

Judy Jones, Patient Resources for Cutaneous T Cell Lymphoma November 15, 2009 Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Francine Foss, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Foss is a Professor of Medical Oncology and Dermatology specializing in the treatment of lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1888-234-4YCC. This evening, Francine welcomes Judy Jones. Judy is the director of the Cutaneous Lymphoma Foundation and is also a survivor of the disease. Foss Judy, can you start our listeners off by explaining to them what the Cutaneous Lymphoma Foundation is? Jones The Cutaneous Lymphoma Foundation is an organization that was formed to deal specifically with cutaneous lymphomas. There are a lot of other cancer organizations but our patients have trouble identifying with those different treatments, and so that's why we are very specific. Foss And you founded this organization. Can you explain a little bit about that? Jones Well, when I was first diagnosed, I had nobody to talk to and nobody that knew anything about this disease and it was very, very lonely. So, I got on the internet and tried to find a couple of other people to talk to and one thing led to another and we formed the foundation. Foss Cutaneous T-cell lymphoma is a very rare disease. Can you tell our audience a little bit about how rare it is compared to other kinds of lymphomas or cancers? Jones Only 10% of lymphomas are T-cell lymphomas, and only about 2% of those are cutaneous T-cell lymphomas. There are probably about 1,500 new cases diagnosed every year. Foss There are other foundations like the Leukemia Lymphoma Foundation, for instance, were they helpful to you as a patient or did you just not find enough information that pertained to you? Jones Since they handle all of the different lymphomas and leukemias there wasn't that much information on cutaneous lymphoma because it is so rare. Foss You started this whole thing out as a patient with a disease; was it difficult for you as a patient to find the right doctors to get the right treatment for your disease, given that it was a rare kind of cancer? Jones I happened to be very fortunate because I was near a major cancer center that actually had a clinic in cutaneous lymphoma. Most people are not that fortunate. It actually took me about a year and half before I got to that place because I was misdiagnosed several times. Now with the Internet we are able to post information on the clinical centers that specialize and patients are able to get to them a lot easier. 3:19 into mp3 file <http://www.yalecancercenter.org/podcast/nov1509-cutaneous-T-Cell-lymphoma.mp3> Foss Can you take us through the steps that went through your mind as a cancer patient that led you up to the point where you actually got up enough energy to put together this foundation? Jones The first hurdle that I had to get over was the fact that I probably was not going to die. Getting a diagnosis of cancer is really scary, and I had to go through several treatments before I could finally get it under control. Once I got it in under control, I thought, you know, I wish that I had had some of this information a lot sooner and I wanted to make sure that other patients did not have to go through the long period that I did with no information. Foss What was the first step in terms of actually starting a foundation? Jones I started a

ListServ, which is an online support group, and all I was doing was getting patients together for support. Then a doctor found out about it, Dr. Stuart Lessin, and he called me and said, "You need to start a foundation." I didn't know what I was doing at that time, but I figured out how to start a foundation; I learned about nonprofit, I learned about the medical community and it has grown much faster and much larger than I had ever imagined.

Foss Judy, did you have any special background in business or in other areas that helped you in terms of starting this whole effort with the foundation?

Jones I do have a counseling background and that has helped me talk to patients and understand a little bit more about what their emotional needs are.

Foss When you started the list, how many patients found about it and how quickly?

Jones In the first month we had 10. This was about 15 years ago before we had a lot of the Yahoo groups, and it is much easier to get on the Internet right now. Currently we have over 1000 members on this ListServ sharing their experiences from about 26 different countries.

Foss This all started out with a ListServ and then it came to the attention of Dr. Lessin who said, let's get a foundation going. What were the next steps?

Jones Trying to figure out how to learn the nonprofit system, and that is where the business part came in. I knew that if I was going to start this I wanted to do it the right way and make sure that we were following all of the rules and regulations that we had to, and so it was kind of like going back to school and getting a new degree.

Foss Essentially you did all of this yourself?

Jones Yes.

