



*Hosts*

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## A Survivor's Perspective with Robert Shickel

**Guest:**

**Robert Shickel**

*Cancer Survivor*

**Yale Cancer Center Answers**

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*Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is [canceranswers@yale.edu](mailto:canceranswers@yale.edu) and the phone number is 1-888-234-4YCC. This week, Francine and Lynn are joined by cancer survivor, Robert Shickel. Here is Francine Foss.*

Foss Can you start off by telling the audience a little bit about your diagnosis and how you ended up here at Yale Cancer Center?

Shickel My diagnosis is a rare blood cancer. It is a lymphoma, a non-Hodgkin's lymphoma known as angioimmunoblastic T-cell lymphoma. I got the diagnosis in August 2005 and at that time I was told that I was at stage IV. Candidly, I have shortened angioimmunoblastic T-cell lymphoma because it uses all the vowels and most of the consonants. I shortened it to AITL just for portability.

Foss It is a tongue twister and we appreciate that.

Shickel And at cocktail parties, it can really pour salt in the Kool-Aid. As far as the characteristics of the disease, it is an aggressive blood cancer that to my knowledge, and others can certainly comment on this, has no specific treatments. As I understand it, it is an incurable cancer, there is no cure. Once you get it, you got it. In terms of the disease itself, I have learned that it is a very, very intelligent cancer. If you are going to prevail over this, it is tough, you have to become tougher.

Foss Can you tell us when you were diagnosed?

Shickel The diagnosis occurred in August 2005, but the onset of symptoms actually occurred in June 2004. At first, I got what I would characterize as itchy red spots. I changed that to the IRS because there seems to be a great affinity between the two. They started out very small and usually on my lower legs and my forearms, and they were a lot like mosquito bites except that they would never go away. Those evolved into what I characterize as itchy red areas, which also include the mosquito bite like spots with very, very aggressive and intense itching to the point where there was no way that I could avoid scratching them open and they evolved into enlarged and very firm lymph nodes in my neck. From that point on, from June 2004, I began an odyssey of trying to find out what was going on. Over the ensuing 14 months to the time I received the diagnosis, I went through two hospitals. I had eight surgical biopsies. I saw 13 doctors, and I had countless, I mean, absolutely countless blood tests. And all of the results, the pathologies from the biopsies and so forth, came back pretty much with the same thing, that I had a rare sinus disorder and it would heal and I would be cured in 4 to 6 weeks, but 4 to 6 weeks went by, 8 weeks went by, months went by,

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and all that happened is that I got more and more of these symptoms to the point where by the time I was diagnosed, I had about 100 of these red spots that I would dab half a dozen times a day including into the wee hours of the morning with cortisone, and it has just been an endless pursuit.

Wilson How was the diagnosis eventually made and what were the steps that you took to get to that point to figure out what was really happening?

Shickel Reluctantly, I went to see an oncologist, but I talked myself into going to see the oncologist because he was also a hematologist. I had been in the process of eliminating the options as far as what it could be, and in the background I was making progress towards the diagnosis of cancer, and I knew that both consciously and subconsciously. That doctor was Peter Dixon in Essex, great guy, absolutely first-class doctor and oncologist and he stood by me every inch of the way. And one of the things that he said fairly early on in our meetings was that he did not know what I had because I had so many tests and so forth, but, and this is pretty interesting, he said, well, why don't we get whatever you have to tell us what is going on. And he said that it will happen, but he said wherever you are, just drop what you are doing and call my office, be here first thing in morning. And luck of the draw, I was out of state. It was a 4-hour drive back, 3 o'clock in the morning. The cancer just flushed from under my arms down into the groin areas in the space of 36 hours. So I did exactly as he said, 8 o'clock the next morning I was face-to-face with Peter, and we agreed to do five biopsies, five surgical biopsies much more extensive than what had been done before, and it took quite a while for the results to come back, and interestingly, just like before, just like the previous surgical biopsies, they came back as benign, basically a sinus infection, we did not know what it was. And so twice Peter sent the slides back for reassessment, and on the return of the second one it came back exactly the same. Peter decided to break camp, and he sent the slides to a pair of pathologists at another hospital where he had a very good relationship and he knew the quality of these pathologists. And in a bit of humor, he said, "I told them, keep this patient in mind, he does not have nothing, so figure out what it is and do not send it back to me until you have the results, I would like them back as soon as possible," typical Peter.

Wilson And how long did that take between that morning when you went to his office, until after all this finally got sorted out?

Shickel Approximately 3 weeks.

Foss You have been on a very long journey, so to speak, from the time these lesions first came out and sought medical opinions. Had you started to worry about cancer? When did that cross your mind, and what did you actually think was going on?

