



Smart Treatment Approaches For Pancreatic Cancer

Webcast

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Introduction

Andrew Schorr:

We're live on Patient Power. You know, each year nearly 40,000 people are diagnosed with pancreatic cancer. It is a scary diagnosis. We had it in my family, and I know all too well the majority of those people, as you know the statistics, do not survive the disease, but some do. You're going to meet an almost six-year survivor in just a minute who is so inspirational, and we'll tell you about others as well. And you'll hear about smart treatment approaches for the disease, why is it so difficult to diagnose, what are the options, and how does a multidisciplinary center help. It's all coming your way next on Patient Power.

Andrew Schorr:

Hello from Seattle. Thank you for joining us. I'm Andrew Schorr with a live webcast sponsored by the Seattle Cancer Care Alliance and also produced in association with a wonderful advocacy group, the Pancreatic Cancer Action Network, or PanCAN, and I know many of you have heard about this program that way. Thank you. So you may well personally be touched, your family or you yourself with this diagnosis. About 40,000 people a year, a rare cancer but unfortunately often a very deadly one. But it's not always that way. And so we're going to talk about how to give you hope, support, connect you with the best care, and you're going to see that there are things being studied, things changing hopefully that can make a difference and people who want to help you along the way.

Now, we welcome your questions. This is a live webcast if you're listening on March 11th of 2009. You can send in a question or a comment via e-mail. Our address is patientpower@seattlecca.org. Patientpower@seattlecca.org.

Now, I mentioned, we know about the statistics. I think people understand that well, and really the question is, are those the statistics for me. Do not assume that. I have an in-law who was diagnosed. He was on a cruise, became jaundiced, terrible realization that it was pancreatic cancer. She did have the Whipple procedure, that major of all major abdominal surgeries that can be used for some people in this case, and while it was a rough go she is doing well. And I think now she is about three or maybe even close to four years out. So that's given us a lot

of hope. Otherwise, my father's second wife, my mother died earlier of colon cancer, my father remarried, and his second wife, heavy smoker, we'll find out if smoking is a connection, she was diagnosed with pancreatic cancer and did not live long. So it is variable.

We'll learn more about that, but I want to connect you with somebody who is now almost a six-year survivor, and that is Jeff Ross, a CPA, who joins us from sunny, beautiful Laguna Beach, California. And while he's in the sunshine, though, Jeff spends a great deal of his time talking individually to people with a pancreatic cancer diagnosis or other family members. He speaks to doctors, he speaks to patients, and he's very active in PanCAN. Jeff, thank you for joining us. Tell us how it began. I know you've told the story a thousand times, but I think it shows how difficult it is to get an early diagnosis of this condition. So take us back to July 1st, 2003.

Jeff's Story

Jeff:

Well, thank you, Andrew. I appreciate being on here tonight, and I am on here by an invitation through the Pancreatic Cancer Action Network. And just so that I can get that out right now, anybody that ever has any questions about pancreas cancer, it's pancan.org. It's a great website. It's a great organization.

My story actually began just shortly before July 1, 2003. And the reason that Andrew used that date is that's the date of my diagnosis, and for anybody out there, a lot of people start, they have the question of, well, how long have you survived and what does that mean. Your survivorship begins on the day that you receive your diagnosis, and a lot of people don't realize that. And that's a very powerful tool when you look at what you may be faced with in fighting any cancer or any disease. It's when did you first receive your diagnosis.

Pancreas cancer is an asymptomatic cancer. Of all the cancers, and I can't speak to every one of them. I'm not a medical professional, so what I say here today I'll give the caveat that it's not medical advice, it's advice well learned by myself. I do, as Andrew mentioned, I do one-on-one conference calls with people who have been recently diagnosed, with their caregivers, with their family members, and over the last four and a half years I've probably spoken to well over a hundred different individuals.

Andrew Schorr:

Jeff, how did it start for you, though? I mean what were you noticing in your own situation in

Jeff:

For me, I've always, I've been somebody, and you mentioned smoking. I did smoke at an early age. When I was in the military that was the only thing you did, but I quit smoking at age 26, cold turkey, never had a cigarette since, and I was

diagnosed at age 54. But all through my life I've always had an overacidic system. You know, Tums was part of my normal routine. Too much acidic food, too hot of food or whatever, and so that was sort of normal with me. But the one thing that I always adhered to throughout my life was an annual physical. And as I told Andrew earlier I have friends that think that's frivolous, and yet they'll take their Porsche in once a month or every other month and spend a thousand dollars having it tuned up.

Knowing your own body, understanding your own body, listening to your body, that's what I really believe saved me. Because the first thing that was out of the ordinary, right around April 15th, just about tax time of 2003, and I was working in the yard, I bent over and I had such a pain in my abdomen that I literally passed out. Fell backwards. I got up, went right to the phone, called my general practitioner and made my annual physical exam, and she took me in the next day, ran blood work on me, said everything seemed fine. She thought maybe I was having some gallstones or something of that nature.