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Foss What would you recommend to other people out there who are listening to this saying, "Wow! I can't believe she did all this." What would you recommend to a patient who is interested in this kind of thing, stepping into this arena? Do they need legal help? Do they need others to get involved with them or is this something that someone can do by themselves?

Jones If anybody is interested in starting a nonprofit what they really need to do is find out who else is doing something similar and talk to them; find a mentor. I was able to talk to Vicki Kalabokes, who was heading up the National Alopecia Areata Foundation and Gail Zimmerman who was heading up the National Psoriasis Foundation, and they gave me step-by-step instructions on what I had to do to make sure that I was going down the right path.

Foss Are you now partnering with other organizations like the Lymphoma Research Foundation and the Leukemia Lymphoma Foundation?

Jones Yes. We belong to the Skin Disease Coalition, which is a group of several different skin disease organizations and we work with them on a lot of things. We also work with the Lymphoma Research Foundation and do a lot of educational programs. When they have a lymphoma workshop, they will call us and we will give them the names of the physicians for a specific breakout in cutaneous lymphoma.

Foss One of the things that you have done with your foundation, Judy, is that you have been able to successfully network physician, nurse practitioners, and ancillary personnel who are treating this disease from across the country and even across the world. Can you talk a little bit about that process?

Jones Being a small organization there is no way that I can march up to Congress and say I want some money for cutaneous lymphoma, because they wouldn't listen to me. But I can collaborate with other

organizations and I can lobby for additional research money for skin diseases. I can lobby for additional money for blood diseases, and obviously lately with health reform I am very interested in making sure that rare diseases do not get left behind.

Foss For our listeners, can you define what a rare disease is, how does Congress look at a rare disease versus something like lung cancer?

Jones A rare disease is one that has less than 30,000 people.

Foss Are there specific initiatives at this point at the level of the Federal Government, the NIH, or Congress, to address rare diseases like this?

Jones Yes. The National Institutes of Health are very aware of the rare diseases and the different issues that they have. There are a couple of new programs that have just started up to facilitate research in rare diseases.

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Foss Is that research mostly basic research or clinical, or does it straddle between the two?

Jones The new program that is started is for basic research, and I think that basic research is where a lot of the answers are going to come that are going to benefit many diseases, not just ours.

Foss What about the whole issue of patient support for patients who have rare diseases like yourself, who don't understand much about them and it is really hard to get that information? Are there support networks that are building up now around rare diseases?

Jones Yes. There is the Genetic Alliance for Genetic Diseases, there is NORD, National Organization of Rare Diseases, and there are the organizations like ours that are very specific for one particular disease.

Foss Are there organizations that bring all of these rare diseases together under one umbrella, or are they pretty much still independent organizations? Do you think there would be any benefit to that?

Jones The more that we can work together the stronger we can be, and I do work with NORD and with the Genetic Alliance on different issues that come up over the rare diseases.

Foss Can we take a giant step back now and talk a little about you, Judy. You had this rare cancer and you got treated. Did you get chemotherapy?

Jones No, I did not get chemotherapy. Most of the first-line treatments would be skin directed and that is where I started out, with phototherapy, which is called PUVA, and that worked for a while but then didn't work. I went to interferon, I went to a topical nitrogen mustard, and all of these I responded to for a short period of time, but it did not last. And so I ended up going into a clinical trial.

Foss One of the first things that you said when we started the program is that when you figured out that you were not going to die from this cancer, you decided to start a foundation. From the point of view of a patient, when do you make that decision, when do you realize I am not going to die from this cancer? How difficult is it to make that transition from the initial shock of finding out that you have cancer?

Jones That's a really good question. It is one of those things that is a process and I did go and talk to a counselor because I was not living my life at that point because I was waiting to die, and it was not a fun position to be in, so I decided that I had to learn how to live every day so my life would mean something.

Foss Well you certainly have taken it a long way from there, getting to the point you are at now with this foundation. We are going to take a break now and come back and talk a little bit more to Judy.

