Us TOO International Patient Teleconference: Intimacy and Prostate Cancer

Moderator: Elizabeth Cabalka
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Elizabeth Cabalka: Welcome to tonight's program, Intimacy and Prostate Cancer. This program is brought to you by Us TOO International Prostate Cancer Education and Support Network and funded in part by a generous contribution from the Erectile Dysfunction Institute.

We have an excellent program for you tonight with a very knowledgeable panel. The purpose of tonight's call is threefold; first, to provide you with information about the physical link between prostate cancer treatment and impotence or erectile dysfunction, also called ED.

Secondly, to allow you to hear from two couples who have faced prostate cancer related erectile dysfunction and the challenges of recreating or redefining intimacy. Both couples have found satisfying solutions to bring intimacy back into their relationship.

In addition, both couples are featured in the Us TOO International original book, The Circles of Love Collection, available through Us TOO International.

And finally, our third objective this evening is to provide you with an opportunity to ask questions and explore solutions that can bring intimacy back to your life.

My name is Elizabeth Cabalka. I'm a member of the Us TOO Companions and Family Advisory Panel as well as a consultant and author. As I said, we have an excellent panel participating in tonight's call.

Our first panelist is Dr. Arnold Bullock. In 2005, Dr. Bullock was recognized in the publication, Best Doctors in America. He specializes in treatment of prostate, bladder, and kidney cancer, which includes -- impotence issues and solutions. He's also an Associate Professor of Surgery in the division of urologic surgery at Washington University School of Medicine, St. Louis, Missouri.

Thank you so much for being on tonight's call, Dr. Bullock and welcome to the program.

Dr. Arnold Bullock: Thank you; it's my pleasure to have this opportunity to talk on a topic which I think goes unrecognized and unaddressed far too often.

Elizabeth Cabalka: Well, we appreciate your time. We're thrilled to also have Jerry and Jo Ann Hardy on tonight's program. Jo Ann serves as the only female member of Us TOO International Board of Directors and is Secretary of the Us TOO International Executive Committee. In addition, she is a member of the Us TOO International Companions and Family Advisory Panel. Jerry and Jo Ann are active participants in an Us TOO support group chapter near Detroit, Michigan.

Welcome Jerry and Jo Ann, it's wonderful to have you on the call.

Jerry Hardy: Hello everybody and we're happy to participate.

Elizabeth Cabalka: Finally, we're very pleased to have Jim and Maureen (otherwise known as “Mo”) Kiefert joining us on tonight's call. Jim is Chairman of the Us TOO International Board of Directors and Mo is a member of the Us TOO Companions and Family Advisory Panel.

Both Jim and Mo are active members of an Us TOO/American Cancer Society Man-to-Man support group chapter in Olympia, Washington. Thank you for joining us tonight, Jim and Mo. It's so good to have you on the call.

Jim Kiefert: Thanks, it's an honor and a privilege to be here.

Elizabeth Cabalka: Tonight's panel presentation will last approximately 30 to 40 minutes, followed by a 15 to 20-minute question and answer session. If you, our listening audience, if you would like to submit a question for our panel, please press star one on your touch-tone keypad at any time during the call.

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As I mentioned earlier, we have a terrific panel this evening. Our first guest is Dr. Bullock. We appreciate your presence on this call. Thank you so much for sharing your knowledge on the topic of prostate cancer and related erectile dysfunction, and perhaps, most important to our listeners, the many solutions available today.

Dr. Bullock, let's start with the basics. What is the link between prostate cancer treatment and erectile dysfunction?

Dr. Arnold Bullock: Prostate cancer is a very common condition, as most listeners on this program know, but unfortunately, many of the treatments of prostate cancer result in erectile dysfunction. Prostate cancer, in and of itself, should not cause erectile dysfunction, but all of the treatments have a significant risk of causing erectile dysfunction.

Elizabeth Cabalka: Could you talk a little more about the physical function and the treatment process?

Dr. Arnold Bullock: Yes. So first of all, I think that what I'd like to start off with is just defining some important terms -- to make sure we're all talking about the same topic. One of the problems with

erectile dysfunction is that most patients will not bring up erectile dysfunction to their healthcare provider.

Unfortunately, even patients with a history of prostate cancer and prostate cancer treatment, most healthcare providers won't introduce the subject of erectile dysfunction. It's just one of those subjects that both parties should understand there's a significant risk for the patient to have ED, and due to each side being uncomfortable, they just don't bring it up.

They just don't talk about it. And so, in order to be treated, you have to make sure that you and your healthcare provider are talking about the same problem. Erectile dysfunction is just one of many male sexual disorders, so some of the men will come in and say that they have erectile dysfunction and really what they have is failure or inability to ejaculate.