The next morning she called me up and told me to get in to her office immediately. She had already made an appointment with a GI specialist in her building, sent me down there, and at that point they thought was gallstones, and they wanted to get me through the system. So they did first an ultrasound, then a CT scan, then a PET scan. Then they sent me over to another medical center that they felt was more equipped for this. They did an internal ultrasound.

Andrew Schorr:

And we should say that they were all showing negative, negative, negative, negative.

Jeff:

They were all showing negative. She showed nothing. However, the one thing to keep in mind is they were focusing on my gallbladder. Now, the pancreas, where it sits, it's sort of off to the side. So if you're not really looking for pancreas cancer, if that's not your goal or your target, it could be overlooked.

Andrew Schorr:

We're going to talk about that.

Jeff:

They were seeing that entire bed of my upper abdomen, and nothing was showing up. Nothing showed up anywhere. So ultimately I was scheduled for what's called an ERCP, where basically a scope is going down through your throat and they're going to look firsthand and see what's going on in both the common bile duct, in my gallbladder and in my pancreas. Two days before that I became jaundiced, which was a sign for some type of real problem. When they did the ERCP they attempted to do I believe it was nine needle biopsies of a growth that they could see on the head of my pancreas. Because there was so much scar tissue there they were unable to get any live tissue, and that's why I had no diagnosis.

However, because they had upset my pancreas I came down with a severe case of pancreatitis the next day which kept me in the hospital for eight days.

At that juncture they made the decision that whether it was malignant or nonmalignant I was going to have to undergo what's called the Whipple procedure which was started by Dr. Whipple back in I believe 1935. It's come of age, but it's still the tried and true surgery for pancreas cancer.

Andrew Schorr:

Jeff, in the interest of time, I'm just going to pick up the story a little.

Jeff:

Absolutely. Please do.

Andrew Schorr:

You help me, make sure I get it right. So 12-hour surgery followed by quite an extended course of radiation and chemo, right?

Jeff:

Right.

Andrew Schorr:

Okay. And happily now if we get to early July, right, you'll have your sixth anniversary, and your situation now remains, please god, cancer-free?

Jeff:

As of this moment I am five years, eight months, 11 days absolutely cancer-free.

Andrew Schorr:

Okay. Now, we're going to come back to you, and you are wonderful. You are the Eveready Bunny here for inspiring people.

Jeff:

Thank you, Andrew.

Andrew Schorr:

I want to introduce our medical expert guest, and that is Dr. Sunil Hingorani. He's a GI medical oncologist but much more than that, and he's the director of the new multidisciplinary pancreas cancer clinic at the Seattle Cancer Care Alliance. Seattle Cancer Care Alliance, if you're not right from around Seattle, is the renowned Fred Hutchinson Cancer Research Center and the Seattle Children's Hospital here, and then also the University of Washington, which is one of our preeminent medical institutions and research institutions in the country.

Now, Dr. Hingorani, as I introduce him I just want to set the stage. He is very personally involved in this. He made a decision after his own father was diagnosed and treated in 1999 with pancreatic cancer that he would focus his attention as a GI

medical oncologist and as a cancer researcher on pancreas cancer, and he came to Seattle to do just that. And this new multidisciplinary clinic is that dream.

And while I know your dad did not survive, Dr. Hingorani, you are so committed to working with a multidisciplinary team to try to help everyone get the best and hopefully a cure or the result certainly like Jeff's had. Why is having a multidisciplinary clinic, how does that provide better care? Because I know talking to Jeff earlier and I remember with my father's second wife it was go to this clinic then go to that clinic. Is it having it all in one place for families that are just touched with a very emotional and serious diagnosis?

Multidisciplinary Approaches for Treating Pancreatic Cancer

Dr. Hingorani:

Well, that's certainly a big part of it. Let me begin first of all by thanking you, Andrew, very much for your interest and for taking time to do an excellent program like this, and, Jeff, to you also for sharing your inspiring story. The goal is to have many more stories like yours.

In terms of having a multidisciplinary clinic, I think first and foremost from the patient's perspective I think dealing with a diagnosis or a potential diagnosis like this is difficult enough without having to then also try to navigate the medical system itself, find out who the right people are to see, schedule appointments, so on and so forth, and sort of have that drag out. So certainly at a minimum I think one of the important services that the medical community can provide is to bring all of the experts into one room and to provide you with one-stop shopping, so to speak.

But it actually does much more than that as well. By having all the various care providers in the disciplines in the room simultaneously and evaluating the same data together we feel that we get a much more nuanced and deeper understanding of an individual patient's specific presentation, but we also get a better sense of how you each one of us would approach certain aspects of the disease and of how best to sequence the different kinds of therapies that we might use. And I can give you one example. It sounds like Jeff's cancer was diagnosed early enough so that they could take him straight to surgery, after which I know that he's explained that he had both some chemotherapy and some radiation therapy. And all three of those modalities, surgery, chemotherapy and radiation, are important parts of the treatment plan.