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Cell-lymphoma.mp3 You are listening to Yale Cancer Center Answers and we are here discussing advocacy and the Cutaneous T-Cell Lymphoma Foundation with Judy Jones. Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am joined by Judy Jones, Executive Director of the Cutaneous Lymphoma Foundation. Judy, before the break I made the mistake of calling it the Cutaneous T-Cell Lymphoma Foundation, and that's because I know that originally that's how it started off, but since then it has evolved. Can you talk a little about that? Jones Yes. We started out being very specific and called it the Mycosis Fungoides Foundation because that was a subset of T-cell lymphoma, and then we realized that we were actually serving patients that had more T-cell lymphomas and so we thought, okay maybe we should call it T-cell lymphoma, and then we realized that there were a greater number of people that had cutaneous lymphomas that were not T cell, they are B cells. So, we changed the name of the organization to cover all cutaneous lymphomas because they are all very very rare and all treated similarly. Foss How has the foundation changed over the last five years from the very nascent group that you put together from the ListServ to where we are today? Jones When we first started we were only interested in giving support to patients, and that evolved into providing education. We have a website that has a tremendous amount of information now. We have a medical advisory board that goes over this information on a yearly basis to make sure that it is accurate and up-to-date. We also realized that there were a lot of physicians out there that were not working in academic centers and only saw maybe one person with cutaneous lymphoma in 10 years. So, we had to get information out to them as to how to treat this disease. Foss Most recently, Judy, a real feather in your cap I would say, is that you just came back from New York City after having conducted the first Cutaneous Lymphoma Summit, which was sponsored by you and your foundation. Can you talk about that, and don't be shy? Jones It was a really exciting weekend. This disease is treated by dermatologists, oncologists, and radiation oncologists and a lot of times it's hard to get the different disciplines together to share information on how the disease is treated. I wanted to get them all together and answer some questions in this conference. What I wanted to know is what do we know about the disease, what we don't know about the disease, and where do we have to go to put all of this information together? So, from this summit we hope to put together a roadmap that will show us which path we have to take to fund research and move the understanding of this disease forward. Foss Having just participated in that summit, Judy, I just want to let our audience know that this was a summit for both patients and physicians and that we had the world's experts in cutaneous lymphoma not only from the United States, but also from overseas as well attending this summit and it really was a multimodality approach. I think that's an important point you made Judy, and we talk often times on this show about approaching cancer from more than one point of view. So, in addition to having the physicians there, you also had a component for caregivers and for the nurses who are taking care of these pa-

tients. Can you elaborate a little bit about that part of it? Jones It is really interesting to get everybody together. Patients are just amazed when they see all of these physicians in one room. Lots of times patients think that the only thing that their physicians do is see patients, and it's good for them to know that they are out there doing research, they are out there sharing information with their colleagues and they are working to provide better treatment for the patients. Foss It was also important to us as physicians to hear from patients about how interested they are in clinical research and how much they want to be a part of that whole process. Jones Yes, I think that patients are willing to participate in clinical trials if they know about them and we really need to get information out about clinical trials and how important they are. Foss Are you excited about some of the new drugs that have been developed for cutaneous lymphomas? Jones I am very excited. When I was first diagnosed there was one new drug approved and it had been 10 years since a drug had been approved for this disease. A year later another one was approved and it was 7 years until another one was approved. This past month we have had two new treatments approved and there are several things in the pipeline right now, so the research has accelerated. Foss And I think a lot of that has to do with organizations like yours who provide advocacy, say to the FDA as well as to drug companies who have drugs, to really push them to develop those drugs for orphan diseases, because as you know, there is not a huge amount of profit for some of these. Jones Yes, I think that's true. Foss I'm going to put that into mp3 file <http://www.yalecancercenter.org/podcast/nov1509-cutaneous-T-Cell-lymphoma.mp3> companies to develop a drug that has a small number of patients out there who are going to benefit from that drug. Jones It is extremely expensive to develop a drug and it takes a long time. The most recent drug that was approved, I had been following it for 10 years, and I know that it had been in research even longer than that, and 10 years is a long time and you can imagine the millions of dollars that it has taken to bring that drug to market. Foss As you think about that now and all the work that you have done with the foundation, do you feel that foundations like yours should play a stronger role in lobbying with the FDA and with Congress in general about the development of drugs for these rare diseases? Jones Yes, I really think so. When I first started I was obviously very naive and only interested in patient education, but you really have to look at the bigger picture and it's looking toward the future. These things are not going to happen overnight. Foss Another thing about Judy is that I can't tell you how many airports I have been to around the country where I have seen Judy with her bags. Judy, you have really taken this organization from the ground up and I think that the success of an organization like this is all in the networking and getting the word out there, disseminating information and pulling people together and you have been able to do that successfully, but it is certainly a huge effort for you. Jones Sometimes I do feel like a bag lady, I have my computer and my entire office in a backpack and it goes with me wherever I go. Foss And I understand that you are not even paid to do this, that this is still voluntary on your part? Jones Yes it is. When I first started, we had no money and I thought okay if I get to a certain level I will be really excited because most non-profits do not ever get to the \$100,000 level and