After radical prostatectomy, they're making an ejaculate. The prostate is an accessory sex gland that makes the majority of the males ejaculate and that man may have good erections, but just because he's not ejaculating, he says he has ED. So, to clarify, ED, erectile dysfunction, is the inability to achieve an erection that's satisfactory for sexual activity.

But all of the treatment options for prostate cancer have similar threats. What are the treatment options? For instance, a radical prostatectomy. In the best of hands, Dr. Patrick Walsh , who invented the operation who is at Johns Hopkins, reported that he had around a 70 percent chance of men regaining erectile function.

So that means at least 30 percent of men don't regain erectile function after a radical prostatectomy, and again, that's in the best of hands. I would say that around the country, most practicing urologists, at best, have a 50 percent return of erectile function after a radical prostatectomy.

And school is still out as to what the rate of regaining erectile functions from laparoscopic or robotic prostatectomy. It is still unclear what those rates are because there's still such a large learning curve around the country as urologists learn these new techniques.

Another treatment option is radiation therapy. Half of all men who have radiation therapy for prostate cancer lose their erections within three years. So, even though it takes longer to occur, the risk of erectile dysfunction is actually considered higher with radiation therapy in the younger men than it is with the radical prostatectomy performed by a very experienced urologic surgeon.

And hormone ablation, large numbers of men are still treated with hormone ablation for prostate cancer. These therapies include removal of the testicles, called bilateral orchiectomy, or receiving Lupron or Zoladex injections, or even getting a (Viader) implant in the arm.

This treatment is very effective because it lowers a male's hormone level and the testosterone is necessary for the development of prostate in the first place when us males were in our mother's wombs.

And by lowering the male hormone level, there is not the fuel to allow the prostate to grow, but also by lowering the male hormone level, seven out of 10 men lose their erectile function and lose their libido. So we know that it's not the prostate cancer that causes erectile dysfunction, it's the treatment of prostate cancer.

But just in case there are any listeners on the line who haven't had treatment, certainly you still need to treat the prostate cancer because prostate cancer is the second leading cause of cancer death.

So the person who says, oh, I don't want treatment because I don't want to lose my erections, well, you know, if you don't get treatment and you die from prostate cancer, well, you know, obviously you're not having erections if you're not living.

So still you have to think of the most important problem first, which is managing the prostate cancer and dealing with the erectile dysfunction second. So fortunately, there are many, many different treatment options for erectile dysfunction. Many of the men after treatment who can still get some degree of penile fullness might respond to oral therapy.

Studies have shown that drugs like Viagra or let me just say the PD5 inhibitors be it Viagra, Levitro, or Cyalis, all of the products that are available, have around a 40 to 50 percent response rate in those men with erectile dysfunction after radical prostatectomy.

Many people think the response rates are similar after radiation therapy, so unless a person has a contraindication like the use of nitrates, nitrates are drugs typically used for severe heart disease and angina, and those drugs are contraindications to the use of Viagra type substances. But short of that contraindication, men with ED should try the oral medicines and there's really little risk or harm in these agents.

A large number of the men, roughly 15 percent, so one in six, one in seven, will develop a headache. One in 10 will have some flushing or stuffy nose, so these side effects are very common, but they're mild and short-lived. I tell men they could have these side effects because I don't want them to think they have an ensuing heart attack or stroke.

The real risk of heart attack, strokes or real complications from these drugs are very low, so most all should try these agents, again, unless they're taking a nitrate or some other indication -- contraindication according to your doctor. Short of the oral medications, there are other options.

There are options that include new suppositories, which is a little pellet that you can slide into your urethra. It's as simple as a man going to the bathroom and urinating. The urine acts as a lubricant. You introduce this pellet just a few (sonometers) into the head of the penis into the urethra, you push a button, release the pill.

If you rub your penis for around 30 seconds to get the pill to dissolve and stand up, you might get an erection in around 10 to 15 minutes, definitely worth a try. There are many doses, but most men need the full maximum dose which is 1,000 micrograms. Then there is injection therapy.

Injection therapy is a wonderful option for men who are already used to giving themselves injections such as diabetics. The needle is the same size as a syringe and needle used for injecting insulin. It goes into the base of the penis, into the corporal bodies, or the erectile bodies of the penis.

Literally, after cleaning the skin with alcohol and injecting the medicine, five to 10 minutes later, that man could have a pretty rigid erection. This is especially effective in men who have had radical prostatectomies, because the radical prostatectomy disturbs the neurologic input, the nerve function to the penis, but the blood flow into the penis after prostatectomy is typically normal.

So these men would respond to this injection therapy very well. And of course, there's a vacuum erection device. That's kind of mechanical. It's a little plastic cylinder that you put over the penis and it's hooked to a pump that creates a negative pressure like a vacuum and it literally sucks up the erection.

