Myeloma Survivors Jim & Kathleen Bond Share their Myeloma Story

On this On-Air Myeloma Support Group Meet, myeloma survivors Jim Bond & Kathleen Bond share their myeloma story and give out tips on surviving everyday challenges myeloma brings along.

Full Transcript:

Priya Menon : Hello everyone and welcome to the Cure Panel Talk Show.I am Priya Menon, Scientific Media Editor at CureTalk/Cure Panel joining you from India and I welcome all of you this evening to Cure Panel's On-Air myeloma support group meeting. This is our Live On-Air Support Group Meeting headed by myeloma survivor/author/advocate Pat Killingsworth. Cure Panel's on-air myeloma support group meets every month on the Cure Panel Talk Show. The show is broadcast Live on BlogTalkRadio.

Today we have with us myeloma survivors and advocates, Pat Killingsworth, Mary Ming-Mosley and Cynthia Chmielewski and our guests for the show are Jim and Kathleen Bond.

James D. Bond II and Kathleen M. Bond are Myeloma Ambassadors. Jim is a retired Ernst & Young partner. He has actively lived with multiple myeloma for 22 years and leukemia for 2 years. Kathleen is Chair of the American Cancer Society East Central Board, Trustee of the Oncology Nursing Society Foundation Board, Director of the Oncology Nurse Society Foundation, and the ACS Cleveland Hope Lodge Boards, and formerly served on the ACS National Board of Directors. Kathleen founded the ACS Pan Ohio Hope Ride, a 4-day cycling tour, and Jim has cycled 328 miles across Ohio each of its 7 years, and he is training to ride again this July. I will now hand over to Pat to commence the meeting, but before that I would like to remind our listeners that they can press 1 on their keypads to join the conversation and share their views and experiences with us. Pat over to you …u are on air…

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Pat Killingsworth : Hi Priya. I am hearing some interference, do you here that too.

Cynthia Chmielewski : I was hearing that too, this is Cindy. Priya: I will try to see what that is Pat.

Pat Killingsworth : Ok thank you. Cindy we have got you here. Mary are in here. No Mary yet. Maryan Mosely, hopefully we join us later from California. Jim and Kathleen are you here.

Jim Bond : I am here, can you hear me?

Pat Killingworth : I do Jim, just a little faint.

Kathleen Bond : Pat can you hear me, its Kathleen.

Pat Killingsworth : I hear you loud and clear Kathleen.

Cynthia Chmielewski : Hi Kathleen, How are you doing?

Kathleen Bond : Good. How are you Cindy.

Cynthia Chmielewski : I am doing great.

Kathleen Bond : I am so gad to hear that. Its a pleasure to be with you all.

Pat Killingsworth : Thanks for taking the time. Jim why don't try again. I am sure we will figure this out, we don't always have these technical difficulties, although I got to tell you, it's always something.

Jim Bond : Is this better if I speak into this phone?

Pat Killingsworth : Much better. Thank you Sir. Welcome everybody, you know it is challenging on these broadcasts a little bit because we can't see each other. You know there isn't a monitor, we don't have ear buds, so sometimes we talk over each other, sometimes a little glitches, but all in all, we are able to share some wonderful information. We have to be approaching our 1 year anniversary for Myeloma On air support group, I am not sure exactly when that will be, I am sure Priya can tell us. But Cindy has been with us in a couple of them, and it is nice. Sometimes people call in sometimes they don't, but by the end of the month, in about 30 days, between 2000-3000 people listen to the broadcast. So I think they help and that is what its all about. Right??? So, let's start, you know, I would like to start with Kathleen, the caregiver are so often an after-thought. So we are gonna give Kathleen the lead position here. Could you share a little bit about your life with Jim, and my goodness, it is 20 years, isn't it Kathleen?

Kathleen Bond : 22 and counting.

Pat Killingsworth : And that's been since he was diagnosed, to clarify right?

Kathleen Bond : Right. 22 and counting since diagnosis, and this September, Jim and I would be celebrating our 44th wedding Anniversary. So we are at the half way-point of our marriage, where half of our married life has been stamped with a third partner and that has been Multiple Myeloma.

Pat Killingsworth : I just lost a good friend, and hopefully more survivors will live so long. That is wonderful, I am so glad, it has worked out.

Kathleen Bond : Well, it is a long story and I won't go through the whole story, but Jim was diagnosed in 1992, and so many of you probably went through, we had never heard of multiple myeloma. And we were like everyone, it was like a kick in the stomach, everything you ever heard from everybody, and we decided we are gonna get after it and not let this thing dominate our lives, and so we decided, we were gonna just making plans and keep putting one foot in front the other, and we really were pretty clueless about what was in front of us. And we just marched on. But we did know, I know for me the important thing was learning everything I could about the disease. For me getting information was empowering and I also decided I was not only get mad at this disease to get even, and learn everything I possibly could and I was able to actually to the medical school library here in Cleveland, Ohio, Cape Western, and gather information. It was usually helpful. That was back in the days before computers.

