it the tail wagging the dog, which way is it, I don't really know, but I don't believe that patients should be, if you will, babied through their disease and I really try to push people to be active, to stay active.

Matt Goldman : Right and like I said, when I first met you that I really appreciated your philosophy and your attitude and I think I would also add sort of touching on my past that when I was first diagnosed, I really wanted to go on the internet and read about success stories and read about people who were fighting and, Don, for me too you were actually one of the first people I read about and it was real important just to see how great you were doing and what your attitude was.

Don Baylor : Well, back in 2003, they try to go on the internet to find out some things about myeloma or go to a bookstore and try to read about and there was just nothing there. That was more stressful than anything. Then, I picked up the phone and called Mel Stottlemire and got more from him, you know, just the outlook was more positive than anything I could do at the time.

Matt Goldman : Right. I think... I think we would all agree that not only....

Dr. Berenson : Well, you should... You should join chime in, Matt. This is Dr. Berenson, what you were able to do recently, pretty amazing. Tell them about your little trip up to Seattle. See, like probably the second amazing feat, Matt will tell you.

Matt Goldman : I did recently, I have done this... There is a thing called The Big Climb up in Seattle that the Leukemia and Lymphoma Society puts on and its climbing the stairs of a 7030 building in order to raise money for that organization and I had done it maybe six years ago when I was healthy and frankly I didn't really even know what the LLS was. It just sounded like a fun event. Two months ago, about a week before my two-year anniversary, I gave it another shot. I went up there and did it again and had team Goldman with me, family and friends, and they stuck with me. I was a lot slower than I ever was before, but I just keep on focusing on moving and I made it all the way up, but I wasn't going into it. I was nervous if I wasn't going to do it, I mean I was nervous if I could make it, but I did and it was probably in this whole journey that was the most exciting thing for me is to have that success and like Dr. Berenson was saying I think it was really important for my mindset to know that I could still do stuff like that. I can still do physical things. I am older anyways, but you know, I am not doing things as quickly or as intensely as I used to, but I still do them and...

Don Baylor : Congratulations on doing that!

Dr. Berenson : Hey, you are doing pretty darn good, Matt. I can say that, Dr. B here. Great attitude that you have to have, you know #1, you know, and I think if you sit around, you know, feel for yourself and lot of sympathy, I think to me, that's more stressful than anything. You know, if you think about just living your life and doing the things that you can do and you want to do, I think you are a lot better off. That's always kind of been my attitude, you know, I will deal with the disease and, you know, just keep living my life.

Matt Goldman : Ummm... Yeah and I think for... I almost feel like an old, almost 26 months into it, I almost feel like an old timer, but I think (laughter) that's a really great message though for newly diagnosed patients to keep active and I think also having a caregiver that you can rely on, but also having like you had, Don, and like others have had is to have someone else who has experienced these things, that you could turn to to get bounce things off. The stress of..., the mystery of it all could be overwhelming and having positive role models I think is really important, which leads me to another question for you, Don, in terms of your future in baseball, I am sort of curious if you sort of personally see any limitations on what your choices would be in baseball because of your myeloma or because of the stress involved, you know. Would you see managing in the near future or is that something that you want to avoid because you have a really good routine right now with what you do?

Don Baylor : Nope. I do not want to avoid managing again, I like to do that. Again, I have dealt with stress before and I don't think its, you know, a problem as far as, you know, with myeloma. The others, managers



out there, coaches, guys have prostate cancer and thinks, you know, my stress is no different than other guys. So, to deal with that, managing, I like to stay in the game. You know I have been in the game just about all my life, you know, so its not a problem for me.

Matt Goldmann : Uhmm... And if you don't mind me asking, do you think there is any sort of perception about your capabilities based on your myeloma?

Don Baylor : Possibly, you know, but I can't say who has shied away or whatever, you know, I don't know that for a fact.

Matt Goldmann : Might be you are just trying to do the best that you can do and hope people know that's right.

Don Baylor : That's all I have ever been able to do. Yeah. I have dealt with it, yeah, openly, more than anything else than most people probably would have, but that's just..., this is the way I am.

Matt Goldmann : Uhmm... Great! Pat, how about you sort of looking forward in what you do? Do you see limitations or are you making decisions, Pat? You might not have made about what you do everyday or how you picture your future based on just knowing that myeloma is in the background and that you need to sort of avoid certain circumstances or do you just do what you have always wanted to do?

