The Connecticut Challenge

Guest Expert:
Jeff Keith
Cancer Survivor
Founder, The Connecticut Challenge

Yale Cancer Center Answers is a weekly broadcast on WNPR Connecticut Public Radio Sunday Evenings at 6:00 PM

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Hi, I am Bruce Barber and on this week’s Yale Cancer Answers our host, Dr. Ken Miller, will discuss cancer survivorship with the Connecticut Challenge. Dr. Miller is a medical oncologist and Director of the Connecticut Challenge Survivorship Clinic at Yale Cancer Center. Yale Cancer Center Answers provides you with the most up-to-date information on cancer care and also gives help and hope every Sunday evening here on WNPR. If you would like to submit a question about cancer to the show, please e-mail your questions to canceranswers@yale.edu or call 1888-234-4YCC. If you are interested in listening to past editions of Yale Cancer Center Answers, or if you would like to learn more about a specific kind of cancer, all the shows are posted in audio and written format on the Yale Cancer Center website at www.yalecancercenter.org. This evening Dr. Miller will discuss the Connecticut Challenge, an annual bike ride to support cancer survivorship initiatives at Yale Cancer Center. He is joined by a very special guest Jeff Keith. Good evening Ken.

Miller Good evening Bruce. Today I am joined by Jeff Keith, a cancer survivor and also the founder of the Connecticut Challenge. Jeff, it is a pleasure to have you here today.

Keith Thank you for having me.

Miller Can you tell our audience a little about yourself? How old were you when you were diagnosed with cancer and what do you remember about it?

Keith I was 12 years old when I was diagnosed with cancer. I had osteogenic sarcoma. I was playing hockey when I was bumped into the boards and cracked my knee; subsequently a tumor was found underneath. I had my leg amputated at age 12 and spent the next 18 months receiving chemotherapy. I am fortunate to be a survivor and alive today to tell my story.

Miller Jeff, a number of years ago you ran across the country, which is hard to even fathom. What inspired you to take on such a grueling task?

Keith When I was in college I continued to challenge myself as an amputee. I played lacrosse for Boston College and skied competitively. One of the things I wanted to challenge myself to do was to have a big event to raise money. Terry Fox, the young Canadian who ran across Canada, died on my birthday in 1981. It was that day that Terry gave me the inspiration. Terry lost his leg to cancer and ran two-thirds of the way across Canada raising over 20 million dollars. It was because of him that I committed myself to running across the country. I spent the next two years of college training and waited until I graduated in 1985 with my five best friends. We ran from Boston to Los Angeles and raised close to 2 million dollars for the American Cancer Society. Through the process, I ran through 45 pairs of running shoes, visited hospitals along the way and lost 30 pounds. At the end I was pretty much emaciated. I averaged about 17-18 miles a day and at the end my

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friends threw me in the Pacific Ocean as a celebratory finish.

Miller  
How many calories were you eating a day?

Keith  
I was probably eating about 5000 to 7000 calories a day. It was mostly pasta and a lot of carbohydrates.

Miller  
I am sure. Jeff, this is a difficult question, but people change after having an experience with cancer. How are you different having been through that experience at age 12?

Keith  
I have always felt like I won the lottery because every day is a gift. Survivor rates were 25% in the 1970s, today they are 65%, so I am very lucky to have survived that period. I have always felt extremely lucky to be here and I challenge myself in everything I do; whether it's school, athletics or trying to raise money for cancer-related causes. It has made me a better person. I do not take things for granted and it definitely pushed me to become more driven and persistent. This has paid off in terms of the money we have raised and the people and organizations I have been involved with. I have been able to work with some really, really bright people. Collectively we have raised a lot of money over the last 25 years.

Miller  
From what I understand, during your life you have raised over 25 million dollars to support cancer patients in survivorship for a number of organizations. Is that drive to continue to raise money still there?

Keith  
That number is a little overstated due to the fact that I did not do it alone. I was involved with organizations across America and now I'm involved with the Connecticut Challenge. They have thousands of volunteers and many people that are alongside me. I am just one person that was involved with raising 25 million dollars. I am still driven, but I think I am driven in a different way. There is a lot of government funding now, although recently it has been cut back in patient care and research, but there is no government funding in survivorship, and survivorship is at the front of the line in cancer care today. Thankfully, we have organizations like the Lance Armstrong Foundation who have elevated survivorship and are down in DC becoming advocates to have the government spend more money and more time on this lost generation of 10.5 million survivors out there that are dealing with all these issues now, 20-30 years after their cancer treatments.