If you recall there was a medline, back in those days and you could get articles, from medical Journals and I used to print those things out. Some librarian took pity on me, because she knew I wasn't a medical student, but I would come home and I would read them and highlight it, and these were the days of the tractor feed paper, and lo and behold, couple months later I want to reference something and the ink disappeared, because that was thermal paper. So I just had yellow lines all over it. But doing that, I could find facts about the disease, did help me to ask thorough questions, and Jim and I also were able to get in touch with the doctors that we determined seem to be the top five authorities in the disease because they were the ones that always mentioned or had written the articles. We were able to compose a short fax, and that was back in the days where people ran in with faxes, because they seemed important. I got the fax numbers of these doctors from the various hospitals, and I faxed them a simple letter.

Jim said I am a 43 year old, diagnosed with multiple myeloma, light chain only. Here what they are telling me in Cleveland I should do, what would you do if you were me? Amazingly, we heard back from two of those docs that afternoon and eventually heard from all five. And we have maintained our relationship with these

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docs, almost all of them to this day and they have been a great resource for us. So that was hugely helpful. The other thing that realized early on, the importance of trying to stay even, and by that I mean with all the good news and more often than not the bad news that we got, we tried not to get ourselves in the peaks and valleys.

And that is really easy to say, but every hard to do. And when we would get bad news we would say Ok, well, you know what, that is today that is right now, who do we need to talk to? What do we need to do, we just kind of pull it up. So we were some where in the middle and by the same token if we got good news, we would say to each other out-loud, – Now don't get too giddy, because that can change. And we do that to this day and it has taken a lot of practice and we coach each other to say – Hey don't get too giddy, or don't get too down, let's see what tomorrow brings, and it has really helped us avoid the extremes of the hideous roller coaster that everybody refer to as cancer. And that's been very helpful, but we have to work at it.

We had 22 years of practice working at it. The other thing that I think has been helpful for me as the caregiver – In gathering information, Jim and I discuss next steps, and we discuss the next steps with the doctor. We make our decision based on the facts that we could gather at the time and information we have at the time. Once we make decision that is it. We do not look back. There is no point in second-guessing, we move forward, we give what we could at the time, and there is no point looking backwards. And we have held on to that for 22 years. The other thing that we do is we have instituted an 8PM rule. And our 8PM rule, and its good thing this call isn't later, our 8PM rule is at 8'oclock at night it doesn't matter what is happening, and Jim could even be in the hospital going through some kind of treatment, at 8'oclock at night we are done with cancer. It does not exist in our world, we will not talk about it anymore, our family and friends know not to call us, because we are not going to talk about it after 8'clock, and I have to tell you Pat and Cindy that, when we first instituted this rule, it was actually a 9 PM rule, and now we are just old and we can't stay awake, so in order for us to have some sort of evening, we had to move it to 8'o clock, but it works for us, because then we can have a normal evening, or whatever it might be, watching something silly on TV, fun folding laundry, whatever it is, cancer is not in our world.

We know how ever the next morning we are gonna be back at it . But it has helped us hugely. It helped us actually to get better sleep at night, you know there were times when Jim was in the hospital. Two years ago, Jim was in the hospital for 75 days, that was when he was dealing with the AML, the Leukemia. And at 8'o clock at night he would say to me – Well do you want to go home or you want to sit here and watch TV and I would make that decision. And it really helped us, it truly have. The other thing we have done is, we have point people in our different spheres of relationships, and I am not one to get on and do a lot of emails, I do email, but I am not gonna report to everybody every night on email, but I do have a couple people in each of our spheres of influence and relationships that I would let know what is going on, and that just takes the burden off me. And that has been hugely helpful. I think the other thing that I hear everybody say and it is very important – If you are the caregiver, you have to take care of your self, because this is a marathon. You in it for the long haul, and you have got to take care of yourself. And there are days when it is easier to dod than other days, but you have to make time for yourself and maybe get together with a friend, have coffee, you can sit there and cry and laugh and you know, talk about it, but it is really important that you have that, I try to do that. And exercise as well, eat well, do what you can.

Cynthia Chmielewski : I like the 8 PM rule. I think I am gonna have to instituting that.

Kathleen Bond : It has worked so well for us, and will tell you what – it actually works for other thing in life. We used it for other things that we have been butting over, but the 8PM rule has really been helpful. And the other thing that I thought was really the most stunning for me – I was not one to go to a support group – in fact there weren't any, so there was no group to go to, and there weren't programs like this. So we were pretty much on our own, and I would frequently ask Jim's doctor – "Do you have anybody to point toward that we can talk to" and he really did not. And that was pretty scary for us, but the thing that I found probably the hardest, was after Jim's first transplant. And over the course of these 22 years Jim has had 4 transplants. The first one was in '93, it was an Auto, the 2nd one was in '99, it was an auto. There were separate collections. Then in 2001, he had a transplant using his sister's cells. She was a perfect match.

That bought him some time and then with the AML, in 2012, he had his 4th transplant, which was a matched unrelated donor. With all that going on, I think after that first transplant which was, Actually Jim did very well through it and set a record for the fastest anybody had been in the transplant unit. But when he got out, he was back to work the next month. Not hooked anything, not taking anything, not having to go anywhere except work, and it was great. I hit the wall. I did not know what to do with myself. I was frantic that we weren't doing anything, because I knew this disease, it was likely coming back and I was scared to death because there wasn't any maintenance, there was nothing.