Shickel When the thought of cancer crossed my mind it was September 2004, when I went to my PCP at that time and I asked him to take a look at the enlarged lymph nodes in my neck and also the other symptoms the spots and the rash and the blood seemed to just drain from his face. He and I had

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known each other for 15 years and he asked me to come into his office and sat there and he told me point blank, eye ball to eye ball, you have lymphoma, you are going to need chemo and you are going to need radiation, and I got the news pretty hard.

Foss Prior to that, when you had the red spots, were you worried?

Shickel I was very worried, but I had made a couple of visits to doctors and they assured me that this was pretty much a sinus infection or just one of those things that happened and I would get over it, but I did not get over it.

Foss A lot of patients are in a little bit of denial and when they hear the word cancer, it hits them like a lead balloon, but you had thought previously that you may have cancer?

Shickel Correct.

Foss So was there still the same impact when you actually heard the word from a doctor?

Shickel If you are referring to the question of did I feel fear, the answer is yes, but it was different than what I might ever have expected. I had pretty much been prepared for cancer, because it did not seem to me that there were many other options left, unless there was something really rare and esoteric, but I did not know what it might be. And it seemed to me that cancer was the only remaining option. In terms of the fear, looking back on it, it was not what I expected. The fear was different. It was the fear of candidly leaving people behind. I knew that wherever I was in this cancer experience, and I was fairly advanced at that time, it was of failing commitments. It was having made commitments to people that I cared very deeply about and failing that. And as far as the other fear, the fear of dying, I have been in kind of face-to-face confrontations with life-death situations a few times, and one of the things I have learned about fear is that it cannot be a stop sign. You really have to galvanize the fear into something that can be put on a shelf and then make priorities and put action in play.

Foss How did you tell your loved ones?

Shickel Honestly, with a lot less elegance than I would like to admit. I kept my family in close contact and they knew pretty much everything that was going on, and so I did not think at that moment it would be a big surprise to them, but in fact it was much more of a surprise to them than it was to me. And so the way I handled it, as I said, was less than elegant, and it was through phone contact and email. We are a close knit family, but there is quite a bit of distance, physical distance, between us in terms my wife and I live in Essex, but one son lives in the Boston area and the other one lives in San Francisco. So, there was not any good efficient way to gather everybody together.

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- Wilson        When Dr. Dixon got this information back and the diagnosis was at least preliminarily made, what sort of steps did you take with Dr. Dixon at that point?
- Shickel       Peter is very much a pragmatist and he looked at me and he said, I know you want to go fast. He says I know it's in your nature and type A's like to do that, but he said, we are going to go slower. And he said this is so rare, we cannot afford to make a mistake. He said that time was very much of an asset or an adversary and so what we are going to do is a second opinion. I listened to the second opinion thing and I thought, I have come so far and I just do not want to lose it now, but I trusted Peter implicitly. And so we did do a second opinion. He selected a cancer hospital, Dana-Farber in Boston, and he selected a doctor at Dana-Farber with lymphoma experience. And so the diagnosis was confirmed fairly quickly at Dana-Farber.
- Foss            Can you give advice to patients on that issue of getting that second opinion? Is that something that you think that all patients should do after they get a diagnosis or only patients with these rare cancers?
- Shickel        I think that one thing that a patient has to do, first and foremost when they receive a diagnosis of cancer, is learn very quickly to become their own advocate, and if nothing else, the second opinion should be the next thing that they do. If for no other reason than to set their own minds at peace as to this is the problem I face and now we can go forward so there is no doubt, there is no looking back over your shoulder.
- Foss            And in fact, most oncologists are willing to do that, as your experience with your oncologist, I think most oncologists are willing to entertain a second opinion if a patient asked for it.
- Shickel        If I take a page from the Yale experience, and I may be jumping ahead here but nonetheless, Yale uses a multidisciplinary approach to many things in treating patients with cancer. And so I benefited from that and we have done multiple second opinions on a variety of things at Yale and I cannot endorse that too much.
- Foss            Do you want to talk a little bit, just briefly, about your treatment? We only have a minute before the break, but do you want to just tell us briefly what you have been doing?
- Shickel        In terms of the treatment here at Yale or the other treatments that led up to coming to Yale?
- Foss            The treatment here at Yale.
- Shickel        The treatment here at Yale was with ONTAK, and it is interesting the way I got to Yale quite frankly it was based on two factors, number one, time; I knew I was running out of time. I did not

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know how much time, but I was running out of time. And secondly, I maintained a list of doctors and of treatment options, and I think that you, Dr. Foss, know this, you were next on my list.

Wilson We are going to take a short break for a medial minute. Please stay tuned to hear more about Robert Shickel's experience with cancer.