The erection is maintained by sliding a ring at the base of the penis and as long as that ring stays on, the erection will be maintained. And it's safe to keep an erection for up to 30 minutes. Thirty

minutes is considered a pretty long time if you think about the fact that most American couples have penile/vaginal intercourse that last somewhere between three and five minutes.

So keeping that ring on for up to 30 minutes, that should be more than sufficient in terms of time. The problem is it's very mechanical and it's not very comfortable for the man. And then last but not least, are penile implants. Penile implants, penile prostheses are fairly simple surgical procedures to do.

There are I would say roughly 100 neurologists around the country who do a lot of penile prostheses. The more prostheses that your urologist does, the better the success rate, and the lower your risk of having complications from this surgery. It's typically done as an outpatient or 23 hours.

You stay overnight one night and you go home the next day. You really should not engage in intercourse for five or six weeks while you heal from surgery. The operation is typically done entirely through a one to one and a half inch incision that's on the front part of the scrotum. After a few weeks, the scrotum is already so (rugated) and, you know, hilly and bumpy that most people can't even see where the incision is and it's extremely effective.

Penile prostheses have a life span of around 15 years. That's a very conservative number. Some will last well over 20 years, and when a prosthesis is in place, this man can stand up absolutely naked in the shower or like a swimming pool and there's no way that someone can tell that he has a prostheses in.

There are many different types, but basically, most prostheses entail there being a little small pump in the scrotum that sits somewhere between the testicles and two cylinders, small little inner tubes that line the portions of the penis that would normally fill up with blood.

And then a small reservoir which is hid in the abdomen that holds the fluid so that the fluid can go back and forth from the pump into the cylinders so that the erection can go up and go completely down. Penile prostheses are wonderful too, but the first step in treating erectile dysfunction is having an open discussion with your doctor.

Not all doctors are going to be comfortable discussing erectile dysfunctions, but if they aren't, they should at least know a urologist in your area who is comfortable and a specialist in this area who can -- to whom you could be referred.

Elizabeth Cabalka: Sounds like, as you said, letting go of a bit of the embarrassment or emotional response to the challenge is the first step.

Dr. Arnold Bullock: Absolutely.

Elizabeth Cabalka: Having a discussion that's frank, becoming educated about the options, and having hope. I've also heard people say that a big success tool is being able and willing to explore options, committed to a solution. Would you agree?

Dr. Arnold Bullock: I absolutely would agree. There are a few very important points. Most everyone in the United States over the age of 12 have seen commercials regarding the oral agents for ED, but unfortunately, even in 2004, after all of these products were on the market, only one in five men with erectile dysfunction ever had a discussion with their doctor.

Is that the doctor's fault or the patient's fault? Well, it's both of their faults, especially if you know a person is at high risk. But knowing that, if you don't bring it up, chances of your doctor asking you about it is pretty small.

Elizabeth Cabalka: We **so** appreciate your insights, Dr. Bullock. Will you be able to stay with us for our question and answer session?

Dr. Arnold Bullock: Yes, absolutely.

Elizabeth Cabalka: Thank you so much for laying the foundation for the rest of our call.

Next, we'll hear from Jerry and Jo Ann Hardy about their journey to reclaim intimacy. Again, thank you so much for being on tonight's program and for sharing your inspiring story.

Jo Ann Hardy: You're welcome, Elizabeth. We're really happy to be on the call this evening.

Elizabeth Cabalka: Jerry and Jo Ann, you've been surviving prostate cancer well for six years now. Jerry, you were 46 and Jo Ann was 43 at the time of your diagnosis. Tell us about your diagnosis.

Jerry Hardy: Yes, well, back in 2000, I was in my family doctor's office for a totally unrelated reason and I just happened to mention that I had a little urinating problem, a little backache, so he thought that maybe he should take a PSA.

He had already taken one for a baseline, so when the results came back, it seemed to have accelerated pretty fast, so next in line was the biopsy and that's when the diagnosis was confirmed of prostate cancer.

Jo Ann Hardy: And we were really happy. Jerry's 47th birthday gift was a clean bone scan.

Elizabeth Cabalka: Oh, that's wonderful.

Jo Ann Hardy: So we're happy about that. So like most other patients, we really just started to do a lot of research, a lot of reading about the treatment options for prostate cancer, and by Jerry being so young, we really took our time to do a lot of reading and actually did a lot of doctor shopping and had a first, second and even third opinion before we decided on treatment.

Elizabeth Cabalka: You sound very empowered and committed to finding the best solutions.

Jerry Hardy: Absolutely. Well, one other thing that helped was talking to other people that had the same problems that I have. We were involved in a -- in a support group that helped us tremendously too. That gave us a little confidence and going into this, it was really difficult, but their help really -- their insight really helped us.