And I was badgering his doctor about, shouldn't we be doing something, and there was nothing to be done at that point except let it ride. Well, I was a wreck, and absolute wreck, and I was really shocked that that was happening. And I really was struggling, until one day, when a phone rang, Jim had gone to work, he was gone may be an hour, and the phone rings and its Jim. And Jim says to me – " I am okay Honey, your car isn't". And I said what? And It turned out someone had gone through a light. He had pee-bound him on the driver's side, and I started screaming into the phone – "How could you do that? How could you have an accident after all we have been through?

And that's when it hit me, I said – " You know what", I really laughed in my mind, "but there for the grace of god for all of us" – and I have to tell you, it was a Pink Buick that slammed into him. And I was thinking who has got a pink Buick, and again my apologies to all the Medicaid people out there, they perhaps do – but this pink Buick, actually it turned out, was in our neighborhood somewhere, someone lived around us. And I use to see it, but it was a constant reminder of – just appreciate what you have got today and how fortunate we have been. That's a long answer to your question Pat.

Pat Killingsworth : Well, that tends to work the best in this format and we don't have to have these pauses, you know trying to figure out who is going to talk without any need to really coordinate the things, so I appreciate that and I also appreciate that you have given our listeners, some actual advice and tips. You know that does not happen very often. That was awesome. Thank you. And I have to say. I have never heard Jim that quite. Jim you still there.

Jim Bond : I am Pat, and Kathleen is my She-Woman. And as you can tell from my name, I am the real James Bond, and now that you have listened to Kathleen, and you see her live you will know that she is a beautiful Bond girl and that proves that I am the real.

Pat Killingsworth : I have met her. Yes, I agree with you.

Jim Bond : There is a lot of movie actors, but she is the real one, and anyhow Thank you Kathleen, you were awesome, as always. A couple comments to fill in little bit, when I was diagnosed. I asked the diagnosing oncologist here in Cleveland where we live, I said "How long do you think I will live?" And he said " Jim if you do nothing, you will probably live a few months, if you do everything available", this is back in '92, " you will probably live 2-3 years. And we were stunned as Kathleen said, as you said, that was 22 years ago. So, really what motivated us to go at it. It was really other challenges that I look back in my life, and I say – You know what, they turned out Okay. So, I am gonna treat this like another challenge, give it my best shot, and that started with asking the diagnosing oncologist a 2nd question. " If you were in my shoes, would you have you treat me or some other oncologist?" And that really was a winning comment, because he said, " You know Jim, now that you have asked me there is doctor in another hospital across the street that sees more myeloma patients than I do, and if I were you I would go to him." And that was 10 year winning comment, that got me 10 years, got me through 3 other transplants, and virtually all the treatments that were on the market at that time.

But you know two – I was out of options and I was advised to go to a hospice. And here is the value of a second opinion that Kathleen mentioned. We learned of a clinical trial that were showing good results back in '02 for very sick myeloma patients like me. And I asked my doctor, what about that trial? And he said – "I know about that Jim but there is no openings", and so I said – Well, look I am gonna try" and he was a little bit miffed that I would challenge him and walked out of the room. He actually said I was wasting my time,

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which I found humorous. Anyhow I was walking up to get into a clinical trial. It happened to be in Boston in Dana Farber, and I was very sick. So sick that Kathleen wasn't sure that I was get through the night, But I did. And the clinical trial had amazing results. Within 2 weeks 99% of my monoclonal went into remission, and I was back on my feet back to work. And when the myeloma came back, as I know mine will, I did 2 more clinical trials and that got me 10 more years. So you might imagine, I ma huge believer in clinical trials. And one thing I have learned is, there is a real obstacle to a lot of folks, and that is the cost of out of town lodging.

If you have to do that and here is what the cancer society come in. They have over 30 HOPE lodges across the country. And Kathleen's highly involved in those and in fact that is why she found it. There is a bike ride across Ohio, the Pan Ohio. Hope rides to raise funds and awareness, so that other people can stay free at HOPE lodges and have the access that I have been fortunate enough to have. So back to '07, I did not cycle, she did not cycle. I went on and bought a bike after watching her passion and I made it all 328 days, the first year and I have done it a total of 7 years now. I am training right now for number 8 this summer. I get it after cycling 328 miles is hard to do, I have got some issues, and I say, yeah its hard, but guess what fighting cancer is harder, and I don't need to reinforce that with people listening. We all know what it is. After the 2012 pan Ohio hope ride my counts were not quite right in the ride, but I got through the ride Okay. But couple months after the ride I was diagnosed with Leukemia. Treatment related AML. And they said " Jim you only hope is another transplant" which as Kathleen said was number four from an unrelated if we could find one. "But don't get your hopes up because it is a long road.

Well, they did, they were successful in getting the AML down to an acceptable level for transplant and they did locate a donor. And I thought they were set, and I thought I was set, and they said, " No we are not sure you can live through another transplant because of the three you have had before and other things. Well, so I pleaded my case, and they came back the next day with a decision.

They said " Jim the winning stroke was the fact that you did the Pan Ohio HOPE ride two months ago, that convinced everybody. You have the strength and stamina to get through the transplant." So On Halloween of 2012 I got the Germans. By Christmas they called and said, "Good news, you are in remission for both of your cancers", what I have been ever since. Pardon me. I am gonna take a sip of water. Yeah it feels good. So I am tremendously greatful to the donor and to the program – be the match – which is what you google to sign up and encourage everyone in the 18-44 age group to please consider signing up. You can save lives. It is real easy to get a sample and be a donor. And i found our recently that my donor was a German.