But there are situations in which an operation might not be possible right up front. You might be right on the border as we say, or a borderline resectable case, and in this case when we review the films the surgeon might look at them and say, I'm a little concerned about this area or the tumor is a little too close to this major vessel, and that actually it going to make the surgery more difficult. Now, rushing to the operating room in that situation, what that will mean typically is you will have performed a big procedure just to open the patient up only to then find that

you cannot actually perform the definitive resection, and you have to close the patient up and then relay the news. If, however, you precede that with chemotherapy up front and potentially radiation, you now will dramatically increase

the chances that the surgery will be successful. So it's those kinds of decision-making points that I think really greatly benefit from having all of the disciplines in the room at the same time.

Andrew Schorr:

Wow. Well, we're going to talk more about that and understand what happens, what are the tests that you do, what are the analyses you make, your comment about the statistics, we'll get it from Jeff as well and how you figure out what somebody's prognosis may be. And also where research is headed. There's some genetic news that's come out just in the last few days. You're working very much in research in mice and showing how that translates to humans, so much more.

Call with a question, or send an e-mail to patientpower@seattlecca.org. We'll be right back with much more of our live discussion about pancreatic cancer. Stay with us.

Andrew Schorr:

Welcome back to our live webcast. Now, we have a huge library of programs we've done before and I want to mention where to find it at the Seattle Cancer Care Alliance. Just go to scca@patientpower.org.

We're visiting with Dr. Sunil Hingorani, who is the medical director of the new pancreas cancer specialty clinic, multidisciplinary clinic at the Seattle Cancer Care Alliance, and also Jeff Ross. Many people who are associated with PanCAN, the leading an advocacy group, know Jeff. He's joining us from Laguna Beach, and he is almost a six-year pancreas cancer survivor. So congratulations to Jeff. We'll hear more from him in a minute, but I want Dr. Hingorani to explain something.

You mentioned it to me on the phone yesterday and just a light bulb went on because I never got it before. In this age of digital mammography and super-duper ultrasounds and PET scans and CT scans, why can't you just like hold something over the abdomen and see and spot the pancreatic cancer at an early stage? What's the problem?

Diagnosing Pancreatic Cancer Early

Dr. Hingorani:

So that's an excellent question. Why is it that we're not able to diagnose the cancer earlier in its process? Number one, you typically have to have an inkling to look for something to begin with, and Jeff alluded to some of the very generic symptoms that he was experiencing, some of which he's has had for a long time, for example the reflux disease. Very often a patient might present with low back pain. It's actually the rare case that jaundice reveals itself, which is a tell-tale sign.

But some of the other more common symptoms, you know, when you train in medicine you're trained, the saying goes that when you hear hoof beats you should think of horses, not zebras, basically meaning that common things occur commonly. So if there's a vague pain in the abdominal area you're more likely to think of acid reflux certainly than pancreas cancer.

So typically we tend to perform these kinds of tests when a sign or symptom alerts itself to a problem, and pancreas cancer, primarily because of where the pancreas is situated, it's a cigar-shaped organ tucked underneath the stomach but also deep, almost up against the spine in the abdomen. As a result pancreas cancer or tumor can grow to be rather large before it produces any kinds of symptoms.

Now, on the other hand one could ask, well, why don't we just routinely screen every single person with either a CT scan or an MRI just say on an annual basis. In point of fact, number one, that's not very practical to do that across the country. And there are also times where with a very small tumor the differences in the way the tumor looks compared to the surrounding tissue might not be significant enough even then to be able to pick it up. So what we need to do really is move to a point where we can as an example develop a blood test, find a marker in the blood, in the circulation that will reveal the presence of this disease and to do it in a way that is economically feasible as well.

Andrew Schorr:

We're going to talk about that, but anybody who has learned anything about breast cancer knows when there's something suspected, and prostate cancer too, you stick a needle in it and you do a biopsy. Why can't you do that so easily or why wouldn't you do that pretty quickly when there's a chance of pancreas cancer?

Dr. Hingorani:

So there are a couple of reasons for that. Number one, the pancreas itself is difficult to access for the reasons we just described, and it is hazardous to biopsy. The pancreas does not forgive manipulation. So as Jeff can attest to,

Andrew Schorr:

Jeff's laughing now, yeah.

Dr. Hingorani:

, and described, the pancreas, basically, if we just spend one moment thinking about what it does, it's really charged with two important functions, both related to digestion and metabolism. It's basically the majority of the tissue of the pancreas is devoted to creating enzymes that aid digestion. These are enzymes like trypsin and amylase and chymotrypsin. These enzymes are so potent that they can actually digest raw meat if you were to isolate the enzymes and drop them directly onto the meat. Now, those enzymes then travel through your duct, through the plumbing system, the piping system in the pancreas, and empty out into the first and second parts of the small bowel, which is where it meets the food just as it leaves the stomach, and the stomach provides acid to help aid in the digestion.

Now, the other part that the pancreas does of course, and that's probably even more familiar to people, is the islets that are scattered throughout it make insulin in response to glucose that's in the blood. And the insulin of course helps us utilize that glucose, and a lack of insulin or response to insulin leads to diabetes.

