Introduction:

Andrew Schorr:
Hello and thank you for joining us once again. Andrew Schorr broadcasting live from Seattle, sponsored by the Seattle Cancer Care Alliance. Every two weeks we connect you with leading experts from the Seattle Cancer Care Alliance and always inspiring patients, help you hear a full discussion of important medical topics and really get authoritative information to help you make decisions. Now, in tonight's program it's a topic that really hits home for several of us here on the Patient Power team. Sometimes we're doing programs on cancers that affect women exclusively or more often. Today it is one that affects men: prostate cancer. And I am age 58. I had my PSA test blood taken today. I'll talk with my doctor later, just part of a routine physical, but believe me I'm interested to know what the number is. And then another one of our producers with us today, Ron Kreider, he's 67, he's listening carefully, looking over his numbers and knowing should he make any decisions or have any further tests based on his own results. And then it was my dad who had his prostate removed because of prostate cancer and then had various therapies and then went on and lived a long life, age 92, but eventually died of complications from prostate cancer. So it's something we think about. Will we die? Will we have it? Maybe so. Will we die with it or will we die from it. And how do you make informed decisions on what to do?

So that's really our topic tonight. We're calling it "Navigating Dilemmas Posed By Prostate Cancer Treatment Options," and there are many treatment options. But what are those options based on? Is it based on just what a urologist or urologic oncologist recommends, what they feel comfortable with? Is it what there's evidence for? Is it what's right for your personal situation? So certainly a lot to talk about.

Ted's Story

We're going to meet an expert from the Seattle Cancer Care Alliance in just a minute, but I wanted to introduce you to someone we featured on patient before. He has had to navigate quite a lot with prostate cancer. That's Ted Girgus. Ted is 65. He lives up the road from me in Bellingham, Washington, and he has more
advanced prostate cancer, stage IV. It has spread, and he has had a number of
treatments. Ted, you've been down the whole road, if you will, so this
decision-making and trying to make smart decisions is a topic I know is near and
dear to you, and you recognize there are dilemmas that are posed today, aren't
there?

Ted:
Amen to that, Andrew, and thank you for giving me an opportunity to talk to your
audience exactly about that. I know when I was first diagnosed--well, what
happened, let me take it back. I had gone to my primary care physician for my
annual physical, and at that time a part of the physical was my PSA. And he
noticed that it had gone from 2-plus to a 4-plus. Now, to me that doesn't mean a
whole lot, but to him, he had the courage to say to me, you know, Ted, I think the
best thing for you to do since it basically has doubled, this was 12 years ago,
Andrew, he recommended that I go for a biopsy. Now, he said the chances of me
having it were about 25 percent, based on my age group and the score. Well, lo
and behold, the biopsy, which of course is pathology, proved beyond all doubt that
I did have cancer. The results were told to me the day before my first anniversary
to my beautiful wife, Sherry.

Andrew Schorr:
Oh, no.

Ted:
Yeah. So we had planned a trip so we went on our trip, and we cried a lot and we
were talking about our options. And, you know what, not knowing the first thing
about prostate cancer, I didn't know what my options were, but fortunately, having
my four sons who were in their 20s and 30s at the time, this became a big family
matter. And obviously when a person tells you you have cancer the first thing you
want to do is say get it out. I don't care what you use, whatever you have to use,
but get it out and let's get this rascal out of the way. But then all of a sudden you
calm down and common sense, thank god, prevails, and you're able to really start
to look at this. And about 12 years ago my opportunities were the doctor who did
my biopsy was also a surgeon, so he was very quick to tell me that surgery is really
the best way to go. It has this wonderful survival rate and what have you. And
when you read up on surgery you realize what a major, expensive procedure it is.
Now, it is right for some people because it will add years to your life, but being like
a newlywed at the time I thought, whoa.

You know, prostate cancer, not many men want to talk about it because it affects
us in a most private way. It affects our manhood, so we're really not good about
going out and discussing it, but ever since I have had it I talk to everyone who will
listen because it is important that we work with urologists and oncologists and our
primary care because it--one in six men will be diagnosed with prostate cancer
according to the statistics they have from I think the National Institutes of Health.
It's just, you know, it's just a rampant thing. But then my primary care mentioned
to me his co-doctor just was diagnosed with prostate cancer, unbelievably so, and
he was looking into brachytherapy. And I thought, lord, what is brachytherapy. And that's the seeding which is radioactive seeds implemented in a kill zone placed inside the tumor, and it was a relatively newer concept...

Andrew Schorr:
Back then.

Ted:
Back then, and it was less invasive. They were also discussing cryosurgery back then, and we were looking at cryosurgery as well, which is the freezing of the tumor as well. So my boys hit the internet. We hit the internet. We actually put together a three-ring binder of information, and dad was reading through and reading through, and I finally went back to my primary care physician. And I really attribute not only him but of course my savior for still being alive today. I said to him, if you had it, Doctor, which would you choose? And he said, and remember this was 12 years ago, he said he would probably choose brachytherapy, which I chose.

How to Make Informed Decisions

Andrew Schorr:
Right. I want to skip ahead a little bit because you're framing the issues wonderfully, Ted, and that is that question you asked, Doctor if you were me what would you do?