*Medical  
Minute*

*This year over 200,000 Americans will be diagnosed with lung cancer, and in Connecticut alone there will be over 2,000 new cases. More than 85% of lung cancer diagnoses are related to smoking and quitting, even after decades of use, can significantly reduce your risk of developing lung cancer. Each day patients with lung cancer are surviving, thanks to increased access to advanced therapies and specialized care. New treatment options and surgical techniques are giving lung cancer survivors more help than they have ever had before. Clinical trials are currently under way at federally designated comprehensive cancer centers, like the one at Yale, to test innovative new treatments for lung cancer. An option for lung cancer patients in need of surgery at Yale Cancer Center is a video-assisted thoracoscopic surgery, also known as a VATS procedure, which is a minimally invasive technique. This has been a medical minute. More information is available at [yalecancercenter.org](http://yalecancercenter.org). You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.*

Wilson Welcome back to Yale Cancer Center Answers. This is Dr. Lynn Wilson and I am joined by my co-host, Dr. Francine Foss. Today, we are joined by Robert Shickel, who is sharing his story of survivorship. Rob, after the diagnosis was confirmed with Dr. Dixon, tell us about what you went through in terms of the first set of treatments and what that course was like for you.

Shickel There were multiple treatments and until I reached Yale, they were all failures, and it is not to characterize them badly, it is just a fact of life. The first sequence was with CHOP, from September 2005 to December 2005. I went through a remission that ended in April 2006. Thereafter, on the advice of another oncologist, I got into a watch-and-observe program until September 2006, and that was an unmitigated disaster. In an aggressive cancer, it just did not work.

Wilson Did all of the problems just come back again, the skin, the lymph nodes?

Shickel What happened is it came back more aggressive than anything I had seen before, and each time it returned, it seemed to return with more aggression and smarter. The next one after that was with a nonclinical, clinical, in cyclosporine. That failed. It ran from October 2006 to January 2006, and then I entered into another clinical at Memorial Sloan-Kettering on a new investigational called PR-171. That failed so quickly that I almost could not believe what was happening. In other

17:24 into mp3 file [http://medicine.yale.edu/cancer/podcasts/2011\\_0703\\_YCC\\_Answers -  
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words if I look back from April 2007 to September 2005, I was just failing one after the other with increasing speed.

Wilson What you mean by smarter? Do you think it was sort of figuring out ways to get around these different treatments, if something was going to have any chance of success, the cancer could figure out a way to circumvent that?

Shickel If I put that in my own vernacular, the cancer was evolving to the point where everything that I threw at it, it was smart enough to be able to swat away with relative ease. So, in effect, what I observed was that the chemos were killing the easier to attack, less defensive hardened cells leaving the more aggressive, the more battle-hardened and the more resistant that had learned to adapt. And so what I ended up with was very aggressive, what I call battle-hardened cancer cells, T-cells.

Wilson You have been through a lot, what got you to Yale and to Francine?

Shickel I knew I was running out of time. The clinical at Sloan was 3 weeks but if I am really honest, it was a lot less than that. As I said I maintained a list of doctors and options, and I had gone through all of the doctors and half of the treatment options, and then I came home from Sloan one evening any my wife was just totally bouncing around the kitchen in great spirits, and I am trying to tell her, Val, I need to get some dinner and go to bed and get up so I can go back to Sloan. And that was an all-day event, getting up at 4:30, getting home at 6:30 and so forth, but the reason that she was so animated was that she had heard about a woman, a doctor who was giving a presentation on my cancer. She was totally unable to be suppressed. So, I said, okay, dinner, and I will go see this thing. And it was a presentation given by your co-host, Dr. Foss. And I think I am a relatively quick study. So, I sat there in the audience and in the first minute I can tell that Dr. Foss probably knew more about my cancer, AITL, than all of the other people I had met. So, with no shyness at all, at the break I went up, introduced myself, and said that I am your next patient.

Foss When I first saw you, Rob, you were in a position where people had pretty much thrown up their hands and did not have really a whole lot to offer you and were kind of sending you away and saying, well, if you do not get a bone marrow transplant, there is nothing left out there for you. So, you were very aggressive in terms of pursuing the next step for yourself.

Shickel The bone marrow transplant was a very important issue, but the aggressiveness or what I will call the advocacy and the perseverance, were things that I just could not let those people down. It was not in me to do that. And so when we first met, I had just come off of two clinical trials that had failed. I had not seen anything other than CHOP. I went through the watch-and-observe, and I was very much of a Doubting Thomas. And without too much reservation, I thought I was a pretty tough case. However, at that time, I had never had a PET scan, and I think that that is important.