Jo Ann Hardy: Yes, we were lucky to land into the support group before we made our final decision, which was a radical prostatectomy. As the doctor said, all of the treatments for prostate cancer have ED as a possible side effect, but by Jerry being so young, we had to figure out like the doctor said, you can't have sex if you're dead, which is a book title (my apologies to the author) but we went ahead and decided to have a radical and we chose the hospital and the doctor. We moved right on and had the radical done and we did it right after Thanksgiving in the year 2000.

Elizabeth Cabalka: Well, tell us a bit about your recovery, Jerry, and specifically realizing that all types of cancer can affect a couple's sexuality and intimacy, share a little bit about your relationship, Jo Ann and Jerry, after Jerry's recovery.

Jerry Hardy: Sure. After the recovery, which took about six weeks, then we started to think about intimacy. We took a long time. We tried the oral medications. We tried the Viagra, Cyalis. Unfortunately, all those things didn't work.

Jo Ann Hardy: It was really interesting. We did go out and give a lot of those a try. Like the doctor said, in Jerry's case, there was a fullness, but not erection satisfactory to complete intercourse, so we went through all of the treatments to continue with treatment options for the ED and it was really kind of a -- we really kept close as far as our conversations about it and talking it through, but it really does get to be a kind of sad time.

We were, you know, literally enjoying our empty nest at the time. My daughter just left for college, so we really just got back to thinking, you know, how we would handle it, what things were available to us, and what we could do.

Now, on the other hand, even though we weren't able to satisfactorily complete intercourse in the same way, there really are a lot of fond and intimate things that a couple can do while you're trying to make a decision on where you go after being treated for prostate cancer.

We don't want to make it sound like we were (tooling) ourselves while we decided, but that was something that we did want to look into was, was there a way to restore the ability to have sexual intercourse.

Elizabeth Cabalka: Of course. It sounds like also the journey was to redefine intimacy in a way.

Jo Ann Hardy: Absolutely, to be able to actually take that time just to be together and just really to celebrate our lives together, and Jerry's life and his good recovery from prostate cancer were a good bonding time for us and it's something that we actually enjoyed and we really enjoyed each other's company as we always had.

But really, for us, maybe not for all couples, but for us, the ability to have intercourse was important for us to see if there were ways that we could restore that to our relationship.

Elizabeth Cabalka: And when you did decide to have an implant, did you go about making that decision together?

Jerry Hardy: Well, once again, we sort of doctor shopped. We talked to a few doctors about it. Also, those who had them before I was able to talk to the support group, I actually had a video of the operation, which actually didn't scare me off; it gave me confidence to go ahead and have it. So we did decide to have it.

Jo Ann Hardy: And also, Jerry, if you recall, we went to an AMS presentation where another couple who had had an implant done was so honest and open about their experience and how it had worked for them, and after we went to that presentation, which actually was almost three years after Jerry's surgery, so it wasn't a snap decision.

We did try a lot of things in the interim period, but after we actually saw another couple and talked to them and had a chance to ask them questions, we really decided that it was time to move forward and to find a doctor and schedule an implant for Jerry.

Elizabeth Cabalka: Good for you! Now tell us about the surgery and Jerry's recovery period.

Jerry Hardy: OK. Well, I was in the hospital overnight. The recovery took about four weeks. There was quite a lot of swelling. I was wondering what have I got myself into, but the swelling went down and after about four weeks, I went back into the office and learned how to manipulate the implant and we took it for a spin.

Jo Ann Hardy: Yes. If I could add right there a little bit, this is not the sort of procedure that a couple would have without really discussing it and really planning to do it together. I could imagine some spouses or some partners that would have a hard time wanting to engage in this activity or trying to learn how to use it, if they hadn't been a part of the decision-making process.

So I can't emphasize enough, right, how to communicate with your partner and this is really a good decision to make together. I don't think it's a good surprise like, “hey honey, guess what I decided to do, or worse, hey honey, guess what I did while you were out of town.”

So you need to decide to do it together and I think that the success rate increases with couples that actually do decide together and do take that part of the journey together as well.

So like Jerry said, after I think maybe six weeks, he went back to work and the healing was complete, we decided that we'd both take a run for it. Maybe I held the instructions while Jerry tried to pump it up or whatever and it's been working fine ever since.

Elizabeth Cabalka: Wonderful! Now, how has the implant enhanced your sexual intimacy?

Jo Ann Hardy: Well, like I said, it was for us, and maybe not for all couples. I think you really need to look at your relationship and how you want it to be and for us, the ability to have actual sexual intercourse again was wonderful for both of us.