Pat Killingsworth : Sure and it sounds like Don was fortunate to have..., that they caught his myeloma before there was much bone involvement, bone damage. Unfortunately, I am sure I had myeloma for three, four, or even five years before I was diagnosed. So, I had a lot of bone damage and its caused some pain and some difficulties, but I recently following... I was in a short remission. We all got excited, it lasted 10 weeks and the myeloma came back and was gaining some momentum and fortunately we have been able to knock it back, so after six months of stable disease, I made the decision to go ahead and get my hip replaced, so its been just six weeks that I had a hip replacement and I have got to tell you not having the... You know, having less pain and being able to get around better, I can tell already it was a great decision and it was a (uhmm...) decision made looking forward. You know, If I thought I had a year left and probably don't want to go through the pain and, you know, inconvenience of having a hip replaced, right, but I could see... I could see out farther than that and I went ahead and I think it is one of the best things I ever did and yeah, and I think agreeing with everybody, you know, looking forward, staying positive, and trying to do as much as you can do with what you have got is probably the best any of us can do and I think it helps keep you... It helps keep you moving forward.

Don Baylor : I believe, you know, the belief and the dedication that we have from our doctors are just more important than anything. That's when you walk out of the doctor's office and its not that dim and gloom, you know its the...

Don Baylor :...look in the head, so the doctors, they work on this, you know. You know, I can't get enough respect for them and what they would like to do. I mean its a disease that's to be maintained with and lived with and, you know, they are on top of everything. So, you know, my hats off to them for the work, you know, dealing with the patients.

Matt Goldmann : Yeah, exactly. Yeah, for me this might be the death speaking, but I love my doctors. I think they are all amazing and I think none of us can do what we are doing without them.

Don Baylor : Absolutely.

Pat Killingsworth : And, Matt, the work they have to do. I mean, Dr. Berenson, I have, you know, go figure it. You get cancer and you find a new career and I was a medical journalist. I traveled to these meetings, these oncology and hematology meetings and conferences and Dr. Berenson is there, presenting, taking notes, meeting, conferring with his, you know, with other physicians and researches in the lobby and over



lunch and there is a lot of travel and a lot of extra work and right there, I know that Dr. Berenson's clinic... Dr. Berenson, you might talk about how you are doing research right there in your offices and its just a lot of work and I think I speak for Matt when we all say thank you.

Dr. Berenson : Yeah. I think what's unique about our setting is I was at the university for 20 years and the slowness with which things got done was pretty frustrating, so we set up our own institute with several grateful patient donors and we are able to accomplish the ability to see about 30 patients a day, 150 a week, with myeloma and then in addition we have our own basic lab where we garner a lot of materials, bone marrow blood from patients to study new drugs, new ways to follow myeloma. We just uncovered a new serum marker, which I think is going to be an important one to follow myeloma and importantly we have the ability to do clinical trials throughout many sites around the country through our clinical trial's unit, Oncotherapeutics, and this allows us to translate the lab into the clinic very rapidly and there is nothing more heartening than seeing patients with myeloma that can't be measured anymore and that seven or eight years ago we were literally taking, first in the laboratory in the test tube with myeloma cells that had mice growing in patient's tumors and live animals with human myeloma showing it was effective and then going to the companies and saying let's do trials and then seeing all that success, just great!

Matt Goldmann : Yeah. Great! Umm... Before we get to some listener questions, the three panelists. Don first, is there anything else you wanted to add before we get to some more questions?

Don Baylor : Umm... Don, you said you were in an oncologists' meeting recently. Is that the one in Chicago, that's all the noise, I heard there in Chicago. All you guys were there through the weekend. I think they had about 30,000 or so in Chicago at the time. So, I know they are after working and trying to get the best possible data on myeloma and all the other blood diseases that are out there.

Dr. Berenson : That's right. We were out there trying to get it all figured out and we still have a way to go. I think the future of myeloma therapy (audio break).

Priya : I think we just... Dr. Berenson has just dropped his call. Don, Becky, its wonderful to have you here. Don, do you think that myeloma medications or treatment has ever come between you and your game?

Don Baylor : No. Not at all, you know, because I can schedule...

Priya : That's wonderful to hear! Yeah?

Don Baylor : I can do my scheduling the way I need to, but as far as the medication taking, you know, I make sure I get the proper rest and things. When I do take my drugs, they are normally at night where I can get six to seven hours of sleep.