Ted:
Right.

Andrew Schorr:
So really what our program is about tonight is what's behind that answer. What's behind the answer? And so you chose that, and we'll talk more along the way about how it's gone for you, but that's really the question that gets asked thousands of times. You do your reading, but at some point you look a doctor in the face, Doctor, what would you do if you were me or if I were your dad, you know, whatever the situation may be.

So let's introduce our medical expert from the Seattle Cancer Care Alliance, and that's Dr. Bruce Dalkin. Dr. Dalkin is new to the Seattle Cancer Care Alliance and he is happy to be there and invited to be there because what he has been making a study of, even though he's been treating prostate cancer for 20 years, beyond treating it he's been trying to measure outcomes, what do we base our decisions on. So he's a urologic oncologist, new to Seattle, and now a guest on our program.

Dr. Dalkin, this whole question, as I said, Doctor, what would you do, what are you try to go accomplish with your research, sir, so that men can make informed decisions rather than almost ones based on anecdote?
Dr. Dalkin:
I think that's obviously a great question, Andrew, and the answer is here we are 12 years later after Ted gets treated and can we honestly and accurately answer that question today, and the answer is really, for the majority of people, the answer is no. I think we've been slow to accurately identify issues of what is the best treatment for cancer control, what are the true actual side effects and how often do they occur with all of the various treatments. We now have the method by where to do that, and if we do, can then sit down with each patient and give them an honest, accurate assessment of their situation and predicted outcomes.

I always love that question, Doc, what would you do. And I think the honest answer to that question is until you're in that chair with that problem I don't know that you can honestly answer that question. But one of the deficiencies in radiation and surgical field and medical oncology is we haven't really done a good job of accurately assessing how well our treatments work, and that's essentially what I've been doing with surgical patients in Arizona, and I came up here to do that for the entire expanse of prostate cancer care up in Seattle.

Andrew Schorr:
Well, I think that will be a tremendous contribution to men worldwide. And we don't have a shortage of approaches, I mean, I've done programs on watch and wait or active surveillance. I've done programs on brachytherapy. Now, cryotherapy was mentioned by Ted a minute ago. You do have some feeling about that, don't you?

Dr. Dalkin:
Cryotherapy and brachytherapy are classic examples of failures to measure outcomes. Cryotherapy is a good example of a treatment that's been around for 13, 14 years and we've actually never proven that it's highly effective. Every couple of years we come out with some new instrument or way to deliver the treatment which therefore should be better because it's technology, but in honesty we've never really shown that it's better, or ever that it is an effective treatment. Cryotherapy has seen another resurgence in the last year or two with this concept of focal therapy where you're only going to treat an area that was positive on biopsy and not treat the whole prostate, but that has no basis in outcomes fact either. So I think it's a classic example of technology pushing treatment when really we need to sort of rein it in and say, hey, is this something that really works and what men should we treat ideally, if any, and not just adopt it.

Andrew Schorr:
Now, this program is going to be controversial tonight, and we invite you all to call in with questions and comments.

I want to give thanks to a couple of groups that have been helping us a lot besides the Seattle Cancer Care Alliance. Care to Live, and Ted has been very active with that, and also Us TOO, which is a very active patient advocacy group in prostate cancer. So look, all these things we're mentioning and what you just heard
Dr. Dalkin say, you know, that may not go over so well with your urologist or even medical oncologist. We're going to talk more about it and try to separate fact from fiction. It's all coming your way on our live webcast, Patient Power, sponsored by the Seattle Cancer Care Alliance.

Andrew Schorr:
Welcome back to our live Patient Power webcast sponsored by the Seattle Cancer Care Alliance. I'm Andrew Schorr broadcasting live from Seattle. Now, obviously we're not going to ask Dr. Dalkin to tell you what treatment you should have by you questioning on this program. We're going to talk about these issues that are posed, trying to help men navigate around these dilemmas, posed by all the different treatment options, the different situations.

When Treatment is Unnecessary

So let's go back to Dr. Dalkin for a minute. So, Bruce, every man is different. As Ted was mentioning a significant percentage of men will be diagnosed with prostate cancer, but is the cancer ever going to affect them in any way. And I've always heard if you have older men and if you do an autopsy, their prostate, you will very, very often find that there was prostate cancer there although it had no effect on the man's life. So isn't the $64,000 whether you need treatment at all?

Dr. Dalkin:
Well, I think that in each individual that's diagnosed we would love to be able to have better information that helps us to predict the behavior of that cancer. There is a lot of investigation to try to identify higher risk cancers or more active cancers, but what we have learned, and a lot of this comes from Sweden where they've been very hesitant to treat people until recently, is that in general if a cancer is identified based on an elevated PSA or an abnormality in the finger exam of the prostate that if a person is projected to live more than 10 to 12 years they have a high likelihood of potentially losing life years. Now, a 50-year-old is trying to live 35 years, he may lose 15 or 20 years of life, whereas a healthy 70-year-old who may have a projected survival of 15 or 16 years if they're not treated may only lose two to three years of life. And then if you throw in other medical problems that people have there's no question that there may be overtreatment.