It was an important part of our lives and we were happy that there were medical procedures that were available that would bring that part of our relationship back and help us restore that. So we've been extremely happy to, you know, to be able to do that again and great.

Jerry Hardy: And the physical part of it, it's a natural feel. It's easy to operate. It really works well and we're happy we did it.

Elizabeth Cabalka: So what does the future hold for you two?

Jerry Hardy: We hope more of the same. We're really enjoying it very much.

Elizabeth Cabalka: Good for you! You know, what I hear when I hear you talking about your journey together, I would imagine that there is also some level of intimacy in simply sharing the journey, by talking about it, by experiencing it together, by trial and error. There is a certain level of intimacy in that journey together as well.

Jerry Hardy: Well, absolutely. It's just part -- it's just part of being married. You go through the good times, bad times, and it's all part of growing.

Jo Ann Hardy: Yes, and you make it work, and one of the most wonderful things we get to do, Elizabeth, is to be able to talk to other couples that are going through similar things.

It's so important for them to see that there is hope available and to see a couple that may be rather young for this prostate cancer journey, to see the way that we've handled it in our lives and to be able to just offer that whole inspiration and let people know that there is something out there.

And virtually all men, as the doctor said, can be treated for ED and everybody won't immediately decide to have an implant or maybe the implant is not for everyone, but for some men and some couples, that is the answer.

Elizabeth Cabalka: Thank you so much, Jerry and Jo Ann. No doubt your story will provide hope for other couples facing similar challenges.

Now finally, I'm so pleased to bring you dear friends, Jim and Maureen Kiefert. We thank you so much for your time on the call tonight!Now, you two had been married less than two years when you were diagnosed. Tell us about that.

Jim Kiefert: Yes. We both had children that were raised and gone and so it was this empty nest and whoa, did we make a nice nest. And we were very sexually active. It was really great and I happened to be diagnosed because at the time, I had to have a physical exam for part of my job and in 1989, there was a new test out there called the PSA.

And of course, my wife who loves me dearly says, now you check his blood sugar and you check his cholesterol and you check his, what is this PSA stuff, do whatever you have to do. And thank God she did because my PSA came back at 19.

And we went through the same process of having a digital rectal exam, the needle biopsy and this was -- I mean, we were newly married. We had moved to a new job and a new home, a lot of new things in our life and getting diagnosed with cancer was like a 2X4 between the eyes. But back in 1989, there weren't a lot of options. There was radical prostatectomy and external beam radiation and so we decided to start reading and investigating. We bought a lot of books.

We thoroughly researched every one of the options and its side effects and said, the most important thing for us was to get the cancer out of me. And I had my radical prostatectomy and the PSA came back and they said, gee, I'm sorry, we must not have gotten it all because your PSA didn't go down.

So I had 35 sessions of radiation and we followed up and the PSA still never went below 0.2.

I go to every appointment with my wife. One of the things Us TOO emphasizes is that when you go in for an examination or especially for getting results of a test, always bring somebody with you because you're going to not hear everything.

You need to have a partner who can hear the other things. We even suggest taking a tape recorder along with you because when that doctor told me I had prostate cancer, I couldn't tell

you what he said after that. And I'm sure my wife also went into that same trauma of, oh my God, he's got cancer and you always think you're going to die when you hear that kind of a diagnosis.

So we went through all of this and the doctor called me and he said, we didn't get all your cancer. Your two treatments have failed. You may have one to three years. Why don't you get your life in order and we set out to prove that he was not right. And it's been 17 and one-half years.

Elizabeth Cabalka: My word! Now, clearly the fact that you're on tonight's call, your prostate cancer treatment must have impacted sexual function. How did that impact your relationship mentally, emotionally, physically?

Jim Kiefert: After the radical prostatectomy and the radiation, they did have to remove part of a nerve bundle and there weren't any oral treatments available at the time, so we talked about how important it was to have an erection or not.

Well, it was interesting because our journey into intimacy started when I was in the hospital recovering and my wife came in and at 2:00, she just shooed everybody out of my room and she brought a white linen tablecloth, we had tea and we had some cookies and we made a ceremony out of our recovery.

And we started this discussion about the value of our relationship and our life and as we talked about my sexual function, my biggest fear is if I'm not able to have an erection, is my wife going to leave me? She's still here.

Maureen Kiefert: She IS still here. For me, I was so surprised at his fear and I will tell you that it took a long time to convince him that I was there for the long haul, but really, the change of our -- our definition of intimacy really changed.

I heard Jo Ann say that what they were really interested in was celebrating their life together and that's exactly what Jim and I wanted to do for every hour that we were a couple. And we know that change happens.

Change happens in many ways and this was just another way it was going to change for us because things like oral medication didn't exist and nobody talked to us about it, we just sort of followed through on our own.