Priya : That's great! How has your team supported you throughout your transplant, stem cell transplant, and treatment?

Don Baylor : Back when I was diagnosed with the New York Mets, they were great. You know, I just missed probably couple weeks, three weeks of spring training and they were wonderful about it. You know, Fred Wilpon, the owner there, I just took the time in spring training and came back, I was fine and that's the only time I have missed and that was just spring training games, so I have not missed a game at all because of myeloma.

Matt Goldmann : Wow! So, when you did your transplant you only missed three weeks of spring training? That was it?

Don Baylor : That's it. I told my...

Matt Goldmann : Wow!



Don Baylor : I told my doctor, I said okay, this is the date that I won't be here in spring training, you know, so I just...admittedly just set that date more than anything.

Becky : I think the transplant was February 5th and he reported at the spring training middle of March, towards the end of March.

Matt Goldmann : Wow!

Becky : and didn't miss a day after.

Don Baylor : Or since.

Matt Goldmann : Or since. Yeah. Again, I think that's a great message for patients to hear is, again its all such a mystery and just hearing other peoples's experiences I think is super helpful in managing the whole thing.

Don Baylor : And there's probably... I know other myeloma people out there who have done just about the same thing I have done. So, I don't consider myself any special person, but I just followed my doctor's orders and you know stay on top of things and get my regular exercise and deal with it.

Matt Goldmann : Uhhh... Pat or Dr. B, is there anything else that you wanted to add or ask of the other panelists before we get to listener questions?

Dr. Berenson : No, I lost you for a minute, but its very... I think its a big thing. All of the really overriding message now is myeloma patients live for really long time and as I like to say, its now a marathon and you need to run the marathon and finish the race and in the 90s you are running sprint races unfortunately. So, I like to let you finish the race.

Matt Goldmann : I like that too.

Don Baylor : Love that, doctor.

Dr. Berenson : Yeah. Couldn't ask for anything more.

Matt Goldmann : Priya, I think we are ready for some listener questions. Do you want to handle that or do you want me to?

Priya : Yeah. Okay. No, I will do that. Thank you so much, Matt. Callers, if you have a question for our panel, please press 1 on your keypads and we can bring you live on air to ask your question. Callers, listeners can press 1 on their keypads and we can bring you live on air to ask your questions. Yes, we have a caller on line. The person calling in from 248-354, please ask your question.

Brenda Jenkins : Hi I am Brenda Jenkins.

Priya : Yes, you are on. Please ask your question.

Brenda Jenkins : I am a myeloma patient and I just think this program is awesome. I love to talk with other survivors. I personally know Pat. Hi, Pat!

Pat Killingsworth : Hi, Brenda!

Brenda Jenkins : And, Matt, I didn't hear how long you... When did you get multiple myeloma?

Matt Goldmann : I was diagnosed May 2nd, 2011.



Brenda Jenkins : 2011?

Matt Goldman : Yes. May 11, 2011... May 2nd, 2011, so I am coming up on 26 months in about a week and a half.

Brenda Jenkins : Fantastic! Like I say, I just love listening. I have been listening and I love listening to the program and, Don, I cannot believe after three weeks you were out and at it and that is not normal. I am sorry.

Don Baylor : But they have always said I am not normal, so that's okay.

Brenda Jenkins : Okay, okay. Well, that's all I had. I didn't have a specific question. I just wanted to commend you, all of you, for having this program.

Don Baylor : Thank you.

Brenda Jenkins : Bye, bye.

Matt Goldman : Thanks.

Priya : Right. We have another caller on line. Caller from 904-992, please ask your question.

Gary Petersen : Hi, Priya! This is Gary Petersen.

Priya : Hi, Gary! Yeah. Hi, how are you?

Gary Petersen : Good, good. You have got a great program, Matt, going here.

Priya : Thanks, Gary.