And that explains to me Pat, why I have got this overwhelming desire to go to October Fest this year. But that may be coincidence. I have had some side effects from the disease and treatments, a couple I would like to highlight. I look shorter, my back is a bit crooked, I have metal holding some bones together, I had hip replaced from long term use of steroids. But one that lot of us aren't aware of, at least I wasn't was – After a stem cell transplant, we are at high risk to skin cancer, and lo and behold, I had about a dozen spots removed from me that were some sort of pre-cancer or the mild form of cancer, not skin cancer not the bad one, but the basal new squamous I had. So that is a heads up if you had a transplant and you are lucky enough to live for a while. Think about having a dermatologist check out your skin, which I do on a routine basis now. So anyhow, the last one I will also point out,

It is kind of weird, but because of my Allo-transplant, my last one, I have got ocular graft vs. host disease. I could barely see, I couldn't drive a car and I am now wearing a prosthetic device in both eyes, that have returned my site to normal. So that is a real blessing, that just happened. So in my advice it was worth it, hell yes, it was worth it. Being with Kathleen, being at our son's wedding, seeing our grand children, playing with them, it is absolutely worth it. A couple things, may be tips to take away – like Kathleen gave you – We believe and strive to be equal partners with the medical team. We don't try to be bossy but on the other hand we take our say counts too. We have been fortunate enough to have doctors that have allowed us to do that encouraged us. I ask a lot of questions and I capture as much information as I can. Certainly setting goals is absolutely necessary for us. And exercise is a daily activity for me. And I know some days when I am hospitalized quite on your back, it seems like funny comment, but I make myself do whatever I can. To

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me I think that is helpful for surviving. My case is not typical, that is not what I ma trying to say. And yes, I have been lucky. But I think of the famous golf instructor who is now the part of the Harvey teen ex. And he talked about luck, when a special golfer facing a thirty, forty fifty foot pud across a rolling green, sure the golfer is lucky if the ball drops in. But Harvey's point was – You have got to hit that ball hard enough to hit that hole to give luck a chance. And that in nutshell is I think what we have done. We have done second opinions, we have done clinical trials, we have done exercise we identified the myeloma, doctor who has got lot of myeloma patients, and I have am blessed to have the greatest caregiver on the world Kathleen. So yes we have given luck a chance and that is all we can do. So I thank you and Kathleen thanks you for listening and we really appreciate the opportunity to share our story. Thanks Pat.

Pat Killingsworth : Well, you bet Jim. You know, I just want to share with our listeners a couple things – Number 1 – Jim is one tough little guy. I can say little because I am no, you know NFL flame in myself, but Jim you are one of the toughest people I know. You have been through a lot and you just have a burning desire to live and the story you just shared about your last transplant, I think highlights that point.

Jim Bond : Well, thank you Pat.

Kathleen Bond : The word "stubborn" comes to mind.

Pat Killingsworth : That is a god adjective. Cindy, you know this couple, come up with a couple adjectives of your own.

Cynthia Chmielewski : Also wonderful, like I said before, Jim Bond was the one who saved my life, because it was him who enrolled in a trial of a drug that, they were thinking about keeping them on, and that is when he decided to positively do that trial of a drug that helped me. So I forever thankful to him and his passion for enrolling in trials, because I think that is our future, that's gonna lead us to cure. And I really, I love sharing stories, because every time I hear someone's story I convinces me of something else, and no matter how much I read on the internet and my logical mind tells me that exercise is something that is important and I should be doing everyday, sometimes I get in the habit like – I don't have time. But hearing Jim's story just now about the thing that determined whether or not he was going to have that life saving Allo transplant that he had for his Leukemia, was the fact that he just did the Pan Ohio – is what it's called? – yeah that story is going to ever for live in my mind and every time I think I am little bit too tired or have too much on my plate, I am gonna think of that story. Stories are very very powerful, you know.

Pat Killingsworth : Thank you Cindy. It is very inspirational, when we were in Boston, a group of survivors, we got together in Boston, we do every year for the – Light the night, Yellowless light the night program, and Jim was down and I was down working out in the health club of the hotel, and Jim was, I know that he was on a bike at the other end of the facility, and I walked down, before I got there, I just stopped an watched him, and he was Pedaling at about a half mile an hour. This wasn't that far removed from that transplant, you know, and he was sitting there and just slowly making those pedals go around. Seriously, Jim I bet you were pedaling at, I don't know 15 cycles a minute or something. I mean he could barely push those pedals, but you know what, the guy was on the bike, pushing those pedals, no matter how slow, as hard as he could. And I think that really hit me, I will never get that image out of me Jim, that was very inspirational for me, just the determination that you had to get back on that bike and be your bike ride and to live and spend time with your family. It is truly inspirational, and I think most of us have Jim Bond stories tucked away someplace.