So we just, through other things that we began doing and certainly those things Jim talked about in the hospital, began reading on a daily basis to one another and just finding out what we meant to each other. That really helped redefine intimacy for us.

Jim Kiefert: There were things like -- and I -- in a very intimate way, when we were preparing for intercourse, we did a lot of touching and talking and wooing and when I wasn't able to get an erection, we talked about this, about how gratifying all the talking and the touching and the wooing and closeness, how wonderful that was as far as satisfying ourselves intimately.

And we explored a lot of different ways to touch each other, to be with each other, and we have a whole bunch of little ceremonies. And one of them is -- it's kind of cute because every time we take a shower, the other person comes in as soon as the water stops, you bring a towel, you get a kiss, and then you wipe their back and you kiss them on the back and you give them that wonderful gentle touch.

And we have all kinds of beautiful little intimate things like that that have been so satisfying and gratifying for us.

Elizabeth Cabalka: And it sounds like, through it all, you kept the lines of communication open.

Maureen Kiefert: That really was the big thing. We were always good communicators I think, but we really became huge communicators after that.

Part of the problem that Jim ran into is that on his job, he really needed to -- he changed jobs right after his surgery and they didn't know about his cancer treatment, and we needed to keep that quiet for fear of his not being able to have that job, so there wasn't anybody that I could talk to at that time either.

There was no Us TOO group, so we had to talk to each other. We were forced into it and that was a really great lesson for us. What we learned is that there was nothing, after this, there was nothing that we couldn't talk about.

Jim Kiefert: And then we got involved with Us TOO and one of the things about Us TOO is if you want to find out what it's like, if you want to know what the road ahead is like, talk to someone who's coming back. And I went to it and attended a lot of support groups and it was great.

Elizabeth Cabalka: Wonderful! It sounds like you're very committed to keeping intimacy alive and exciting in your life, and redefining that regularly.

Maureen Kiefert: That's the key. It's redefining it regularly. We have great fun. We do a lot of work separately, but a lot of work together and just we enjoy being with each other. We're living right now in this little 400 square foot park model here in Tucson, and loving every bit of it, so I think that sort of describes intimacy pretty well too.

Elizabeth Cabalka: Indeed! Oh, I thank you so much for sharing your story tonight, Jim and Maureen. It's always a pleasure speaking with you. Thank you for sharing your story and your insights.

Maureen Kiefert: Thank you.

Jim Kiefert: Thank you.

Elizabeth Cabalka: Now it's time to hear your questions. Before we do that, I want to acknowledge Terri, a member of Us TOO International's incredible support staff. Thank you for helping us with this evening's question and answer session, Terri.

Terri: Oh sure, Elizabeth, and we've had a lot of great questions, so it's going to be kind of difficult to pick out all of them and I hope we can have enough time to answer as many as we can.

Elizabeth Cabalka: Well, let's get to it. Will you tell us about our first question this evening, Terri?

Terri: OK. Our first question is for Dr. Bullock and it comes from David. David wants to know if he has an artificial sphincter installed, can he still use a vacuum pump or injections along with that?

Dr. Arnold Bullock: Yes, you can. An artificial sphincter is a device that's used for men who have stress incontinence. An artificial sphincter has a cup that goes around the urethra, but it's pretty far back at the level of the scrotum and there's a little valve or reservoir that's in the abdomen.

So using injection therapy, it really shouldn't be possible to hit the tubing, so you can use a vacuum pump or injection therapy without risk with an artificial sphincter. Obviously, if you have a penile prosthesis, you don't want to go sticking a needle into your prosthesis.

Elizabeth Cabalka: And do I understand correctly, Dr. Bullock, that oftentimes incontinence and impotence are related?

Dr. Arnold Bullock: Yes, that's right. Incontinence is also -- stress and continence is also one of the risks of a radical prostatectomy, but incontinence associated with radiation is usually due to an

overactive bladder, one of urgency. Men have an inability to suppress bladder contraction, so unwanted bladder contractions.

Those are typically treated with medicine. Many of the men will have an artificial sphincter and a penile prosthesis put in at the same time.

Elizabeth Cabalka: Excellent solutions for two challenges.

Dr. Arnold Bullock: Yes.

Elizabeth Cabalka: Terri, tell us about our next question.

Terri: OK. Our next question comes from a couple, Martin and Debra, and Martin and Debra want to know, Debra still has her libido and Martin has absolutely no sex drive whatsoever and they just want to know -- I guess this question would just be -- you know, would be directly to Jerry, Jo Ann, and Jim and Moe.

How can they -- what can you suggest to achieve more intimacy and how can she help to get him into the mood?

Elizabeth Cabalka: Who wants to take that? Jo Ann?