So if you now stick a needle in the pancreas then instead of those enzymes traveling safely through that piping system they're released into the surrounding pancreatic tissue. You've got a little bit of injury there because you've stuck a needle in there, and those enzymes are released, and what they do is they start to digest the tissue just around it. Well, the tissue just around it is more pancreas, and that results in the release of even more enzymes. So what you do is you set up this process of auto digestion, and you don't necessarily know exactly when that's going to stop. There is no real direct treatment for pancreatitis, which is what has now been induced in that situation, and what you kind of have to do is hope and pray that it quiets down on its own.

So unlike, for example, colonoscopy, in which we can do routine screening, pass a scope up into the colon and if we see something abnormal we can take a little piece, a little biopsy and look at it under a microscope, we are probably never going to arrive at a point where we will just routinely be sticking needles in the pancreas just as a surveillance procedure to see if there's anything going on. It's just too risky.

Andrew Schorr:

All right. We'll talk about the research and hope for a blood test that's doable. So for people listening where maybe they're at the point where they say, well, we suspect this, how do you confirm the diagnosis of pancreas cancer?

How Experts Confirm a Pancreatic Cancer Diagnosis

Dr. Hingorani:

So the series of steps that we use were also alluded to by Jeff, it sounds like he went through a number of potential imaging modalities, probably one of the most sensitive is to use a specific form of a CAT scan. So there are particular ways in which you can give the contrast material and the way in which you use the CAT scan that focuses attention on the pancreas so you get the best resolution images. You can complement that with another procedure where you pass the scope down true the esophagus, and you can do an endoscopic or internal ultrasound. And in that case you can put a scope, while it's in the stomach you can push against the inferior wall of the stomach and pass sound waves then directly up against the pancreas and get very good images of the tissue and of the duct itself. Those are the two primary imaging modalities, and you can complement that with other tests.

If you see something in the pancreas that is suspicious, you then do take the risk of sticking a needle into it because you do definitely want to establish a diagnosis

before you do anything as aggressive and invasive as either a surgery or giving chemotherapy or radiation, and you attempt to get back some of the cells that you can then look at under the microscope.

Andrew Schorr:

All right. So now let's say you confirm there is a diagnosis. We've talked about this Whipple procedure. Jeff had it, my in-law, Yona had it, another woman had it on the program one time, Mary Sharkey had it. They're all alive today, so it sounds like you want, it's a very difficult procedure, and maybe there are people who don't survive it, but it seems like a hope of life. How do you assess whether someone is a candidate for it either right off the bat, or with chemo first or maybe radiation could be a candidate for it?

Dr. Hingorani:

So this is again another area where we strongly feel that this multidisciplinary approach helps you arrive at the best decision. What we do in our clinic here is we have the radiologist who is actually an expert in the particular type of CAT scan that I mentioned that focuses on the pancreas. We have the surgeons present. We have the medical oncologist, a radiation oncologist and the entire support team present, and we review the films in very fine detail looking at them from different angles. In addition we have the endoscopic ultrasound information and the visual impression that the gastroenterologist had while he or she was doing the procedure. So you don't necessarily always capture that information on the film, but the impression in speaking directly to the person who performed the test is very important. And if we believe we have adequate views and clean views where we can see that the tumor is sufficiently separated from surrounding vessels and structures that might be of concern, then we would recommend going to surgery right from the beginning.

Now, at the other extreme if you already have evidence of disease that you can see on a film that's spread to other organs, then we know that there is no benefit, potentially some harm from doing a surgery as aggressive as a Whipple because that procedure is designed really only to focus on disease that is in the pancreas.

Now, it's in the in between cases that can often be the most difficult in terms of how exactly to proceed. A tumor that you feel you may have a chance at removing if not for the fact that it's up against a certain vessel or a cluster of vessels, and in that case those are situations where we begin to think about using either chemotherapy and/or radiation together to try to shrink that tumor sufficiently so the surgeon can perform a procedure. And these kinds of decisions and this kind of surgery in particular really are best done at places where they do the procedure a lot. And there are centers across the country that have tremendous expertise in this procedure. This is really one of those areas where practice really does make perfect, and the more you do the better you are at it.

Andrew Schorr:

Right. Now I want to ask a quick question of Jeff before we take a quick break. Jeff, the first providers you saw early on said basically, you're a dead man, put your affairs in order and you're not going to live out a year. You did get to a very well qualified team, and here you are today. So it sounds like the team really matters, right, and it did to you.

Jeff:

The team is the most important thing in the world, and as Dr. Hingorani was talking about if in Southern California we had had a cancer center where I could have gone and had all the disciplines there, for example going to Johns Hopkins or one of the other cancer centers, Sloan-Kettering or someplace like that where you have all the disciplines at one place, unfortunately where I went they had a surgeon who specialized in the Whipple procedure but not beyond that, not for the follow-up care. And so I had to go search out the radiation oncologist, the infusion oncologist, and basically what course of action I was going to take.