Cynthia Chmielewski : Yes we do. And the other thing that I wanted to bring to light too, was what Jim – the chemo brain sometimes gets to my way – I think it was Jim that mentioned it, not Kathleen, but one of them mentioned that – sometimes patients are hesitant to move out of town for a clinical trial because of the cost of housing. And they were talking about the American cancer society's HOPE lodge which is such a wonderful program, and you know, I think it is something that we need to bring to light to many patients. Because I know when i was first diagnosed, I wouldn't think of moving because I didn't have the funds. But because the program like the HOPE lodge, it makes it possible. And the other thing that I wanted to mention too – for if the patients are listening in that aren't available – that don't underestimate the available

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resources. There are all sorts of flights – different American airlines, will provide free flight to cancer patients to get them to major treatment facilities, so that they won't have to worry about their, how much do they have to pay for that flight. So, there are resources that are available 120 out there, for us to get to where we need to be so that we can participate in these trials.

Kathleen Bond : Cindy those are excellent points. I don't know if I neglected to say that, when you are in HOPE lodge there is over thirty rooms??? And you stay for free with your caregiver. And its a community feeling where everybody is in it together and its a wonderful home away from home, and that is really what drives me Pat to keep cycling, as I have been fortunate to have access in where I live and where I have been able to go. But other people I know have not, and I have seen the results of not getting the leading treatments that are out there and so I am committed to giving others, the kind of chance that we have had, and I will keep cycling as long as I can.

Pat Killingsworth : And I know we all appreciate that. I was gonna Ask Kathleen, Kathleen are you still on the American Society board of directors?

Kathleen Bond : I am for our eastern division, which is a, we have 11 divisions for American cancer society which is Ohio and Pennsylvania.

Pat Killingsworth : IS the HOPE lodge part of that program?

Kathleen Bond : Yes. we have 4 HOPE lodges in our eastern division. There are 2 in Pennsylvania and 2 in Ohio.

Pat Killingsworth : Now that's great. Can you add anything more about that program, have we missed anything?

Kathleen Bond : I think Jim said well. It gives you access to care and its no cost lodging. And often times the patient is in the hospital, the loved one, caregiver stays at the lodge. And it enables the patient to know that their caregiver, loved one is in a safe place and is finding support among the other residents of the HOPE lodge. You can't make reservations like a hotel. You do have to be referred through the hospital. Usually it is the social worker and there is no income requirement. Its really who needs a place to stay. And I talked to lot of people who admit the difference in their treatment, because they were able to go out of town to access leading edge treatment and more access the clinical trials, that they don't have in their little hometown. They don't have access to it but they can go to one of the major cancer centers and be in a trial that can save their lives. So there is a magical thing that takes place at these HOPE lodges, it is great.

Pat Killingsworth : We have a beautiful facility here adjoining Moffitt cancer center in Tampa.

Kathleen Bond : Yes, I know that there is two in Florida, I guess there is 3 in Florida. So Florida has got 3, and actually the American cancer society will be building more of these and are looking to build them near major cancer centers, because that is where a lot of people need to go for the latest treatment and for the clinical trials. So there will be more coming up. There is about 5 more on the drawing board right now across the country. But it is a wonderful program.

Cynthia Chmielewski : That's wonderful, Yeah. And that's why I wanted to highlight that, that is why they call it the HOPE lodge. There is Hope for people who are out of town will be able to access treatment. And before I was kind of wooshy washy, and I was saying, I looked this up online, the names of the air free medical transportation are called Angleflight, and South West Airlines also does medical flights, and there is also something called core group, support group Angle network where there is a corporate jet and you are going to an area where could go, you could get a free space there. SO there are resources out there for patients that really need to help where they need to go.

Jim Bond : Excellent points.

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Pat Killingsworth : I wanted to note that Jim mentioned that he had graft vs. host disease, the reaction in his eyes and Jim and Kathleen were kind enough to forward me some information about it, and I believe it was either the beginning of this month or last month, I wrote a pair of post about that on my blog, highlighting, I mean some of the amazing thing, not only things that Jim had to go through but the help that you received when he was up in Boston. Who wants to jump in and tell us about that?

Jim Bond : Yeah Pat, I would love to. There is really two places, and how did I get to these places, simply by asking questions of my team here in Cleveland, and listening to their answers and then as Kathleen said, she did a little bit of research on who the mains were that we were given, and she was able to find out, and you know what, all these people were trained up in Boston. And we zeroed in on the guy who is doing all the training on ocular graft vs host, and he was at Mass eye and ear Institute, which is affiliated with Mass General Hospital. And I saw him, and he gave me some stuff, and it helped a little bit, and he said, okay, you are ready to try these prosthetic devices that I wanted to hold up, because its gonna be hard for you. You never wore contacts and its other suburb, and this place is called the Boston Foundation for sight. And there, you can google that and you can go to bostonsight.org. And I want to tell you if you got my problem which is a cornea problem, very dry very scratched up cornea from the graft vs host, it was life changing for me. And it took me 3 weeks and Kathleen had to learn how to insert and remove these things everyday. But again its determination perseverence and you know, you go through it and is worth it, because now I can see. And it will be much easier to ride my bike this year. You don't have to follow somebody.