Jo Ann Hardy: Sure. I should just clarify this, Jerry didn't have a libido problem. It was purely the erectile dysfunction problem, but I think that really a lot of the picture is the same.

It's just communication, and also I suggest that they really talk frankly with their healthcare provider and they're really -- I'm certain that in the gentleman's case, that there is treatment that will help with the libido issue as well.

But just open communication and just talking together and sharing some special moments together will kind of help bridge that time until maybe there is a medical solution for the problems that they're facing. I wish them very well.

Maureen Kiefert: I guess in our case too, Jim's libido sort of dropped, particularly once he was on hormone therapy, but we had had some time before that to do some readjusting and I guess it again was through, quite frankly, through prayer for me and just rethinking things through about what was most important to me.

And so I had to do some work on myself about, think to myself where he was, and again, remembering that this was a long time ago before some of these options were available. So I really agree with Jo Ann that -- to talk to the doctors and let them advise you.

Elizabeth Cabalka: Since we have a physician on the panel here, Dr. Bullock, I want to ask you, are there currently medical interventions for increasing libido? Or what do you suggest in this scenario?

Dr. Arnold Bullock: Well, many of the men with prostate cancer have decreased libido if they're on hormone replacement therapy. Your libido comes from your male testosterone and the hormone ablation or hormone therapy is designed to lower your male hormone level. It's sort of a missed term.

We aren't really giving you hormones, we've giving you medicine to lower your male hormones. And so a drop in libido is expected. I think the best way of dealing with it is to have a man come in along with his partner and to make sure that the partner understands that his libido is going to be suppressed.

He may still be able to achieve erection, he just won't think about it. And so it won't bother typically the patient because he doesn't have a libido, but the spouse is the one who really in this situation would you might say suffer.

Therefore, if the spouse understands this and sometimes the roles are reversed, the spouse has to be the one to initiate things, usually the husband will follow along. Unfortunately, there are some men who are given testosterone.

I've seen situations where a man is getting Lupron to lower his testosterone by his urologist and he's seeing his internist who is giving him testosterone to help with his libido. That's why it's very important for you to be knowledgeable about your own disease.

But certainly, you really would not want to be on testosterone replacement therapy without seriously considering the potential consequences.

Elizabeth Cabalka: Thank you, everyone, for addressing that question. Terri, can you tell us about our next question?

Terri: OK. This question comes from Becky and it's for Dr. Bullock. And she's wondering what are the differences between Viagra, Cyalis, et cetera, and how can you decide which one to take?

Dr. Arnold Bullock: Yes. Well, they are different drugs. They all have different patents and so the drugs are different, but Viagra and Levitra are fairly similar in terms of the general effect. These agents have very rapid onset. They achieve maximum concentration in your blood in about 40 minutes.

At least half of the patients say that these drugs are effective and as fast as 20 to 30 minutes. The drugs have a - Viagra and Levitra have a half life of around five hours and so you might say that parlays into being actually effective for patients for six to eight hours at least.

So the benefit of these drugs is that they have a very fast onset and are very effective, and most couples have relations only once in a four-hour period or once in a 24-hour period and so the sexual patterns of most couples. Cyalis takes longer to get into the bloodstream.

It takes two and a half hours to reach maximum concentration, but it stays around and has a half life of 17 hours. We all have heard the commercials that say it's effective for 36 hours and that depends on how severe your condition is. Many people feel that if you have severe ED, then Viagra might be your better drug.

But if you have milder ED or younger or might be more sexually active or going away for a weekend, Cyalis might be your better drug. There are some people that use Viagra one day and use Cyalis a different day, which is legal, which is OK and not harmful.

Elizabeth Cabalka: So it sounds like getting the facts about the various drugs and finding a physician that will work with you and educate you on these options is really an important first step.

Dr. Arnold Bullock: Absolutely, yes. I certainly hate the idea of patients getting drugs from friends who don't really tell them the proper way to take a drug or even some doctors who give patients all three drugs without instructions because the proper way to take all three of them is different.

Elizabeth Cabalka: Thank you so much. Terri, tell us about our next question.

Terri: OK, Elizabeth. The next call, this call is from Jim and it's for -- probably anyone on the panel could answer this question, maybe just through experience, but his question is, he's two months after his surgery.

He had the radical prostatectomy and he's finding that orgasms are helping his incontinence and he's wondering if having orgasms, even if he's not having erections, is something that might benefit him in the future to achieve his erections later on?

Elizabeth Cabalka: I'm going to suggest we start from a medical perspective and then perhaps move into the experience of the couples.

Dr. Arnold Bullock: OK. Well, having sexual activity and achieving climax orgasm is perfectly OK. You're not hurting yourself by doing that. This really doesn't have anything to do with your incontinence, but if in your case, you think the more you have an orgasm, the better your continence, than have orgasms. But the two are unrelated.