But I like to sort of focus on if you're talking about aggressive therapy on the men who clearly need to be treated, are the essentially healthy men under 65 and many men who are physiologically healthy between 65 and 70. So we are testing and biopsying and diagnosing men over 70, 75. Some of them may have their life shortened, particularly with high-risk cancers, but it's an ongoing area of investigation. But in younger men they're all going to probably have some negative impact if they're not treated. The difficult part is deciding on the best treatment and then making sure that that treatment will be effective.
**Peter’s Story**

**Andrew Schorr:**
All right. We're going to quiz you more about that. I want to bring into the discussion an old friend of mine who is my age. Peter, I guess you're 59, right?

**Peter:**
That's correct, Andrew.

**Andrew Schorr:**
Peter joins us from New York City, Peter Frishauf. Now, Peter, being a really smart guy, has investigated this himself, and I'll let him tell a little bit of his prostate cancer story, but also though he's spoken with doctors around the world many times because Peter is the founder of one of the leading websites to educate doctors, and that's called Medscape. So Medscape is well known. Peter, thanks for being with us. So, Peter, tell us from a personal point of view how prostate cancer got into your life and then how you began to try to figure out what to do.

**Peter:**
My pleasure. Well, I would say it first got into my life when my father at age 75, and this was about 12 years ago, on digital exam had a PSA. This was in the early days of PSA, and his PSA was a very striking 35, and the issue was what to do. And we elected after doing some research to have brachytherapy at the time at Mount Sinai, which did reduce his PSA to zero following therapy, and then gradually increased, but he's now been successfully treated and he's alive and well and healthy at the age of 88 with a combination of periodic hormonal therapy which has always been successful in knocking his PSA down to zero. So he knocks it down to zero and then it gradually rises about a year later and he has another round and it goes back down. So he seems to be one of the lucky people who has the type of prostate cancer which is responsive to hormonal therapy, and it's been a good strategy for him.

Now, my own, I started getting PSA tests back in 1994, and my levels at that time between 1994 and 2000 were between 1.6 and 1.8, sometimes going as high as 2.8. I would have these tests yearly, and they stayed at about that level through 2005 at about 2.4. And then in 2006, in April of 2006 my PSA was 4.7. So that was of concern, and my primary care physician and I agreed that we should do a repeat in 90 days, and that was 4.10. Then we agreed that we should wait another couple of months, and we did another PSA which was 5.75. So it seemed that because there was a doubling from the prior 12-month period that a biopsy was in order.

So I went ahead and at Sloan-Kettering I had a biopsy of 15 cores in July of 2006, with 15 cores, and the good news was that it was relatively negative, and I say "relatively," and this is one of the Never-Never Land results of the biopsy is that ASAP was detected in the right apex medial part of the prostate. So somewhat apparently vaguely predictive, but on further reading and further education it
seems that no one really knows the impact of this. And the recommendation was that I have a repeat biopsy six months later, which was done again. This time I had 14 cores in presumably some different sites, and there again the biopsy was benign with a finding of high grade PIN, prostatic intraepithelial neoplasia, something suspected of being precancer.

So I asked at the--doing some reading about the wisdom of--and knowing that a lot of abnormal lab findings and enlarged prostate and BPH and elevated PSAs are simply the result of inflammation--what the wisdom of going on finasteride might be. And I was told--this was at Memorial Sloan-Kettering--well, yeah. It's a reasonable idea. You might want to try that. And I was a little bit disappointed with the lack of education that I received from the clinicians there, and I made the decision to basically conduct a search for a new urologist. And the kind of urologist I was looking for was one who was no longer doing surgery but was still actively involved in the diagnosis of prostate cancer and following of patients with diseases. Because I was really looking for someone who I could see and pay to think more than to do and who didn't really have a vested interest in doing a procedure of one form or another.

And I did find a good clinician, a urologist at NYU who is no longer doing surgery, and we went over my records and I had already started finasteride at the time, and the results of the finasteride were really quite dramatic in reducing my PSA levels and the size of my prostate, which is expected. And my PSA was reduced from 5.75 in October of ’06 to 2.58 in April of ’07. Now, knowing of course that when you take finasteride you should basically double those levels to normalize them because the prostatic volume is less. At a doubling it's still elevated, but it actually continued to go down and I remain on finasteride. It went to 2.1 in January of ’08 and 1.54 most recently in October. So so far so good. I’m on finasteride. There are some side effects, but they're not terrible, and it has had a dramatic shrinking effect on my prostate, which now has a volume of 18 centimeters which I understand is normal for an 18-year-old.

Andrew Schorr:
Okay.

Peter:
So I have a much, much smaller prostate, much lower volume of ejaculate, but other than that everything is pretty much normal.

Andrew Schorr:
Peter, thank you for sharing that, but of course involved in all that are the issues we're talking about tonight. Let's go back to Dr. Bruce Dalkin from the Seattle Cancer Care Alliance. Just for comments on that, so the thing that strikes me, and Peter was reacting to it too, well, the doctors he was talking to first said, well, you ought to try this, but he was looking for evidence, you know, what is this based on. He ended up doing that, but how do we make decisions with confidence now?
Dr. Dalkin:
Well, there are a number of points in his story that are important. One is the fact that when we do biopsies nowadays it's not just necessarily the number of biopsies but how much tissue is removed. You can get small pieces or big pieces, and the accuracy of biopsy when we talk about counseling patients on biopsy and rebiopsy is related to how good a biopsy was done the first time, not only in the number of samples but how much tissue was removed. So that's one point.