Miller  
There are a number of different definitions of a cancer survivor. I wanted to ask you what your definition of cancer survivorship is.

Keith  
I define someone as a cancer survivor starting the day they are diagnosed. They
have survived the day they receive their diagnosis. Receiving treatment is a tough period, and then once treatment is finished, you have to go out into the world and live your life. Everybody is different and everyone is impacted by their cancer treatments and the cancer trauma they go through differently. We are cured, which is great, but we need tools and we need to be monitored as we move forward because everybody is impacted in a different way. Some specifics are the medical long-term effects of chemotherapy and a growing list of medical complications. I do not think the medical community has fully embraced these long-term affects of chemo yet, and the more cancer centers out there that take on survivorship as a component of their cancer care, the better off those 10.5 million survivors will be. Remember, that number is growing by about 750,000 per year, so we will have 12 million survivors in two years.

Miller A lot of people that have not been through cancer themselves look at someone who has finished chemotherapy, their hair has grown back, they're going back to work and they look great, and think they must be absolutely feeling great and at the top of the world. Is there a difference between how someone looks and how they might be feeling at the time? What are some of the messages you want to get across to the public?

Keith They might look healthy and they very well are healthy. However, over the course of time, remember, those toxic drugs from the radiation treatment have long-term effects; they can create medical complications. There are also psychosocial issues. Cancer is a traumatic experience that can reveal itself years later in different ways. People find different ways to deal with it. I personally found it helpful to focus on my quality of life through athletics, whether that was just walking down the street, and nutrition was also very important. Incorporating yoga into your daily life or some type of alternative medicine program may be beneficial. All these resources can be found on the Yale Cancer Center web page, www.yalecancercenter.org, or the survivorship clinic web page. Another resource out there is the Lance Armstrong Foundation. Their web page has many resources that are available to cancer survivors. At Yale Cancer Center Survivorship Clinic we not only want to be a clinic for patients, we want to be an educational resource so that people sitting anywhere in the country can tap into our web page and look at the stories of survivors and say, "if they can do it, I can do it."

Miller Jeff, can you tell us about the Connecticut Challenge?

Keith The Connecticut Challenge was started by John Reglan and myself. John is a local friend of mine in Fairfield. Some friends joined us in our goal to create the first Comprehensive Survivorship Clinic in the State of Connecticut. We have a charity 12, 25, 50 and a 100-mile bike ride each year. It is not a race, it is just a ride we have every summer. The first year we had over 150 riders, the second
year we had 300 riders. Our goal is for 450 to 500 riders this year. It takes place on Saturday July 28, 2007 in Fairfield, CT. If you go to our website www.ctchallenge.org you can sign up as a volunteer. As a rider, you can watch the video and slide show and read stories of survivors who have participated. The event is for everyone. My 8-year-old daughter rode 25 miles last year in the pouring rain and raised 3200 dollars. She is my role model.

Miller  
She is my role model too, because most of the time she was riding in front of me, and I was thinking to myself, "I have got be able to keep up with this incredible 8-year-old!"

Keith  
The ages ranged from 7 to 70 in the event. Anybody can participate and the mission is to raise money to fund the survivorship initiative at the Yale Cancer Center, which will in turn help 10.5 million survivors across the country.

Miller  
I would like to remind you to e-mail your questions to us at canceranswers@yale.edu. We are going to take a short break for a medical minute. Please stay tuned to learn more information about cancer survivorship and about the Connecticut Challenge with our guest, Jeff Keith.

The American Cancer Society estimates that in 2007, over 11,000 people will be diagnosed with colorectal cancer in Connecticut alone. Early detection is the key. When detected early, colorectal cancer is easily treated and highly curable. Men and women over the age of 50 should have regular colonoscopies to screen for the disease. Patients with colorectal cancer have more help than ever. Each day, more patients are surviving the disease due to increased access to advanced therapies and specialized care. New treatment options and surgical techniques are giving colorectal cancer survivors more help than they ever had before. Clinical trials are currently underway at Yale Cancer Center, Connecticut's federally designated comprehensive cancer center, to test innovative new treatments for colorectal cancer. Patients enrolled in these trials are given access to newly available medicines, which have not yet been approved by the Food and Drug Administration. This has been a medical minute brought to you as a public service by Yale Cancer Center. More information is available at www.yalecancercenter.org.