Gary Petersen : I am, you know, I am actually overjoyed at some of the stories that Don, Pat, and you are coming up with because I know that I wasn't quite, you know, as mobile and, you know, I didn't feel as though I had all my faculties, you know, as far as, you know... I, I... You know, I used to have a very trying job with travel all over the place and I just didn't feel, you know, because of my kidney failure and few other things that I just couldn't do it, but, you know, one other thing is if any time, you know, its kind of stress, what stress, you are told at least when I was there, you know, seven years ago, that you are going to die in just three to five years, that its going to be a painful death because your bones are all going to fall apart. You know, that you have to live in a bubble because you have no immune system, that your jaw is going to fall out, that you are going to have non-stop diarrhea, you are going to lose your hair, you are going to have digestive tract slough off painfully during stem cell transplant, you are going to have millions in medical bill, your kidneys and heart can fail, and you may get a stroke with a stem cell transplant, you will turn into a human petri dish, meaning that you have no immune system, you know, kind of etc., etc., etc., so I guess...

Dr. Berenson : Hold back, Gary.

Gary Petersen : (Laughter) Well, and to think, you know, as you guys talk about it, you really are a bunch of hard asses, I got to tell you.....because you never even mention all that stuff. You know, you are just saying, oh, I just punched through it, you know, and my hat's off to you guys, it really is, and I know that Pat was doing all that, but, Don, you being a, you know, in professional baseball and flying all over the place and making that all up and you are nuts.

Don Baylor : Yes, sir. Yes, I am.

Gary Petersen : But very, very strong, you know, unbelievably strong. I think you are the iron man, you



know.

Don Baylor : Well, some of the things you talked about, you know, your hair falling out and all those things, you know, I told the nurse, I said okay, let me shave it off because if I shave it off and it doesn't come back, I don't have anyone else to blame except me, but it all came back, so, you know, those things you get through, you just punch through.

Gary Petersen : Oh, you guys are amazing, you really are! But my question to Dr. Berenson, hey Dr. Berenson, did you have a few wussies that you treat? Well, that may require a little extra care, meaning that, you know, are there... How many patients do you treat that require therapy, whether its..., you know, with a psychiatrist or with antidepressants?

Dr. Berenson : Well, I think that one mistake that's often made is that we don't talk to patients about these issues or the other thing is an automatic reflex, that oh, you have myeloma. You must be depressed. You need to be on Prozac and I won't name names, but one of my patients who went down to see a famous cancer or myeloma expert was told that he takes Prozac and all his patients must take Prozac if they were seeing him. Hey, that's not my philosophy. My philosophy is get active, do stuff. You will probably be able to get through it, but certainly I have a large number of patients who do see psychologists and psychiatrists and I am a big supporter of that. I think we often forget about that. Not only is the patient, believe it or not, is the caregiver, not only the caregiver smells like Don Baylor's wife, the doctors, the nurses, its pretty tough at times. But, I don't think we should pretend to be psychiatrists and many of my colleagues hand out Celexa, Prozac, Effexor like water and that's just not a good thing to do. These are drugs that need superb help. Now I will add something very interesting in, however, I think many of these drugs cause significant fatigue and mental dysfunction and we have just completed a randomized trial with a placebo or sugar water control and we should have the data shortly with a drug called Nuvigil. You may have heard of Ritalin being used for hyperactive kids, this is the drug that helps your energy and there is another drug called Provigil, both are approved and we think these drugs help immensely with fatigue, which I think today is the number one problem with myeloma, its mental dysfunction and fatigue. Its no longer bone disease, which happens to be the area many of you know I am an expert on, but the number one problem right now is the effects of the disease long term and the treatment on mental function. We do not deal with that. We need to deal with that.

Gary Petersen : Very good. Well, thank you. And one of the things I always, you know, I was told when I was getting my treatment that I needed 30 minutes a day and I kind of have my own little saying that 30 minutes a day keeps the cancer at bay and I think that it helped, you know, physically and mentally.

Matt Goldmann : But, Dr. Berenson is right. I mean I went on Prozac when I was diagnosed in... I am actually at the point where I wanted to wean myself off of it. I don't think its necessary at this point.

Gary Petersen : So, you want to be a weaner?

Matt Goldmann : I probably already am.

Don Baylor : This is Don again. Now those energy drinks and caffeine, we are around all those things anyway. I have never been a coffee drinker and I have never been one of those energy drink things, you know, I... But, when I did discover I had myeloma, you know, where it came from energy, you know, I was out walking one day training and I said, okay, now how am I going to get back, you know, that was the only time that I really kind of felt like, you know, there is something, something wrong with my energy level. So, I still to this day, I just don't, I shy away from all of those energy drinks and caffeine that try to keep you up all the time, that's, that's not how I do. I do it with...

Gary Petersen : Iron man!

Don Baylor : I do it with diet and exercise.