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Kathleen Bond : I have to tell you Pat, Jim riding that bike last year, I didn't realize how poor his vision was. And it shakes me up to think how he made it. But he got lost a few times, and now I know why? But again he was pedaling very slowly and there were times I didn't see where he could keep the bike upright because he was pedaling so slowly, well it turned out to reasoning with pedaling so slowly, because he could not see and didn't want to hit something on the pavement, because of the fact that his vision was so poor was causing him to really slow down, so it was amazing how he managed to get through these 4 day of bike riding that he did.

Jim Bond : with medical sciences out there, and its really, I look at our part. I said i like to be a equal partner with the medical team, we like to be. I say it my responsibility, our responsibilities. You know we have got to advocate for our own cause. And it was time to say hey I can't see I need to do something. We don't wait for somebody else to come and say, here is your answer. You know we get on it, and we treat it like anything else. We would make it a project and what is out there is totally is startling to me. I mean medical science has done so much and we can do a lot by knowing our case better than anybody, because we live our case. So we can really help that medical team by getting in there and doing our bit and like Kathleen said – You make these relationships out of talking to the second opinion guy or gal, you stay with them.

Kathleen Bond : Yeah, it is a resource, its a great resource. You contact them and want to know more information about something, you know have they heard something, its really part of another thing that I think is very important, is keeping your eye on the horizon. Always know what is out there, because there is new things coming up, there is, you know things they are finding out all the time, and we are in a good place right now, but we are never complacent. We always make sure we know what is on the horizon, so if Jim's disease becomes active again, we know who we are gonna call and what we gonna talk about.

Pat Killingsworth : ???? have to do some heavy lifting and the caregiver, right? its amazing and its not fair, you got cancer and then you are supposed to be an expert in your field so to speak and take 3weeks to try and learn how to use the devices that can change your life. Its a lot of work its hard. Its just really hard, and you make it sound easy, but its not.

Kathleen Bond : You are right, none of this is easy. Jim Bond : No Pat, its very hard, the transplant is hard and 4 of them were very hard, the Leukemia one was harder than the myeloma ones, because of the drugs they gave me to get me ready. You know 75 days consecutive in a hospital is no fun. But ?? to your exercise comment Cindy, my transplant doctor told me – he said Jim the reason you got through this is because you made yourself get out of bed everyday. On days you didn't feel like it, you did, and some days that wasn't a lot of walking but… Some days it was just getting up and sitting in a chair in the room, that was the highlight of the day.

Jim Bond : But we have been asking, we volunteered to be on the local cancer advisory board here in University hospitals in Cleveland and when they build a new cancer center, one of the things we pushed hard for, and they decided to go along with is – there is a workout room on the transplant floor.

Pat Killingsworth : That would be great.

Jim Bond : Its there, and there is some restriction to when you can use it. But everyday I was allowed to use it. I was on another stationary bike Ped or a treadmill. But my transplant doctor tells me this is why you made it through. And he has asked me to speak to other folks going through transplants about exercise. I am just committed to it. Some days I don't feel like it but I do it anyhow.

Kathleen Bond : This doctor actually ?? to get other patients on this floor to get out of bed and walk the hall like you have done. They would all be better off. That was pretty stunning getting up and moving your body around. It does help your body understand, hey I am supposed to start working and fight this thing.

Jim Bond : Another comment that shocked me from my first and long-time 10 year oncologist here in Cleveland. He said Jim, I know you have done a lot of things and drugs and clinical trials and that is great, but he said – One of things I think is leading reason why you are alive today – is you are the most compliant patient I have ever had. And this guy had a long career as an oncologist. And I was shocked, I said – you are kidding. Other people don't comply with what they are supposed to be doing? And he said you would be amazed. For words worth, I mean taking those drugs when you are supposed to and doing what you are supposed to do, I mean I am not the most go along guy in the world, but once I agree to something, by Gosh, I am gonna do it and he noticed that. And I was shocked when he said other patients don't do that. So, for what its worth, I mean, there is one oncologist who I have a high degree of respect for things that was crucial to being alive.

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Pat Killingsworth : Very worthwhile advice. Cindy I was gonna ask you, how are you doing?

Cynthia Chmielewski : I am doing pretty good. To me it is very very boring. I am always the same. you know what I am saying. But instead I am learning to accept that stable is good and what I am doing is keeping me work fair and I am Not gonna complain. So I am doing good right now.

Pat Killingsworth : That's great. I thought your numbers have started creasing up a bit.

Cynthia Chmielewski : They did and then they kind of stabilized there and then they went down and you know – my doctors told me that when you go up from a – 935 my M spike was around at 0.4 and went up to 0.5, they say, you know it went up, but they tell me not to worry. Of course you know I worry a little bit, but it stabilize at 0.5 and that is where it is, and it hasn't moved since then, so you know I stopped with thinking it was going to, and once again that is where your docs put some confusion??? they were thinking it was the beginning of a trend. It wasn't the beginning of the trend as for me, you know, I was advised and I was pretty good. Yeah, I have appointment with one of my specialist this week, you know, because we are trying to think, and that's where the question is now, I speak to doctors and sometimes they agree with each other, and sometimes I am the one that has to make you think, and sometimes that is hard, you know what I am saying, because, these are big doctors in the field. They are specialists they are the ones that write the papers and we all know, not everyone agrees on everything and I ma just learning that. And I am the one that has to make that final trace and my doctors are going to be upset with me if I do not follow his directions, and I could still stay their patient, you know. And it took me a while to feel that way, however Jim does that ever occur that your doctor recommended one thing and you decided to go another way.