He is correct, that you can have an orgasm without ejaculating, and that's what happens after the surgery. Doing Kegel exercises is absolutely the best thing that you should do, you can do, and it's what you should be doing for the first several months after radical prostatectomy to achieve your best level of continence as possible.

Elizabeth Cabalka: Very quickly, Kegel exercises are designed to strengthen of the muscle in the bladder area, is that correct?

Dr. Arnold Bullock: The external sphincter muscle is the muscle that's under your control that normally sits below the prostate, so it's the same muscle that goes around the urethra and the rectum in a man, same muscle that goes around the rectum, vagina and urethra in a woman.

So a Kegel exercise is a technique to strengthen, to bulk up that muscle to that it better squeezes on the urethra to keep you dry.

Elizabeth Cabalka: Excellent information. Thank you so much. Now Terri, it sounds like we have time for one or two more questions. What is our next question please?

Terri: OK. Our next question is from Harold and I think this will go along with the libido -- the libido questions, and he has absolutely no sex drive whatsoever. How can he get that back and will he ever be in the mood again?

Jerry Hardy: I'm sure he'll be back in the mood again unless there's a physical problem. Just going through treatment, going through just the trauma of having this disease is going to certainly lower it, but again, communication, talking with your spouse, and perhaps talking with your healthcare provider will certainly go a long way in restoring your libido.

Jo Ann Hardy: And also I would like to add that sometimes what might be difficult to tell is a man that --if he's not having a libido because he can't get an erection is sort of like the chicken and the egg sort of thing, so that's really something you can sort out with your healthcare provider.

If a man can't get an erection, he loses interest in sex, so I think that has to maybe be sorted out as well.

Elizabeth Cabalka: I also heard recently that fear and a lack of information can be an inhibitor to libido. Would you agree?

Dr. Arnold Bullock: There's a thing called performance anxiety and fear of failure and it can happen in patients with erectile dysfunction in general, that a man who is not confident that he can get an erection tends to avoid intimate relationships unless he and his wife have that level of communication.

If you have that level of communication with your partner, then she understands where you are and it's a mutual trial and error thing. It's a mutual let's learn, let's work through this together. It's not as if you're trying to keep a secret from your wife or you're only going to approach your wife when you're confident that things are working great.

So yes, it's performance anxiety and fear of failure, these are definite causes or definitely associated with a low libido.

Elizabeth Cabalka: I love the way you said, 'trial' and, you gently said, 'error', and I think perhaps part of that is redefining 'error'. It kind of goes back to Thomas Edison's thought after trying to illuminate a light bulb and only succeeding after 11,000 different ways of trying. They said to him, "Did you fail?" And he said, "No, I determined 11,000 ways not to light a light bulb."

Dr. Arnold Bullock: That's right. And the fact of the matter is after a radical prostatectomy, it can take a year, a year and a half before the erections come back. The only way they come back is by keep trying.

You want to either take these oral agents or use a vacuum pump or just stimulation on a regular basis, to try your best to maintain the blood flow through the penis and prevent fibrosis or scarring within these vascular chambers.

Elizabeth Cabalka: I'm so sorry to cut you off. I'm recognizing that we need to wrap up our call this evening. Thank you to everyone who submitted questions this evening and I'm sorry that we weren't able to get through more questions. Thank you also, Terri, for supporting this part of the program. It was most helpful.

For additional information about prostate cancer related erectile dysfunction or for further information about some of the solutions discussed on today's call, please call Us TOO

International's toll free line at 1-800-808-7866, Monday through Friday, 9:00 a.m. to 5:00 p.m. Central. Again, that's toll free, 1-800-808-7866.

Thank you for listening to tonight's program. Be sure to watch our Web site, that's www.ustoo.org in the coming weeks for a complete downloadable transcript as well as downloadable audio recording of tonight's call.

In addition, we encourage you to explore ustoo.org for excellent information for free materials and valuable links on many prostate cancer related topics. We ask you also to pay special attention to Us TOO International's new prostate cancer awareness campaign called Sneakers @ Work Day, taking place on Friday, June 15th.

Please help Us TOO International raise awareness about prostate cancer as well as raise funds so we can continue to provide services for survivors and their families such as tonight's teleconference. You can register and learn more about Sneakers @ Work Day by going on line at www.ustoo, that's U-S-T-O-O.org and click on the Sneakers @ Work icon at the top of the page.

Special thanks to our panel, Dr. Arnold Bullock, Jerry and Jo Ann Hardy, and Jim and Maureen Kiefert, for their time and invaluable insights this evening.

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For all of us at Us TOO International, we wish you and your families the best of health. Good night.

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