And the other that he brought up really nicely was that he twice had these "precancerous" changes. You have to remember that biopsy reports to some degree are somewhat subjective, and they can vary from pathologist to pathologist, and if you have small areas or a focal area of some premalignant change that doesn't necessarily put you at dramatically higher risk.

The third point that I think is very important is finasteride is an interesting medicine in that it did gain some notoriety as potentially a prostate cancer prevention medication, but after closer review it really didn't do that. The concern from a urologic standpoint, as he alluded to, is it lowers your PSA. This has some potential concern to hinder cancer detection in the future. Shrinking your prostate and your PSA doesn't necessarily reduce your risk of cancer.

Now, to get to the question of trying to make all these decisions, I think that clearly from a urologist standpoint we probably need to be better about talking to patients, educating them about all these little things and trying to give them some guidance. The purpose of what I did for the past eight years was I always struggled with that discussion ten years ago with patients who were newly diagnosed is how best to treat them. You're talking to them about treatments that you might provide and what are the cancer control results, what are the side effects, and I thought, boy, doing this type of assessment is a way that you can honestly sit down with newly diagnosed patients and give them accurate information. And that's really what drove me to do these prospective studies so that when people like Peter and Ted--well, Peter hopefully never will be diagnosed, but if they are you can sit down and say here are the different treatments, here is the cancer control success of each, here are the side effects of each based on accurate assessment, and see how that impacts on your life and your goals in life and then make a decision.

Andrew Schorr:
We've got a lot more to talk about, and we're going to go back through some of the issues Peter brought up. One of the things is, well, he wanted to talk to a urologist who no longer did surgery because he didn't want the weight on, oh, well, I can remove that for you, so we have a lot to talk about. We're visiting with Dr. Bruce Dalkin who is really studying this and the outcomes and measure IT at the Seattle Cancer Care Alliance now. We have Peter Frishauf joining us from New York who has a personal interest, family, himself, and he is the founder of Medscape, a major website for doctors. And Ted Girgus joining us from Bellingham Washington. We'll be right back with our live webcast. Stay with us.
Dr. Dalkin’s Research

Andrew Schorr:
Continuing our discussion about navigating dilemmas posed by prostate cancer treatment options. Now, I should mention that Dr. Bruce Dalkin, a urologist oncologist who has just recently joined the Seattle Cancer Care Alliance, he's been doing surveys of his patients for eight years, and he just mentioned that. So help us understand these surveys, Dr. Dalkin, and what you're learning from them and what you hope to learn. I know you've presented some of your research in some of the top urology and cancer journals. What have you been learning?

Dr. Dalkin:
Well, what these surveys are is basically a series of questions that patients need to fill out at home. They're anonymous to the doctor. They don't put their name on them. They're mailed to third party centers that do the data analysis, so there's no bias there. And these are surveys and questions that ask all sorts of domains of life; energy, physical well-being, emotional well-being, but they also focus on urinary issues, sexual issues and bowel issues that are side effects of many of the treatments of prostate cancer. And so what we did eight years ago is we began giving surveys to every person who was going to have surgery, and then I had a third party group that did all the data. They would mail the men surveys every year thereafter, and everything was anonymously and we were able to capture 90-plus percent of people after treatment.

So what we've been able to do is to find what truly happens to people. We've also been tracking cancer control, and I think this is a system process that's so critical to honestly and accurately tell people what to expect, and to be honest with you there aren't really more than a handful of urologists and/or radiation oncologists in the country who have done it. So I think that when we look at the internet, one of the gentlemen mentioned the internet, there's a large percentage of information on the internet that's wrong or not based on accurate assessment. So it's something we're trying to push more on a national scale to be able to honestly counsel patients on what to do.

Andrew Schorr:
Well, you've got two people listening carefully. Peter Frishauf and I have been sort of on the ground floor of health information on the internet. We'd like to help. Peter, you had a question for the doctor?

Peter:
Yeah, actually I have two. First of all, I’d like to commend Dr. Dalkin on doing this registry of patients. I think it's very, very important. But of course this is, what you're doing is you're collecting self-reported data from patients, which I applaud you for, but it seems a little, to hear if I understood you, that you’re damning information on the internet that comes from patients when in fact what you actually did is patient-generated information. I actually think there's tremendous merit to having a registry of all therapy in patients and collecting the data in a structured
way from patients who volunteer it, and the more of it the better. So I think sites like PatientsLikeMe and others that are collecting real data should be encouraged, and I hope you're in that camp with your example.

Dr. Dalkin:
I am. Let me answer that one first.

Peter:
Okay.

Dr. Dalkin:
I'm not damning the patient-based information. I think that the physician-based information that's put out on the internet is the information that isn't accurate.

Peter:
Okay.