Jim Bond : Yes that has happened a couple times. Once I mentioned the doctor here who is very good, did my first 3 transplants. He said time to go to a hospice. He said don't waste your time finding opening on that clinical trial, and I disagreed and he was miffed, but I didn’t care. Second one that comes to mind, is a I found out that my hip knee replaced and it was 435 because of long term use of steroids, according to the hip doctor. I challenged my doctor from then on, on every regimen I had. They always wanted to throw a steroid in the mix, and I said what if we try without the steroid and see how I do, and we can always add these steroids if that doesn’t work, and I got pushed back on that. And I got the doctor to say I don’t agree with you but I don’t think you are gonna kill yourself but I will let you know if gets to the point where I think you are really endangering your life.

And then the other one I can think of is where he wanted to take me off one drug I was on. This is long way out like, around 18-19 years, and he wanted to take me off one drug and put me on another and I said, wait, before we do that, what if we increase the dosage of the drug I am on, because what I look at, like Kathleen said -This is a Marathon, and I want to keep as many things available down the road as I can, so before I jump off of the drug I want to try increasing that drug. And got pushed back, but guess what it happened to work, and I got more years out of that drug at a higher dose. So, yeah, I have disagreements and yup, you got to worry about loosing the relationship but, this is not like fighting dandruff. This is our lives, so I am happy if I ruffle some feathers if I think its gonna do something to give me more time with Kathleen and the kids and grandkids, I will do it.

Kathleen Bond : A point that Jim just made I think is really a good one. We always want to know if we do this, does doing this knock us out of other options, and we always ask that question, because we don’t want to pick something or decide something, knowing you just knocked out three options you could have had, had you not done that made that decision. So we always ask that question and we kind of feel like, we got to ride one horse as long as we can and then jump to another horse if we need to. And that is kind of how we have viewed this. And I can give you and example of, again when Jim was up against his doctors telling him to go to a hospice and we weren’t gonna hear that, and we found out what options were out there, we found out about the one drug that was in trial, we got in that trial, but Jim was so sick, he was running a very high fever, his kidneys were starting to shut down. Jim barely got in the trial. And was by the skin of his teeth. Well we had to go to Boston, we had very little notice, we quickly had to leave our town, because the only place this trail was open in the entire country was in Boston.

And as soon as we got to the hotel next to the hospital, it happened to be Dana Farber, we were in the hotel, I neatly picked up the phone, called the hospital, because I didn’t think Jim was going to make it through the night and it happened to be the doctor on call was Ken Anderson. And Ken Anderson called me right back and told me what to do to get Jim through the night and he said to me, he said – Mrs. Bond, had anyone told you that your husband is the 7th patient that is been admitted in to our study, and I said no, and he said – well, his study number is 007. And he said I have to believe that is good Karma, and I said – well I hope so. Well, obviously it was, and here we are today but again that is an example of we were willing to just uproot and we were fortunate enough that our kids were grown and we just did it and you know it really comes down to what do you prepare to do, and we were prepared to go that far and do what we needed to do to get over that hurdle, and we did and you know, and I am sure we have jumped a few hurdles since then and I am sure there is gonna be more down the road, but you know if we can keep our eye on the horizon, we will see those hurdles coming and we will be able to jump them. Hopefully.

Pat Killingsworth : Wonderful, wonderful advice. Thank you and yeah we have cancer. There are people who act like they are in-convenienced. And you know Jim make a great point. You have got to attack this thing, you got to fight it and got to be willing to do what you got to do in order to stay alive and I think sometimes myeloma patients and caregivers are loafed in to a sense of complacency because of the fact that we all know that majority of the patients its not so bad, and you get that long honeymoon period that long first remission or stable disease and, it sort of rolls you into a sense of complacency but there is this hard and its life and death stuff.

Cynthia Chmielewski : The other thing that I wanted to mention because, its something new that’s been on my mind. I heard Jim mention that now because of anybody that has a transplant they have to be very careful with skin cancer and he has had a few of the squamish cells removed. Then I heard him mention that

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because of long term use Dex, he needed a hip replacement, because the Dex wares away sometimes at your bones and then had graft vs. host disease – the ocular one, and the one thing that I have been hearing a lot about lately is the survivorship program, and you know – I do not believe in January of 2015, the medical institutions, the cancer institutions are going to have to provide patients with survivorship plan where it will be a plan that has your name has your treatment that you have been taking and because of these treatments it will be saying things that you should look for, the other types of doctors that you should be going to and also included in that survivorship plan will be things specific to you, things that may be, was there because you were on Dex, you need to look more carefully into sugar and what your glucose levels are. So, this is something that, I think its a new term that is bouncing around a lot and Kathleen, do you know anything more about this, have you heard about this survivorship plan.