Andrew Schorr:

Okay. We're going to talk a lot more, and Jeff you'll help guide us through it. There's been some research related to genes. There's been some study here in Seattle about families that may be affected by this, so we're going to talk about all that, the genetic connection and also this detective work going on to see how can we see what's going on in pancreas cancer where we can develop medicines that can do better than what we have now, and we'll understand what the standard therapies are too. All this on our live webcast on Patient Power sponsored by the Seattle Cancer Care Alliance. Stay with us. We'll be right back.

Andrew Schorr:

Jeff Ross from Laguna Beach, California was just talking about how he wished he had had a multidisciplinary pancreas cancer specialty clinic when was diagnosed in Southern California. We're blessed where I am, in Seattle. We have one here, and it's led by Dr. Sunil Hingorani, who as you heard was touched personally with it. Coincidentally he was already a GI medical oncologist, but then when it affected his father he said this is what I'm going to do. So he's leading the clinical team, the multidisciplinary team here in Seattle, and I'm sure people are coming from far and wide. And then there's very active research going on as well.

And of course it's not just about the medical treatment. It's about the emotional treatment for you and your family as well. It's about nutrition certainly comes into play related to pancreatic cancer and a lot of other aftercare, after surgery. Now, I know many people are in the hospital for a long time after something like the Whipple procedure or going through radiation, chemotherapy for an extended time, so there is other support you need. They've brought that all together at Dr. Hingorani's new center.

I want to talk about research for a minute, Dr. Hingorani, because that's made the news lately. Some identification of certain genes that may be at work here, both

some research here in Seattle and also the University of Michigan and some other centers as well. What's going on? How immediate can this hope be or what could it lead to?

Research for a Pancreatic Cancer

Dr. Hingorani:

There have been some exciting developments recently, and actually the pace fortunately of progress in this area has increased over the last several years, in no small part to the organization that you mentioned at the outset, namely the Pancreatic Cancer Action Network. They've been a great advocacy group not only for patients but also for fueling the research behind this progress.

One of the those discoveries involves an investigator here at the University of Washington, Dr. Terri Brentnall, who has been following this really highly unusual cohort of patients in the Pacific Northwest that has a very dramatic presentation of pancreas cancer. In this familial form of the disease for those patients who inherit the mutation they have just about a one hundred percent chance of getting pancreas cancer. And beyond that the cancer tends to occur very early compared to the population at large, namely in their 40s as opposed to the usual average age in the mid to late 60s in so-called spontaneous cases of the disease.

And just about a year ago now Dr. Brentnall after studies that have gone on for the past 12 to 15 years identified the mutation in a certain gene that's actually a structural gene that helps the cell maintain its shape and its morphology. It was an unexpected finding. I don't know that we would have thought to look at that particular area to begin with, but upon deeper reflection it may very well be that this mutation helps cells detach from each other and then begin that insidious process of invading and spreading to other parts of the body. So her group certainly is actively at work now trying to understand exactly how that mutation leads to cancer and endows the pancreas cancer cells with these highly lethal capabilities.

You alluded to another finding recently out of the University of Michigan involving a gene that's involved in DNA repair. And, you know, when you think about what cancer cells and pancreas cancer cells in particular are capable of it's really quite extraordinary. What in this particular case the cancer cells appear to have done is developed or expressed very high levels of a protein that helps it repair its genome particularly after damage by either chemotherapy or radiation. So you think about those two main modalities of therapy that I mentioned, we often use a combination of chemotherapy and radiation to try to damage the cancer cell and in particular the DNA, the software that drives any cell, and these particular cancer cells have figured out how to increase the expression of the repair protein, so it can respond even faster to that damage. And what you end up doing then is creating all of the side effects from those therapies without getting any or certainly very little of the benefit because the cancer cells have figured a way around it.

Andrew Schorr:

So a lot of the research goes on in mice. You have a whole lab there that you spend your time in as well as your clinical responsibilities trying to reproduce pancreas cancer in mice but in a way that where you can also have learnings that apply to people. Now, a lot of us, and I know my mom had colon cancer and I was following research very carefully there and anybody who has been touched by cancer, see something in the *New York Times*, some other publication, hear about promising research in mice, and then they say, yeah, we've cured cancer a hundred times in mice but it doesn't always apply to people. Where are you now, Dr. Hingorani, with your research and maybe some of your peers where there's learnings going on there that really could promise progress in people?

Dr. Hingorani:

Well, I do think that performing these kinds of studies and investigations ultimately in an animal organism in another mammal that's actually very similar to us at the DNA level is going to be critical. And the reason behind that is this: Some of the findings that we just discussed, which are extremely important, involve looking directly at the cancer cells and studying them in isolation. So we can get small pieces, particularly for example when you do an operation that Jeff underwent, of the tumor, and then we can grow the cancer cells in addition, study them there.