Dr. Dalkin:
I think the patient-based information is critically important. Sharing that information as best you can, is also critically important. I'm critical of the physician-based information that's on the internet.

Peter:
Okay. I stand corrected, and I think what's important is that there be interaction between patients and clinicians so that they can all try a little bit more get on the same page.

Ted:
Andrew, I would love to get in on this.

Andrew Schorr:
Ted, one second. I'm just going to let Peter ask his question. Peter, go ahead.

Ted:
Okay.

Peter:
The other question was if you could comment on the Prostate Cancer Prevention Trial which was under the auspices of your colleague Mary Redmond at Fred Hutchinson Cancer Research Center, which was a big review of a trial of over 18,000 men older than 55 who received either finasteride or placebo for seven years, and that study as she summarized it demonstrated that chemopreventive treatment with finasteride for seven years decreases the incidence of prostate cancer by an estimated 30 percent without increasing of incidence of high-grade tumors. And how much confidence you have in that study which seemed to me on reading it, I've been following that from the initial days and was one of the things that motivated me to ask my clinicians about finasteride, and it was really the
dissatisfaction with their interest in that research that drove me to looking for another urologist who actually thought that it was a very reasonable choice of therapy in terms of reducing my risk of prostate cancer in the future.

**Andrew Schorr:**
Dr. Dalkin?

**Dr. Dalkin:**
When the Prostate Cancer Prevention Trial was first published it was published and made national about how there was a potential cancer prevention role of Proscar, but if you notice carefully it never really caught on as a clinical recommendation. And I think the reason for that is over the next couple years as we sort of more closely perused the data, and you look at some of the flaws of the study, and not that it was designed wrong but there were patient decisions and differences in different sub-groups, that we're not sure that it clearly had a benefit on preventing prostate cancer. There is actually some concern that it may have selected out or made more difficult diagnosis in men who were on finasteride such that they potentially had later diagnoses or higher grade cancers. So that's essentially why when you talk to doctors about it you don't really get this excitement because after closer review we're not sure that that truly was a benefit.

Also you have to remember that even initially when the study found a 25 percent potential benefit in prevention, it was a bit of a misnomer, where in reality, for every 100 people treated it was only six people that would see a benefit. Now, that's not an insignificant number, but then when you throw into that the second look that says, hey, maybe this wasn't really perfectly well done in terms of defining the end point, that's why it didn't really catch on clinically.

**Andrew Schorr:**
Wow. I want to bring Ted Girgus into the discussion as well. And I think what's important here in this discussion, this really shows how we're looking for clear answers, and, man--and Peter is one of the smartest guys I know at looking at some of these medical studies as a lay person is--wow, if there are these other issues that come up how is a poor guy to know what to do. And also as you said, Dr. Dalkin, then there are for whatever reasons information put out by doctors on the internet that maybe you would say in analyzing it is not really doing the greatest service to the patient. Ted, why don't you comment on all this?

**Ted:**
I'd love to. And I don't want to take issue with Peter. One thing I want Peter to understand is that a negative biopsy does not mean you do not have cancer. Cancer always wins. They may have missed it. They're putting these needles in and what have you, and god bless, I hope that is not in your case, but understand even a negative biopsy does not mean you do not have prostate cancer.

The other thing is what Dr. Dalkin was saying. It is so important to listen to the patient, okay. I have been working with CareToLive, okay, and I urge everybody
everyone to look at caretolive.com, our website, on getting this immunotherapy to market because it was evaluated by the FDA's evaluation board, and it was shown 17 to zero it was safe and 13 to 34 showed substantial efficacy and yet it's been delayed by the FDA. And the reason I'm bringing it up is I presented that to my oncologist, and my oncologist--I said, have you heard of Provenge, and he said no. And I said, you haven't, and he said no. And so I brought him into the fold about Provenge and this new immunotherapy that is close to being concluded now. Their impact trial is finalized in June or July of 2009.

I went back to my doctor, my oncologist, I said did you hear what happened at the interim? The interim was a 20 percent improvement offer the placebo, okay, which to people like me I would jump all over that. But my oncologist said no, he didn't hear about it. So I had to educate my oncologist. I did go to a urologist who said, listen--if my oncologist won't let me have Provenge when it's approved can I go to you? He said, listen, you're the one with cancer, not your oncologist. You need to move forward on it.

**Andrew Schorr:**
All right. I want to get at some of these issues with Dr. Dalkin, and then we'll be taking a break in a minute. Okay. So the whole thing is all this is swirling around, potential new drugs for more advanced cancer, whether you can be prevented from it developing into cancer, whether you should have this kind of surgery, that kind, cryo, brachytherapy, proton therapy. So please give us sort of an operating system, Doctor, of where we are today or where we need to get to.

**Dr. Dalkin:**
I think the best way to look at that is twofold. Number one, one of the good things that has happened due to PSA testing in the last five years is the cancers that we're identifying in general are smaller than five and ten years ago, so more people are presenting with treatable cancers. Now, that makes all of the treatments better, not because the treatments are getting better but because the cancers are getting smaller. The dilemma that we're facing and I think the hard part to navigate is that it's going to take us really another five to seven years to be able to sit down and say accurately, surgery results are this, brachytherapy results are this, proton beam therapy results are this, etc., etc., to look at cancer control and quality of life.