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The PET would have told the real story about where the cancer was. I had not had a PET scan. And the first thing that Dr. Foss wanted to do was a PET scan. When I saw the PET scan results, I could not believe what I was looking at. There were about 11 tumors in my neck approximately, but what really galvanized my attention was not the size of tumors but the two or three that were within a couple, let us say, a centimeter of my esophagus. I knew I did not have any tickets left. It was over. I either had to land at a place where there was a team that knew how to deal with this or I had to face the music of what other people had said which was, “There is nothing more we can do for you.” I came to believe along the way that when you hear that, that really just means that that is one person’s opinion.

Foss           What you decided to do, and I think you decided this from the very beginning, was to take charge of this whole process, and that is something that you and I have talked about a lot that patients really need to get involved. They need to take charge of the process of their care. They need to get involved in it. They need to be out there looking at things on their own. Can you comment on your whole journey from that point of view and what you would recommend to other patients?

Shickel       That is absolutely correct. When I began this journey, I will be honest with you, I did not know what I did not know. And so education became an incredibly valuable asset. I would get people to do things that they did not know that they could do. I got a librarian at a hospital to dive into medical documents, publications from literally around the world, publications that would cost thousands of dollars to be able to access, and she became just giddy with the fact that she could do this. I began by chasing down very esoteric terms for myself. I began to understand some of what could be done and what could not be done. I began to locate doctors who had experience and had done publications in this area, and I also had the benefit of people who kept kicking me along. A very close friend in Deep River was relentless, he would not let me rest, and so I did not do it solo, but I had the benefit of a lot of people who kept nurturing me along the way, and after a while, I was able to take the training wheels off and do it on my own.

Foss           You have written about your experience. I know you probably do not want to talk too much about this because it is not published yet but you have certainly taken a role as an advocate in a broader sense. Could you talk a little bit about that?

Shickel       You are really getting into the issue about how cancer can change a life, and I cannot do this unemotionally, so you will have to pardon me, but I have lost two close friends, and I feel that I cannot let those friends down. One of them was actually my mentor, a young lady of only 35 who died as a result of Hodgkin’s disease. And so, what I have done is began a campaign on my own to be able to reach out to people using my skills of 20 years in Silicon Valley based high techs, and my writing skills to create a media that people can hopefully draw upon, not that I am trying to tell them how to manage their cancer experience, but as a resource that they can pick through and use to hopefully get some insight into managing theirs. The first book of which there are now

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approximately 10 in development, hopefully will be published the second half of this year and is called ‘*Cancer Chronicles” Who Gave Me Cancer.*’ And what it does is it chronicles the experiences of three people who have cancer. It is gender and cancer-agnostic so that it deals with three cancers of blood, melanoma, and bladder cancer. It is something that we can all get, and it observes how the odyssey of these people unfolds in dealing with their cancers, some get it and some do not.

Foss And are these real people?

Shickel My comment on that is that I agree with Hemingway, that all fiction has to rest on truth, and so the answer is yes, but they are composites of real people.

Foss How do you see this helping other people, what messages do you hope that people get from this?

Shickel I cannot tell you how many books on cancer I have read, how many publications on cancer, and they all seem to be very dogmatic, do this, do not do that and so forth, but I think that literature in the form of what I will call true fiction gives us a metaphor to be able to see how we might react, and it is less dogmatic and it allows us to pick it up along the way to move on. The book is thematic in the sense that what it does is moves the patient through the cancer experience, and in the first book it’s creating a boot camp, if you will. We get to identify with the characters, they could be us, and we get to identify with their cancer. We engage in their dialogue with their doctors, and then it moves on and the bar is actually raised in the second book, which is, ‘*My Cancer Never Sleeps,*’ and it gets raised in the sense of, here are the tools and we are still watching these people deal with the cancer, each of their cancers, and here are the tools that they are using, here are the steps and missteps, but it is in a real-world environment in the form of fiction.

Foss Rob, you are a survivor but you are not cured. How do you reconcile those two concepts? Do you feel like a survivor?

Shickel There is no doubt that I feel like a survivor. Some time ago, I set a goal to reach 100, and I refused to change that. In fact, the way that I am measuring this goal is against my aunt. My aunt was 100 last year, and she has raised the bar for me because she will be 101. And I know she is going to raise it again to 102 next year. So, if I am going to prevail, I have got some pretty good genes to work with, but in terms of being a survivor, I happen to have drawn a card that gave me cancer. I cannot put it back in the deck. I am very fortunate to be at Yale in the treatment with ONTAK and my team. I have been to six hospitals, six or seven, I am losing track of the number of hospitals, but by the time I reached Yale, I was on my 24th doctor. I look at Yale as being my second home, quite frankly. I look forward to going there. I know I cannot change the cancer. I know it is incurable, I don’t want to have cancer, certainly, but I cannot change that; what I can do is learn how to survive with cancer.

*Robert Shickel is a cancer survivor. If you have questions or would like to share your comments, visit [yalecancercenter.org](http://yalecancercenter.org), where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.*