then once we got there, there was so much to do that I was not going to take a salary because that would take away from patient services and I guess that I am still there today. Foss Do you think that your dedication to this foundation has a lot to do with the fact that you were a patient as opposed to say other foundations that may be started by interest groups, but not people who are particularly patients? Jones Well, patients definitely have a passion. I wanted to get this information out there because it is something that I did not have at the beginning and the more information I get, it is like, "Oh! We got this much, what else can we do now and how can we get more information out?" 24:26 into mp3 file <http://www.yalecancercenter.org/podcast/nov1509-cutaneous-T-Cell-lymphoma.mp3> Foss Another thing that this foundation has done for those of us who are clinical doctors treating the disease is it has really pulled us together to develop what you call a roadmap, and among other things, we are now getting together as a group of physicians in the United States under another foundation, the United, help me with this Judy, the USCCL. Jones United States Consortium of Clinical Trials? Foss United States Consortium for Cutaneous Lymphoma, which is a group that has been founded in part by Judy pushing us all to get together to think about rational designs for clinical trials and to get multiple sites involved in doing the same trials as opposed to having individual sites doing their own thing. Thereby, hopefully standardizing care for patients across the country. Jones I sometimes feel like I am the person who is just poking you and trying to push you forward. Physicians are so busy and it is hard for them to spend as much time as I would like them to spend, but the physicians are so dedicated and I have seen these physicians work so many hours on weekends and I think my job is to find how can we make it easier, how can we get you together so you can do your work? Foss At this point, from the point of view of a patient, and you certainly have talked to many-many patients out there, what are the most important things? Jones Well, the first thing in this disease is that here is a lot of itching, I would say number one, please stop the itch. Foss We certainly wish we could do that, but that is one of the banes of our existence with this disease. Jones I think that patients, when they are really sick and they do have symptoms, that is their main focus, they need support, they need to know that somebody else is out there, and they need to know that their doctors are working on finding better treatments. Foss I think there are two aspects to this disease also, it is a chronic disease for a lot of patients, but it also is a fatal disease that can be a very aggressive disease in other situations. So certainly there is a different point of view on the part of a patient who has a chronic disease I would presume, than a patient who has the more rapidly progressive form of the disease. Jones Patients need to know which form of the disease they have, and the patients that have the more chronic disease need to know that, and there is that psychological part of it that is always in the back of your mind, is this going to get worse? Foss Judy, you have done tremendous work over the last couple of years, can you just tell us in the last minute what is next for your foundation and what is next for Judy Jones? 27:57 into mp3 file <http://www.yalecancercenter.org/podcast/nov1509-cutaneous-T-Cell-lymphoma.mp3> Jones Just keep working and hopefully we will

be able to build on what we did this past weekend at the summit and push research ahead in this disease.Foss We are looking forward to see what happens next Judy. Thank you very much for being on our show today. You have been listening to Yale Cancer Center Answers and I would like to thank my guest, Judy Jones, for joining me today. Until next time, this is Dr. Francine Foss from Yale Cancer Center wishing you a safe and happy week.If you have questions or would like to share your comments, go to [yalecancercenter.org](http://yalecancercenter.org), where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.