Right now as of today I think the best we can do is understand that these treatments, the success of these treatments, is based not only on their technology but on the person delivering them and the cancer that's being treated. So each person who is diagnosed needs to seek out an appropriate treatment based on what they prefer and then someone who is established and has a good track record in that treatment. But I wish there was a simple answer to say how do we navigate this. I think that the burden is on us as physicians to better accurately assess what our results are, and once we do that we'll be able to honestly sit down with people and say here's exactly what happens. The studies that have been done so far haven't really been done well in their design to be able to do that.
And there's a bias, just like these patients understand, the surgeons like to do studies that show surgery works, radiation oncologists like to do studies and they'll show that radiation is great, so on and so forth. And I think we need a little bit more of a nonbiased approach to it.

Andrew Schorr:
Wow. This is a very great discussion. We may even go a few minutes long if we can, and again you're welcome to join the discussion. But we have two men who are discerned about prostate cancer with us. Peter Frishauf joins us from New York. Ted Girgus joins us from Bellingham, Washington, up the road. I'm here in Seattle, I think about it. Our producer, Ron Kreider is down in Vero Beach, Florida, he's thinking about it. We're all wondering what should we do next or first depending on our individual situation. We'll be back with more of Patient Power sponsored by the Seattle Cancer Care Alliance with Dr. Bruce Dalkin and our guests right after this.

Andrew Schorr:
Andrew Schorr here with my terrific guests. We do this every two weeks. As a matter of fact two weeks from tonight we're going to have Dr. Paul Nghiem from the Seattle Cancer Care Alliance. We're going to discuss something I know nothing about, treatments and breakthroughs in Merkel cell carcinoma. So if you know anyone affected by it, that's two weeks from tonight.

And all of our programs, we have a huge library, are found on the Seattle Cancer Care Alliance website, and you can look at the transcripts or listen to the replays, whatever you like, and we'll post our replay there tomorrow. All right.

Sorting Through Treatment Options

Let's continue our discussion. So, Dr. Dalkin, we were talking about the situation now, and you were saying, gee, it may take five years to sort this out, and we as providers need to do a better job. But for the man who is listening tonight who is just diagnosed or has his PSA going up and is worried is it cancer, give us some tips on how we can operate now, whether it's at the Seattle Cancer Care Alliance or elsewhere, to try to get at what's best for us.

Dr. Dalkin:
I think that if you look at men just diagnosed with cancer the synopsis of the information that's out there I think can be stated as follows: In men who are under 65 whose goal is to live 20 years or longer and have favorable cancer parameters, if you look very carefully at the seven- and ten-year cancer control data, a well-done operation probably results in better cancer control than well-done radiation. From a quality of life standpoint, the whole issues of urinary continence and sexual health, I know this is a bit of an eye opener, but a well-done operation probably has less negative impact on overall quality of life than well-done radiation. But all treatment has a negative impact on quality of life, and all treatment isn’t done well.
So across the country if you look at surgical results and incontinence it's clearly higher than with radiation. But if you look at best-case scenario to best-case scenario there really isn't a difference. Same thing with sexual health. Overall, it's terrible in this country after surgery, but if you can have nerve-sparing surgery and it's done correctly, you may actually have a better chance of maintaining some degree of sexual health than if you had radiation therapy. Now, those are complete 180-degree turnarounds from what we've historically been taught, but I think that the problem is each provider defining their own results so that they can accurately tell the patients what to expect.

**Andrew Schorr:**
And if you get a second opinion in a region, then it may be the same because there are regional differences as well. So how do we factor for that?

**Dr. Dalkin:**
Well, that's the financial and political side of medicine that I think is very hard, and I think it's been a little bit of a disservice on our part not to sort of break through that to be able to sit down with each person and sort of accurately tell them what to expect. So there's no simple solution to that one. I think within each regional pocket, though, there are clearly going to be people who see through that and understand how to assess this and then how to counsel patients. But it may be the minority and maybe the exception to the rule rather than the rule proper.

**Andrew Schorr:**
All right. We're starting to get some e-mail questions. This one came in from Tony in Michigan, and he asks, "Is it possible for prostate cancer to be overtreated?"

And thanks us for our great discussion. Dr. Dalkin, want to comment on that one?

**Dr. Dalkin:**
Yeah, I think that is absolutely true on the national scale. When people are biopsied and they're found to have cancer we break them down into sort of low-, medium- and high-risk cancers. And we know that even in healthy men over 70 and particularly over 75 no matter how healthy you are the odds of a low-risk cancer shortening your life is exceedingly low, and yet people are treated or doctors recommend they be treated simply because they have cancer or some people elect treatment because they have cancer. We have programs now of active surveillance where you watch these people carefully and only treat them in the future if there's some significant change.

But I would say that's not a true statement about overtreatment if you take healthy men under 65, but if you look at national scales there are clearly many men over 75 with low-, moderate-risk cancers who are treated aggressively who probably don't need it.