Miller  
Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller and I am here with Jeff Keith, founder of the Connecticut Challenge and a cancer survivor himself. Jeff, I want to go back and talk a little bit more about the Connecticut Challenge Bike Ride. There are some people who are worried because they have not been doing a lot of training for the event.

Keith  
Well, again, it is not a race. We had people come out last year that had not ridden a bike all summer and rented a bike at the start. They went out for 25 miles and it
took them a few hours, but we have rest stops along the way with plenty of food and there is plenty of support on the course. No one needs to feel intimidated and I cannot emphasize enough, it is just a ride, it is not a race and anyone can do it. As you know, cycling has become very much in vogue in this country, especially as we are dealing with the energy crisis and more and more people are looking for alternative ways to get to work. Cycling kind of fits in there. Lance Armstrong did an amazing job of creating an event where cycling is used to support survivorship. We are just taking that one step further and bringing it home to Connecticut. There are 100,000 survivors in Connecticut alone, and we want to go out there and support all those survivors in the state. It is an event that anybody can do and they do not have to train for it necessarily, but if you want some training tools, go to our website at www.ctchallenge.org and click on "Ways to Train for our Race."

Miller The other thing I want to point out is that it is actually a lot of fun. People are out there on the course riding and really encouraging each other. How have you found the event to be?

Keith I have developed some great friendships over the last three years, met some new people, new survivors, and it has made it much more than just a bike event. We have had people come from every corner of the state. We had people from 12 states last year and from 39 towns in Connecticut. This year that list is going to grow and if you are looking to get out and meet some new people and be involved with an event where you are going to have fun I recommend it. It rained the entire time last year and we still had fun.

Miller I remember that.

Keith It rained the entire day but it did not spoil peoples’ enthusiasm and only five people did not show up.

Miller This year you are also having a kiddy ride. Can you tell us about it?

Keith Well, the kids' ride is primarily for those that are officially registered as a rider. They can bring their child down to ride in this little tot ride that is going to take place around the Church Green on tricycles. You must be officially registered on the website as a rider but if you would like to get involved and do not want to ride, we would love to have you sign up as a volunteer. You can sign up on the website right now as a volunteer. There are different areas where you could help us; whether it is for one hour a week or you just come for the weekend. But people should know that if they want to get involved, there are other ways than just riding. You can donate money as well, which is always a good thing.

Miller Where do the donations go?

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We have created a Comprehensive Survivorship Clinic at the Yale Cancer Center where patients who have had cancer, whether they were treated at Yale or somewhere else in the country, can come in and get a full-day assessment of their medical needs as a survivor. This means that you will meet with an oncologist, a nurse practitioner, a psychologist, a nutritionist, a physical therapist and a psychosocial worker all in the course of one day. Survivorship visits typically happen once every two years, but because this is so new, and you are more of an expert than I am, that could change. That is basically what the money goes to support. We also host a survivor's day and are going to be involved in putting together some educational materials for survivors. We are going to continue to build our web page with Yale Cancer Center so that anyone who wants too can learn more about survivorship.

This sort of thing, the nutrition and the exercise work that we do with the patients that come, is it a common service offered throughout the country or is this program unique?

It is definitely unique. I have been to two survivor clinics in this country. There are only 7 of them out there, and I would say that this one has a different form; it is cutting edge. There are studies that have been done with women who have had breast cancer and incorporated an exercise program into their lives after their first diagnosis. The studies showed that these women had a significantly less chance of recurrence than those who did not exercise. It is becoming more and more apparent that building an exercise program is important; it could just mean going for a walk three days a week. An exercise program combined with a nutritional program and some other alternatives, like yoga, clearly can help the quality of life of a cancer survivor. Personally, I have found this to be true and I have talked to hundreds of survivors that over the years have stumbled upon exercise and nutrition and say that it makes their life a lot better. This is what we are doing at Yale, and what is key is that it is done in an organized format for each individual patient; we give them a program when they leave the hospital to work on for the next year where they have an organized platform for nutrition and exercise.