Kathleen Bond : In fact I have that as a note in front of me to bring that up. I am glad you did. I have been in some discussion with the American Cancer Society and national office about survivorship plans and it is something to ask your doctor about and patients, I think you can go to cancer.org, and they will give you a sample of them, and you can find out more about them, but its hugely important because after Jim had been through, I don't know which transplant 2nd or 3rd, I can remember saying to him, while you know, everyone is so busy chasing multiple myeloma, who is to say you don't have a polyp in your colon that needs to be checked on. You know, so I said to Jim its time, you are at the age its time to get the colonoscopy, you know there is things that you need to follow up on while you are chasing around myeloma and certainly from the treatments from the disease, there are side effects, but if you know to look for these things down the road, you can mitigate them as you encounter them, and having that survivorship plan helps you and the doctor keep on task. Because there are people that don't understand that you do need to have your skin checked because you had a transplant. There is all kinds of things that you need to followed up with, and having that is a really valuable plan and plan of action if you do have something that comes up. So I know that a lot of cancer centers are implementing needs and it is certainly something to discuss with your doctor. And you can go to reputable websites to find out more information too.

Jim Bond : Its really I think a happy problem to have because frankly because when I was diagnosed back in the dark ages '92, I really was hoping for 5 years, that was my real hope, and here it is 22 years later, because we are at a position because of a novel drugs, the advances that has been made. People entering clinical trials, we have the luxury of having to worry about skin cancer and having to worry about hip replacements but lets face it. I mean keeping us alive is the job one. So I am okay with my oncologist missing some of these things, again I looked at my self, and I say okay, what can I do. And yeah, its number 1 some of these things luckily, but that is really why we are so anxious to help others. And anybody can contact me anytime they want. Its out there, you don't need my permission or anybody else's, because we can do this, we can empower ourselves, and I think its our job. And our oncologist had a lot on their plate. They are keeping us alive, and good for them, and I applaud their effort. So it really is a great example of team-work and that's the point where we strive to be with medical. And that includes the nurses in the lab.

Kathleen Bond : I was just gonna say that, the nurse practitioner the oncology nurses are just God send, because they can help you with a lot of that survivorship plan type detail, and things to look for things to follow up on. But it really is a prt of family caregiver and the pateint to be aware some of these things and its a lot. It can feel very overwhelming, all the things you have to think about. Fore-warned and fore-armed and you can get after it, you need to.

Cynthia Chmielewski : Yeah, Like you said before, I think its a press education too is to be involved and ask – is there a survivorship plan for me – because I know there were times where I go to the doctors and sometimes they don't give me something and then when I ask, they are like – oh yes we know this – they just don't think about it. They have other things on their mind, maybe they don't have a ?? – I need to do this I ned to do that. As a patient to come with those questions, to come with those concerns, because I think they are more than willing to help you and accommodate you.

Kathleen Bond : Absolutely there is no point that we go into Cindy, that we don't have written down questions that we are gonna ask the nurse or doctor. And I have been known to take tape recorders many

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many times in what may get permission from the doc and all that one have to make sure they give me permission. I am working on that one, they are still out there. But that is how we catch the information. They are like nuggets of gold what we hear these guys say. They are in a hurry and they can always repeat them. But by Gosh, we are going to keep at them to understand them. That is our job and we are really in a position to be able to do it and look forward to helping others.

Pat Killingsworth : Cindy could you email me some information on survivorship plan, I would love to do an article on that

Cynthia Chmielewski : Sure, I will email you, but I have it. I believe that it is just coming up this. Its something that is coming up. We had someone to talk to about this survivorship plan in our last meeting. So I will get in touch with you. Another good websites for now as patients, until the doctors in the hospitals get these plans in order, its called – Oncolink.org and it is powered by university of Pennsylvania. But on their website they have these links to the Livestrong Careplan and the live strong care plan is that you can up with your own survivorship plan. You click on the link and you write down you know what medications you were on, and things like that. And based on the input of information that you put in, they will print something out for you – mine was 12 pages long. It was the basis for me to start with. I planned on asking my big medical centers what their end purpose with something I had in my hand for me to start asking questions about.

Pat Killingsworth : Thanks you Cindy and I am guessing I am gonna get the.. we are running out of time, heads up from Priya here shortly. So I want to take this opportunity once again to thank Jim and Kathleen for joining us and to remind our listeners – One of the nice things about this format – is you can, tomorrow I will post a link after the broadcast to our on air support group. And Priya will do the same on the Curetalk site. And it is nice, its there for perpetuity, so you can go back if you missed something you felt was important. There has been some really very incredible pearls of wisdom this evening. I really appreciate that. Thank you.

Priya Menon : Thank you Jim, Kathleen. It was wonderful having you here. Pat and Cindy thank you so much for your participation. Pat, thank you so much for inviting Jim and Kathleen. It was truly inspiring, I have been listening and they are really wonderful, and it was great to have here. In our support group meeting for May, we will be talking to dentist and myeloma survivor, Dr. John Killip on Osteonecrosis of the Jaw and Myeloma Drugs. Please visit curepanel.carefeed.net for more information on the show.

We also look forward to having all of you join us on 23rd April @ 6pm ET when we will have Dr. Philip McCarthy on our myeloma broadcast.

We have been hearing the importance of exercise and cancer…and we are working on a show discussing importance of exercise and diagnosis of cancer and some of the clinical trials that are happening with regards to this topic, and it will air some time in June.

For more details of our upcoming shows mail us Priya@trialx.com or you can always visit our website.

The link for today’s show will be sent via email to all participants.

Thank you!

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