**Andrew Schorr:**
Wow. So, Peter, got a question you want to pose? You talk to doctors all the time and hear from patients.
Peter:
You know, bad data is worse than no data because you really can draw wrong conclusions from it, and part of the problem, as Dr. Dalkin suggested, is that there's a lot of really bad data. And it has to do with the way cases are reported, even the diagnosis of cancer itself and Gleason scores and so forth. When I talk to a lot of urologists, many of them are suspicious that the very good results reported for surgery are often the result of self selection in patient population that would do as well with less drastic forms of treatment. So I'm really agnostic on the issue of what is a better therapy because, as Dr. Dalkin stated at the outset of the program, you just don't know.

But really it's a terrible indictment of the medical and surgical profession that at this point we don't have better data because the stratification of patients and risks is being done very, very poorly. So really I think the medical surgical profession and the NIH and the National Cancer Institute has to really get together and enforce standardized reporting in a much, much more rigorous way, and really that every single form of prostate cancer therapy, whether it's prophylaxis, which I'm attempting myself with finasteride, which, by the way, I took after my biopsy so there was no risk if I were to be studied for example of polluting a biopsy with my being on finasteride. Of course I'm on other medications too, which could have a similar effect, and we just don't know that.

But the fact is we tend to look at data in a vacuum, and I think the conclusions that we draw from that as a result of that are often wrong. And the medical surgical profession and statisticians and biostatisticians really need to get together and clean their house in terms of bringing a lot more rigor to the analysis before we can conclusively say that this is the evidence one way or another. Otherwise we're going to be sitting around having the same conversation ten years from now, and the answer is still going to be what Dr. Dalkin said at the outset, we still just don't know. And there is plenty of prostate cancer out there that could be studied, so by this time we really should have the answer to that question.

Andrew Schorr:
Amen. Well, Dr. Dalkin, it sounds like you coming to the Seattle Cancer Care Alliance, joining the urology department at the University of Washington, that's all part of it. You're all trying to pioneer this.

Dr. Dalkin:
Right. I agree with what Peter just said, and I think that our goals really are, number one, we have actually a very large database of patients who have been treated for cancer, and we're going to refine and define that database better. But more importantly we're going to begin now and prospectively answer all of these questions. And you're absolutely right. It should have been done ten years ago. But it's labor intensive, it's not free and it requires really a true dedicated commitment. And I'm being honest when I say it's going to take us five or seven years.
Our goal is define the outcomes, define them physician-specific. If we find that there are some physicians that have better outcomes than others, really the goal is to say how do you improve the outcomes in the person who isn’t performing as well, and can you? And what those techniques are, that's what we need to teach the people who are learning. If you can't, then that speaks to regionalization of care, which is what we hear all the time. But we've never really proven that regionalization of care is beneficial. And then I think at that point we'll be able to give this information honestly. But it is not easy to do. It requires a commitment, and I think that that's really been one of the reasons why it hasn't been done.

There's another major reason why it hasn't been done is that if you do something like this and you prove that you're not very good, what do you do? And I think that's been one of the reasons why we haven't seen it done on a larger scale, aside from the fact that it's not easy.

**Andrew Schorr:**
I want to go a couple of minutes longer. I think the men listening are loving this, I'm sure, because these are very important issues for all of us. So, you know, a hospital somewhere buys a new gizmo. Let's say a robot, okay. But you talked about really what's what it's about is the skill of the provider. Is robotic surgery, no matter who does it, necessarily better for prostate cancer? And I'm just using that as an example.

**Dr. Dalkin:**
Right.

**Andrew Schorr:**
But let's use that as an example to help men decide, do you buy the gizmo, is it the doc? How do you make that decision?

**Dr. Dalkin:**
It's an absolutely beautiful example of how we haven't done something right in this country. It's a wonderful technology, and I think over the next 15 and 20 years, whether it or some rendition of it, will certainly become commonplace. But what we did with robotic surgery in this country starting about eight or nine years ago was a number of urologists starting to do it. They were being financially supported by the company that makes the robot and for the first three or four years everything was perfect. In the last couple of years the University of Michigan and Vanderbilt University have done very nice comparative studies with experienced surgeons who have good quality outcomes, and they've shown very nicely that when you look at issues of recovery and blood transfusion, pain and hospital stays that there is no benefit to well-done robotic surgery over well-done open surgery. And when they looked at issues of urinary continence, there was no benefit. When they looked at issues of sexual health, there was no benefit.

And more recently there's actually some concern that there may be some compromise in cancer control with robotic surgery, although that's really being
looked at more closely, and it's going to take us probably two or three more years to get a little bit more data. But when you look on the internet or talk to doctors who do robotic surgery, it's like a walk in a park and it's the optimum outcome. But in reality there's going to be technical differences there, and on best-case scenario it really hasn't been a dramatic improvement.

Andrew Schorr:
Wow. We could go for a long time. I think we have to have you back, Dr. Dalkin. I want to say thank you to the Seattle Cancer Care Alliance for bringing you to my home town and that there's a commitment here to try to continue surveys, to really take a hard look at data, to get accurate data, like Peter's really insisting needs to happen. And Peter's been at this a long time in being around clinical studies and reporting on them. So I really appreciate that.