Matt Goldman : Yeah. I went... I also went... When I was diagnosed I went cold turkey on caffeine. I haven't had any caffeine in almost 26 months and I think its better you avoid kind of the ups and downs, the high and the low, that you get from that.

Gary Petersen : I had another question of, you know, I think you can take somebody else and then come back to me, if there is time.

Priya : Yeah. Thank you, Gary. Thank you so much. We can move on to some of the submitted questions. We have got lot of questions from participants that have registered for the program. Ed here wants to know how much impact does stress have on relapse. Dr. Berenson, I think maybe you can answer this. How much impact does stress have on relapse?

Dr. Berenson : Yeah, I was going to say we don't have good days on this, so question is is the stress causing the relapse or is the relapse causing stress? Its very hard to separate this out. You know, I just don't think we have good data and any objective studies. I am certainly a big believer to keep stress at a minimum, but that's a belief system. That's not based on scientific study. So, I must confess we just don't have the data to tell you that keeping stress away keeps the oncologist's drugs away. I mean I just..., you know, for relapse, I don't know the answer, I wish I did. Its just not clear.

Priya : Okay. Don, Jack here wants to know as a 10-year survivor, what is the number one recommendation you would make to a newly diagnosed patient?

Don Baylor : Newly?

Priya : Yeah, somebody who is newly diagnosed.

Don Baylor : There is so much hope out there that that hope was a small kind of window. In the very beginning when I was diagnosed I just didn't know the things that are in the pipeline today, that they were not in the pipeline in 2003. So, there is a tremendous hope out there that now you can maintain a normal life than before.

Priya : Yeah. Matt, I think this one you can handle. How to manage stress in a very stressful and demanding job? Daniel wants to know.

Matt Goldman : For me, for Matt?

Priya : Yeah.

Matt Goldman : I think on one hand and this was a question I asked Don, I think on one hand my attitude towards stress and stress of the job has changed. I think the myeloma makes you realize that other things are more important than getting a little bothered about things in your job. I mean I am 51, if I have to work, there is not a question about that and I like working. Its a good escape from thinking about myeloma. I don't want to sit around and think about it all day, but I think like you said, on one hand, I think my attitude towards it has changed. I am much sort of calmer and it doesn't bother me as much and I think secondly, I think having to be so diligent and like Don was saying or having to be a lot more organized than I ever had to just in my personal life and how I deal with my cancer. Frankly, I think that kind of translated into how I view my job. I think I am much more systematic about how I do work and if issues arise and there is a stressful situation, I think I am much more thoughtful, sort of picking up the life lessons I have learned from myeloma. I must kind of apply that to my job as well and that's one of the things up in my blog. I think strangely enough, I am a way better worker and do a much better job than I ever did before all this and less stressed about it as well.

Priya : Okay. Pat, this one's for you. Could you discuss how you managed the stress of doing myeloma right? Dealing with insurance issues, keeping track of numbers, updating patient history, making



appointments, reading abstracts, multiple myeloma blogs and tweets along with answering questions from anxious family friends. How do you keep it balanced for yourself?

Pat Killingsworth : Wow! I am stressed just listening to that list, I guess... (laughter) You know I think, like I said before, you try to stay organized. You try to do as much as you can when you feel up to doing it. Umm... You compartmentalize some, you know, common sense the cliches that you hear. I am having trouble wrapping my head around that. That does sound pretty overwhelming.

Priya : Dr. Berenson, Akhilesh wants to know. He was diagnosed with multiple myeloma a month ago. I have no complications as such and I am feeling absolutely fine. I have no pain in any of my bones and I am living a normal life. I am 36 years old and I have started treatment. What is my possibility of survival in this case?

Dr. Berenson : Well, you know, its hard to know without knowing lot of other things...your blood counts, kidney count. So, you know, I can't tell you without actually seeing you, but, you know, it may be that, you know, if you actually have indolent myeloma, you may actually in fact never require treatment, that's a possibility or just bisphosphonate like Zometa or Aredia, but I can tell you that your chances of living a rightful life are a lot better now than they were 10 years ago. The average survival of myeloma patients today in our clinic is measured not in just a matter of a few years but in decades, so I think its pretty amazing.

Priya : Yeah. Another one, Dr. Berenson. What can be done for the stress from the neuropathy from medications?