It is very inspiring because in terms of physical fitness you are in the top 5%. It is an important message that everyone can do something.

They can. I mean listen, lets face it, I am getting older so I do not have the same energy that I used to, but consistency is important; whether you get up and just go for a walk down the street to the local store, if you walk a mile a day five days a week or if you get out on your bike and go for a ride on a Saturday, it's worth it. I mentioned a Pilates or yoga program, a spin class, anything that gets you out and exercising. Really focus on nutrition and you will find your quality of life will get better.

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Miller: Jeff, in terms of the Connecticut Challenge Bike Ride as an organization itself, where do you see the organization going in the future, in terms of the variety of things you might want to do?

Keith: Well, we said from the start that we wanted this to be the largest athletic fundraiser in the State of Connecticut. We think we are on our way. The first year we raised $300,000, the second year we raised $500,000, and we are on target hopefully to raise $600,000 to $700,000 this year in small incremental steps. It is a grassroots event that is growing. We would like everybody in Connecticut to get behind it. I feel that it is my patriotic duty to support the only designated cancer center in the State of Connecticut, which is Yale. Yale can help everybody in the state not only from a cancer perspective, but from a survivor’s perspective as well. This is my rally in trying to get people to come out and support the event and support the survivors out there, because they really need your support.

Miller: Now you have some people that are individual riders and others that work for a big organization or big employer, how can they organize and get their co-workers to come out?

Keith: We have had a number of companies in the local area that have put together teams; a team is two people or more. As an example, the BMW-Bridgeport is a team that has been involved with us since the start. They have their own corporate team they are building and companies often match donations so if you raise $100 dollars, your company may match $100 dollars. The corporate teams have really started to take off and again, it can be a local business or it can be a Fortune 500 company. For ways to raise money, you can send out mail to friends and family. My wife and daughter sent letters to 250 people last night saying that they are going to ride. You can also use e-mail. The beauty of e-mail these days is that you can blast an e-mail out to friends and family across the country and link it to our site; each person will have an individual web page designed on our website that they can direct people to and people can donate online with a credit card from anywhere. We make it pretty simple. We also have personal teams. A group of people got together and decided they want to have a team called Hill Busters, whose capacity now is up to 32 riders. There were there the first year with about 8 riders and they all had fun. They call themselves the Hill Busters because they go out and ride on hills every weekend. We have a team, Noble Cause, which was started by a cancer survivor named Peter Cutler and a friend. They are up to 15 people so far. It gives you a chance to get out with friends and family or buddies from college that you have not seen in a long time. It is a great way to spend a half-day with friends and have fun and smile.

Miller: To share a personal story, as you know my wife is a cancer survivor, almost exactly 8 years now and thank God she is doing well. As I was riding last year, and as I will ride this year, with each hill I'm thinking I can get over that, my wife

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got through cancer, I can get through this. We really want to encourage people. Can you tell us again the information?

Keith Saturday, July 28th at Greenfield Hill in Fairfield, Connecticut. The ride begins at 8 o'clock a.m., and again it is a 12, 25, 50, and 100-mile ride. Go to www.ctchallenge.org and on the web page you can actually live through last years ride. You watch the slide show to music and the video. You can see firsthand the smiles on peoples' faces and just the experience of the ride. You will see why this event is becoming very-very big in the State of Connecticut and we are very proud to be involved with it.

Miller Jeff, I want to thank you for being on the show and also thank you for everything that you do as inspiration for a lot of people, including myself. Thank you for starting and keeping up with this wonderful program that the Connecticut Challenge is sponsoring for our survivorship program.

Keith Thanks very much Ken.

Thank you Dr. Miller and I encourage you to go to yalecancercenter.org for more information about cancer and the resources available to you. You can also listen to past editions of Yale Cancer Center Answers in audio and written formats at the Yale Cancer Center website at www.yalecancercenter.org. Remember, tune into WNPR every Sunday evening at 6 o'clock for Yale Cancer Center Answers for the latest information in cancer care and treatment and our next week show on examination of leukemia. You are tuned to WNPR health forum on WNPR and wnpr.org.