We can learn a great deal about the genetic events, the mutations in the DNA that help drive the cancer and help create the resistance to therapies in it, but what we don't learn is perhaps equally if not more important, which is how those cells survive in context. Because we know that we're actually quite able to kill cancer cells growing in a dish. Cancer cells that are growing on plastic in our laboratory have vulnerabilities that don't exist when those same cells are growing in the native organ from which they arose. So trying to kill a pancreas cancer cell while it's in the pancreas surrounded not only by the normal cells of the pancreas but also an entire armamentarium of fibroblasts and support cells and protein networks and immune cells, all of which really help shield the tumor from our treatments, is a wholly different thing.

So as I thought some ten years ago after being personally touched with this disease as you mentioned, about really whether or not to go on in this specific area, to be honest, the thing I had to think about first was to try to figure out why we hadn't made even more progress in this particular disease and what could we do differently going forward. And so we focus primarily on trying to recreate the human disease in its native setting in a system that we could study experimentally, and that is the mouse. And the reason for that is that our understanding of mouse genetics and our ability to manipulate the mouse genome is extraordinarily advanced compared to other types of species, and so we have tools that enable to us to turn genes on and off almost at will now, and we can study therefore directly whether or not a mutation that's been discovered in a cancer cell studied in isolation really has something to do with the disease or whether it's just a random event because cancer cells start to mutate their genomes at very high rates that's not related to the disease. So is it a red herring, or is it in fact something that's

essential? But as you mentioned, along the way to understanding which steps are important and which are not, if the model ends up being a faithful reproduction of the disease then you can begin to test your therapies instead of just on cells in a dish you can test them in this context that we think is going to be much more predictive of behavior in the clinic.

So what's been really hard and frustrating for scientists and patients alike I think are therapies that have shown a great deal of promise in the laboratory but have failed for any number of reasons in the clinic, and we think that the missing link was really studying the disease in its native context. So what we do now is we take the therapies that we think might be of value and we test them first in an intact organism that has the cancer growing in the pancreas, and if we see effects there, those are the therapies that we bring to the clinic to study in patients.

Andrew Schorr:

Okay. We're going to take a break. Jeff, before we do though, you've been listening to all this. People call you day in day out and they say, Jeff, from what you know, listening as an experienced patient are you hopeful? So when you listen to a dedicated researcher like this does that give you hope?

Jeff:

Oh, absolutely. In November, I think it was actually November 15th, the Pancreatic Cancer Action Network had its national symposium in Los Angeles, and I was honored to be the opening speaker that day and we had breakout sessions. And in fact some of the individuals that you and Dr. Hingorani have spoken about were there talking about some of the advance research that they're doing in both genetics, in gene diagnosis, and it's, I'm almost getting choked up now because to talk to someone like this right now who is spending his career on fighting this disease, and this is the fourth largest killer of all cancers, and yet it only receives two percent of the National Cancer Institute's research money each year, it does my heart good. I have friends that I've lost to this, friends that I've met, all of my phone buddies over the years that I've spoken to I try to follow up on them, and it's amazing how many are no longer with us. So I'm encouraged by it and can't wait for the next step.

Andrew Schorr:

Right. I want to say one thing as we go to the break though is you are here, Jeff, my in-law Yona is here, my friend in Houston, Mary Sharkey is here, there are examples. So if somebody says look at the statistics, oh, my goodness, but you're an individual situation, an individual patient, and Dr. Hingorani and his team and others like him around the country are dedicated to making you not be a sad statistic. We'll talk more about that after the break. Stay with us on Patient Power.

Andrew Schorr:

Continuing our discussion about pancreatic cancer in our live webcast, remember you can call in. Or send an e-mail to patientpower@seattlecca.org. Dr. Hingorani, I want to talk about, you know, we talked about the procedure, the Whipple procedure, one of the biggest abdominal procedures, maybe one of the biggest

operations of all, and I know my in-law Yona when she went through it in Los Angeles it was like a nine-hour surgery, and, Jeff, I think yours was like 12 hours.

Jeff:
Right.

Andrew Schorr:

But Ben in Los Angeles wrote in. I want to talk about other treatments and helping people, supporting people, so Ben in Los Angeles Dr. Hingorani wrote in, "What can be done to control the pain caused by pancreatic cancer?" So talk about that for a minute, just pain control.

Dr. Hingorani:

Well, that's often one of the greatest challenges with this disease. I mentioned that the pancreas sits deep in the body. It actually sits just above a plexus that we call the celiac plexus which has a bundle of nerves and vessels that go into it, and the tumor will very often invade that plexus and create terrible pain that can radiate across the back and the abdomen. So actually one of the main parts of our clinic here is the symptom management and pain management team, which includes Pam Davies and Dermot Fitzgibbon and Dr. Tony Back, and they're really dedicated to trying to control and really remove if possible this pain.