I want to get some comments from our patients and then we'll come back to you before we wind up. So, Ted, unfortunately your cancer is advanced, and you're doing the best you can with the decisions you make with providers you trust so that you can keep the cancer down, if you will, as best you can. For men, whatever their stage as you listen to this discussion and participate, what would you recommend to men so that they as best they can where we are now can make decisions that they can feel as confident as they can about?

Ted:
Well, again, I want to thank Peter and Dr. Dalkin for being on the show with them, but I would strongly urge that, as my urologist said to me, it's your cancer, okay. So what you need to do is find out as much as you can, and that's networking. With prostate cancer men are afraid to talk about it freely because of exactly what Dr. Dalkin was saying and that is incontinence, you know, impotence and all of these things that men would rather not talk about. But we need to. We need to bring it out into the forefront whereby we can talk with our doctors, challenge our doctors.

You know, Dr. Dalkin brought up something had I had that information I might have chosen surgery over brachytherapy. Now, I might have because it was my understanding that brachysurgery had less side effects and yada-yada-yada. But with the information that his organization is gathering, that's an invaluable tool to people like me and every other person who is first diagnosed with prostate cancer. Because when you are told you have cancer it is a very frightening and very lonely feeling, and that's where your faith comes in to sustain you, and your doctors are very important in your life, but we have to remember it's your life and you've got it take care of it. You have a responsibility not only to yourself but your family. So the best way I could say it is get involved and learn everything you can about prostate cancer.

Andrew Schorr:
Okay. Thank you so much. Peter, I want to get a final comment from you. So you've been listening and I think you've really been a strong advocate here too,
and hopefully the field will sort of get its act together. It sounds like Dr. Dalkin and what they're doing here in Seattle is really trying to make a great start. A final comment from you for men who are listening who may be facing all this.

Peter:
Well, I think certainly men who are facing rising PSAs a very important question is, is that rising PSA due to the presence of cancer or how much of rising PSA is due to inflammation. And this of course is an unanswered question as far as I could learn, but there seems to be quite a good lot of evidence that a lot of it is due to inflammation, and there seems to be some evidence by what I read that there are ways of controlling the inflammation as well with drugs like finasteride. But the answer is we really don't know. Steve Nissen once said the road to hell is paved with biological plausibility, and as an atheist I certainly do believe that, that is my faith in science and evidence.

And I'm hoping that with better rigor, with better data and with better information, and this doesn't have to costs a lot of money either. If medicine were practiced correctly registries would be an automatic byproduct of electronically recorded data, and it could be done on a massive scale much less expensively than it is now with a lot of information to be gained by it. So when we talk about getting better data we really have to talk about reforming the way in which medicine and healthcare is practiced in general and that data is recorded in healthcare.

There are a lot of exciting developments with projects like Microsoft HealthVault and Google Health that will help us do that in the future, but once again the medical profession has really been dragging its heels in terms of pushing for these changes, and I think it is up to patients and enlightened clinicians to advocate for these changes and make sure that in the future we have better data about therapies that are collected in a structured form so that we can really say with certainty that well-done prostatectomy may cause overall less risk of incontinence or impotence. But, you know, right now I think the data is so bad that one would be hard pressed to prove that one way or another.

Andrew Schorr:
Right. Right. We're short on time. Peter, we're going to go on, and I want to thank you for being with us and all the work you've done with Medscape. Thank you so much, Peter Frishauf, for joining us. And, Ted, thank you for joining us and all the best to you. Just want to get one quick final comment from our guest, Dr. Bruce Dalkin from the Seattle Cancer Care Alliance. Welcome to Seattle. Sounds like you've got your work cut out for you, but the work that you are doing is helping pave the way.

Dr. Dalkin:
Right. I'm very excited about it, and the Seattle Cancer Care Alliance and the University of Washington is committed to doing this, and actually I think it's the kind of thing that we could do as a city. You have very wonderful institutions here, Swedish Hospital and Virginia Mason Clinic, where if we approach this as a city-wide
endeavor, boy, we could really do tremendous good and get information quickly and helpful and better for all the people in the Pacific Northwest who are treated here. But everything that Ted and Peter said there at the end is absolutely true, and I'm just thankful from an individual standpoint that I've been able to do what I have done and that I have this opportunity to expand it really to an institution if not a region, and that will be wonderful.

Andrew Schorr:
Well, I think to a nation too. Thank you, Dr. Bruce Dalkin, urologic oncologist at the Seattle Cancer Care Alliance. This is what we do on Patient Power. We talk about the issues in an unvarnished way, and I think for men who are facing prostate cancer it's all about understanding the issues yourself. Ted said it so well, Peter said it so well, and hopefully I'm echoing it, and Dr. Dalkin as well. You need to be informed.

We'll have the replay available probably tomorrow and look for that on our website. Thank you so much for joining us. We will back in two weeks with our program, understanding Merkel cell carcinoma. I'm Andrew Schorr. Thanks to the Seattle Cancer Care Alliance for making this all possible. Remember, knowledge can be the best medicine of all. Good night.

Please remember the opinions expressed on Patient Power are not necessarily the views of Seattle Cancer Care Alliance, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.