Dr. Berenson : Well, I think that's a really important area that's often looked over, crossed over by my colleagues. I think modifying the dose down and modifying the schedule making it, for example, longer with Velcade, giving 1 instead of 1.3, I think can be quite successful with the myeloma and yet leave the patient with much less risk of neuropathy, the subcutaneous dosing as well with that drug. We use a lot of alpha-lipoic acid as a neuroprotectant. We think it is very, very helpful to reduce the risk of peripheral neuropathy or if you already have it, that over the counter will reduce its severity, but we don't really have a good objective study showing that. We push the companies to try and do that, but they have not been particularly interested in supporting those studies, but as I say, I do think that neuro, whether its central with effusion or peripheral neuropathy with numbness, tingling, pain in hands and feet, these are the major problems today with myeloma and we really need to focus on how to reduce their severity and their impact on quality of life on our patients.

Priya : Thank you, Dr. Berenson. This is quite an interesting question here. When I read what various cancer authorities say about diet, I find the restrictions very stressful. How does one strike a balance? Pat, maybe you could answer this.

Pat Killingsworth : Well, that's why I like to stay busy. I really think, like everyone has said before, you know, living your life so that you don't obsess over it, its like a downhill spiral, right, so the best thing you could do on a rip tide, you have got to swim to the side until you can break out and I think if you, you know, stress over it, its just going to get worse. So, my solution is I try to stay as busy as I can. Now what happens is that its above myeloma, which someone would say is crazy, but I am able to compartmentalize the two. I could be working on a book about baseball. It just so happens I am, say, writing a book about myeloma or I am blogging about myeloma, but I am still able to separate the two, although sometimes it is a little difficult and it crosses over.

Matt Goldmann : Yes. This is Matt. Let me just add...I had severe kidney damage right away. I mean that was one of my symptoms and so my diet was really restricted and it really pissed me off at first, but I couldn't eat, but it becomes... Like everything with this, it becomes kind of routine and you just get used to it. You know what you can and can't eat and I have actually last week been able to add a few foods back into my diet and to make it a little bit of a game in my own mind is I sort of set target dates on when I am going to eat a certain kind of food, you know, I know I still need to be careful and avoid certain things, but all



set to target dates, three weeks down the road when I am going to indulge in something and I have to go along with what Pat says, it keeps you sort of focused on looking ahead.

Pat Killingsworth : And, Matt, you made a great point. You need to be patient and that's so difficult and so easy to say, but, you know, it looks like the world is going to end and anyone with multiple myeloma has had to deal with the ups and the downs, the roller coaster ride, where everything seems dark and then three or six months later you feel like you were never sick at all and patient, so I am glad you mentioned that. I just think its difficult but try to be patient, take it one day at a time and hopefully then you will get better.

Don Baylor : This is Don. My thing that I never really considered a whole lot was just the hydration. You have to stay on top of and my wife has been after me for a long time to hydrate all the time, drink water, water, water. So, last three months, I have been drinking alkaline water. So, I was trying to see if that makes a difference, but what it has done for me is that I no longer get my 64 ounces plus every single day because I am committed to it and just see if it makes a difference in some of my numbers, who knows but that's what I have been doing for the last three months.

Matt Goldmann : Everything counts. I drink more water than I ever used to.

Don Baylor : That's great advice.

Priya : Yep. Thank you. Yes, I think we are almost done, over our time now. It was a wonderful discussion, Don and Becky. Thank you so very much for taking time out for this discussion. Dr. Berenson, it was great to have you here with us again. Thank you. Yeah. Pat and Matt, it was definitely a wonderful discussion. Thank you so much for supporting us in this. Cure Talk thanks all the listeners and participants. Thank you all for your support and we look forward to having all of you join us for the next Cure Panel Talk Show on myeloma. The link for today's show will be shared with all participants. Participants, please send us your feedback and thank you so very much. It was great having all of you here.

Don Baylor : Thank you so much. Thank you, doctor, for taking the time out today to be with us and give us some great ideas. Thank you.

Matt Goldmann : This is Matt. Thanks to all of you here, participation. I think this is really great and the information we got helps me up and everybody else. Thanks.

Dr. Berenson : Thanks, Matt.

Priya : It was really great, Matt.

Pat Killingsworth : Thank you, Dr. Berenson, and Don. Thank you so much for helping you inspire us today.

Dr. Berenson : I appreciate that. Thank you.

Priya : Thank you. Bye bye.