And the approaches involve anything from medicines you can take by mouth to actually direct injection of therapies into that plexus. Those types of treatments are typically actually designed to blunt and kill the nerve endings. So on the one hand it can be a pretty aggressive approach but also very effective in many cases for treating that pain. So depending on really the precise nature of Ben's pain I think some combination of oral medications and/or either a direct injection or this is a role also for radiation. Dr. Wui-Jin Koh is our radiation oncologist at the SCCA in our multidisciplinary clinic, and he's really quite adept at focusing his radiation just to the areas that might alleviate symptoms like this.

Andrew Schorr:

Now, another issue for people who may be going through chemotherapy and radiation, whether or not they have had surgery, is nutritional needs. Jeff, did I get it right that you went from like 180 pounds down to 135? Is that right?

Jeff:

That's exactly right. I lost, I can't remember the exact percentage, but it was close to 40 percent of my body weight.

Andrew Schorr:

Okay. So what about nutritional support for people at your clinic, Dr. Hingorani?

Dr. Hingorani:

So that too is a very important point, and I think Jeff's case is really emblematic of what can happen. Patients will very often have lost a tremendous amount of

weight even prior to the diagnosis. We then really ask them to undergo in the event that an operation is possible a pretty radical surgery, one of the most aggressive that humanity has invented, and we actually during the course of that surgery also reorganized their digestive tract. We have to reroute things after we remove the parts that are necessary for this cancer surgery, and then they have to convalesce from that. So quite often they have lost a significant amount of body weight, and nutrition is an important part of what we do. And Jennifer Kooreny is our nutrition expert at the clinic, and again all of these people are present simultaneously during the evaluation which we think is absolutely critical.

So we will start a nutrition evaluation and a plan right from the moment we meet the patient and begin that even prior to their going to surgery so that we can try to restore some of their body weight, bring their protein levels up. We think that those contribute to being able to tolerate the surgery better and recovering more quickly afterwards. Then of course these treatments, that treatment plan continues afterwards.

In addition very often patients will present with diabetes that has developed as a result of damage to the pancreas because of the cancer, number one, and, number two, we of course are going to take at least a portion and in some cases all of the pancreas out during the course of the surgery, and so that diabetes is only going to get worse, and so managing those aspects of nutrition are extremely important as well.

Andrew Schorr:

Dr. Hingorani, I have a question for you, and I'm going to pose the same question to Jeff. But you get asked it every day and Jeff maybe on the phone too. So somebody is there in front of you, maybe husband and wife, family members, and they know the statistics, and maybe the diagnosis has already been confirmed, and they say, you know, should I believe these statistics apply to me. And I know it's a rough discussion, but how do you counsel people? I know you have that individual discussion, but before people know their individual situation should they assume that they are on the bad side of the statistics?

Applying Statistics to Pancreatic Cancer

Dr. Hingorani:

That's a very important question, and, you know, I'm going to flip it around a little bit to help explain my approach to it and something that was actually profound for me. I can recall a situation in which I was treating a patient with a different type of cancer in whom we have a very high success of being able to cure them, and in this particular case the success rate was, say, 90 percent or greater, and that of course is always wonderful news to be able to give to a patient. It turned out that this particular patient was sadly one of those people in the remaining 10 percent that do not survive that disease. And when you sit down and think about it, at that point it really matters not at all that 90 percent or more of patients survive if you or your loved one is the one that did not.

And that really, there's a very palpable lesson in that because the flip side is also true. This is a very challenging disease. There's no question about it, and the statistics and the numbers do not necessarily give cause for a great deal of hope. On the other hand a patient is not a statistic. A patient is an individual sitting before you with their own unique presentation, their own unique physiology and their own unique abilities to engage and surmount a challenge. So really at that point it becomes irrelevant. Knowing all the data can help you think about in global terms your approach to the disease process, and it helps inform what I do in the laboratory, but when I walk into a room and I meet a patient all that matters is the person before me.

And the other thing that is very important is that in that given patient I do not know exactly what's going to happen, so it's important to recognize and acknowledge what we don't know, and for all I know this could be the patient that has a marvelous outcome. So I just assume that that's going to be the case, and we go from there.

Andrew Schorr:

So well said. And your dedication, I can't take my hat off to you enough.

Jeff, so you talk to people every day, and they ask the same question of you. How do you answer it?

Jeff:

The way I answer it is first of all, you can go on the internet and the internet will give you all the percentages, when I came out of surgery after 12 hours on the table for my Whipple I was told that I had nine to 12 months to live, get my affairs in order, and that was basically it. What I tell patients is those are just percentages, and those percentages, if the percentages are ten percent of the people that go through pancreatic cancer are going to make it to one year, well, that means you just need to be in the 90th percentile. I tell people, everyone that I speak to that, and Patient Power is, I love the name of the show because that's exactly what it is. You need to draw off your community, your loved ones. You need to, you're basically faced with a war, and you can either go to battle or you can go to war. It's up to you. You need to take charge of your disease.

Sure, your doctors are going to be the ones who are going to make the ultimate decisions, but you need to be in charge of it. If you need to get second or third opinions and one doctor doesn't like that, it doesn't make any difference. This is your disease. You're the one, and you don't want to become a statistic. Ask questions, get answers. Have someone with you to listen. Make lists. Set your limitations in terms of what you can and can't do. If you don't want to see people in the hospital when you're in there, then don't see them. If you need to rest, if you need to change your lifestyle, embrace all disciplines, whether it be Western, Eastern, kinesiology. I actually went through kinesiology, acupuncture, acupressure, macrobiotic diets, supplements. I tried everything because it's a war.

Andrew Schorr:

Right.

Jeff:

And I'm living proof that you can beat it.

Andrew Schorr:

Yes, you are. Yes, you are, and that's my dream for everyone. I want to say I want to remind people they're not alone. So you have Dr. Hingorani and his new specialty center, multidisciplinary center at the Seattle Cancer Care Alliance in Seattle. People come from all over the world to that center for bone marrow transplant, where they invented it, and now with a center like this related to a very uncommon and very deadly cancer, they're all there.

By the way, it was just, Tamara, my producer, just sent me something because we're all aware that there's some very famous people who have been diagnosed with pancreatic cancer. Justice Ginsburg is fighting it, and we wish her all the best. You can't open a tabloid, and Jeff was quoting one, Patrick Swayze, the actor. Here's a quote she just gave me that's in the newspaper today. Patrick Swayze today said, "It's amazing to me that a tabloid such as *The National Enquirer* prints such negative stories about me and my health when there are so many positive things going on in my life right now. I've started chemotherapy, and once again I'm one of the lucky ones with pancreatic cancer that is responding well to the treatment." So we wish that for everyone and wish that for Patrick.

And what's also, I want to point out, beyond the wonderful work that Dr. Hingorani and his colleagues are doing at the SCCA is we mentioned the Pancreatic Cancer Action Network. So they have this PALS program, and that is the Patient Liaison Services Program. So you are not alone. There's a help line for patients and family members. There's a toll-free number, I'll give it one time here, 877-272-6226. Or you can e-mail, get connected with a guy like Jeff Ross, PALS at pancan.org.

Jeff:

If there's anybody out there that listens to this or reads the transcripts who wants to speak to me directly, PALS will give you my number. Or if you want to speak to a woman or you want to speak to someone who is your stage or whatever, they will give you the name.

Andrew Schorr:

Or a family member, too.

Jeff:

A family member or part of your support group.

Andrew Schorr:

Well, as we see, Jeff, I want to say, you're coming up on six years. I hope they can call you in seven years, eight years, ten years, 20 years, and I hope fewer people need to call.

Jeff:

Same back at you, Andrew.

Andrew Schorr:

Thank you for being with us. Going just a couple minutes long. I want to give the last word to Dr. Hingorani. Dr. Hingorani, I'm kind of sitting here, and I know this can be emotional for you, but every day that you go to that clinic, every day you go into the lab you've got to think about your dad and turn it into a positive. I want to thank you for that, but I know you must think about that.

Dr. Hingorani:

Well, I do actually. In a way to this day the biggest failure that I have had so far has been the loss of my father. I actually was his oncologist in the last several months of his life, and although I think he was able to accomplish a lot of the things he wanted to accomplish during that period and was as comfortable as possible in the end we couldn't save him. But on the other hand I think sometimes about that time and I think what has come out of that, and I feel in many ways that he is driving and does provide the motivation for what I do now because it's also changed and informed my perspective. I think about everything now from the standpoint of what he went through, what my mother went through, what we went through as a family, and in the end that's really all that matters.

And I want to second what Jeff said. This disease is not about the physician. It's not about the care providers. It's not even about the entire team. It's about the patient, and the patient needs to do anything and everything to maximize their care to make themselves comfortable. So I actively encourage second, third, you know, fifth opinions. We need to remember that it's not about us, it's about them. And we're fortunate in Seattle, for example, to have a number of outstanding centers here that provide high quality medical care, and I frequently refer patients there for second opinions, and I know they do the same.

I think we're entering a time now where finally the promise that this new era in molecular medicine and molecular biology has heralded is really within reach, and I feel quite optimistic that in the next five to seven years our approach to this disease, how we detect it, diagnose it and treat it will be profoundly different.

And I want to thank you, your group, I do love the name as well, Patient Power is perfect, PanCAN and patients like Jeff for helping to continue to provide the inspiration for this fight and to communicate and get information out to the community about what can be done and what needs yet to be done.

Andrew Schorr:

Well, thank you so much. We are all trying to make a difference, but again thank you for what you do every day and the people you help in your new multidisciplinary pancreas cancer specialty clinic at the Seattle Cancer Care Alliance.

Wherever you go for care, you and your family, make sure it's a team that's working together to help you get the benefit of the latest for your personalized care and where if there's new research that's been studied that you can talk about where that applies to you. Thank you so much for joining us. Jeff, all the best to you. Keep helping people year after year. I'm going to come see you in sunny southern California. Dr. Hingorani, thank you. Thanks to the Seattle Cancer Care Alliance for all they do. I'm Andrew Schorr. Remember knowledge can be the best medicine of all. Thanks for joining us. 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.