The 2008 Connecticut Challenge

Guest Expert:
Jeff Keith
CT Challenge Founder and Cancer Survivor

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

Listen live online at
www.wnpr.org
OR
Listen to archived podcasts at
www.yalecancercenter.org
Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Miller is a medical oncologist specializing in pain and palliative care, and he also serves as the Director of the Connecticut Challenge Survivorship Clinic. If you would like to join the discussion, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening Ed Chu welcomes Jeff Keith. Jeff is a pediatric cancer survivor and founder of the Connecticut Challenge.

Chu You have a very compelling, very inspiring story. For the listeners out there who may not have heard your story before, can you tell us a little bit about your own experience with cancer?

Keith At age 12, going through the loss of my leg to bone cancer and the 2 years of chemotherapy was an education in itself. This journey back to life really shaped the person I am today. My parents had me skiing 6 weeks after my surgery and during one of those ski trips I met a man who was skiing who was a double amputee. I remember him saying to me, "Be thankful for what you have left and not bitter for what you have lost." I never forgot those words. So as I entered my teams and you now started to get more active, I started to become aware of how lucky I was to be alive and then I should try to live every days if it was my last and then I wanted to give back, so it was because of that I decided that I would after college run across the country to raise money for the American Cancer Society, to do a 3000-mile journey across country had never been done before and to really try to show that not only to people that were normal that cancer can be that you can go on and do many, many things whether it is walking down the block or it is you know walking up the stairs or it is running across the country, and I think, you know, my motto has always been I read this in a book one day years ago that attitude determines your altitude in life and this is what really keeps me going.

Chu That is tremendous. So, I am just curious what made you decide you know to take this leap and then you run across the country?

Keith I wanted to challenge myself. I was an athlete before I lost my leg. I was at that time playing lacrosse in college and did not really know what I wanted to do with my life after college and all I did know it was goal that I had since my sophomore year when young Terry Fox died of cancer in Canada. He died on my birthday and he was an amputee who ran three quarters of the way across Canada and died and never got to finish and Terry was an inspiration to me. He was my hero and I always remembered him, and 3 years later, I committed myself to do the same thing across the United States.
Chu: As you have accounted to us on many occasions, which really nice as you were able to bring all of your friends together on this journey.

Keith: Yeah, I mean I have been blessed with a great team in life. I call them my team in life because it is friends and family and those who are the ones that is the reason why I am here today. They have helped me through my Run-Across America through starting up the other non-profits that we have co-founded, Swim-Across the Sounds, Swim-Across America, and now the Connecticut Challenge. I am the cofounder but there is a team behind it and it is you know I have always been a team player, I could not have done this without them and it is very, very important for cancer survivors to be surrounded by a team whether it is just going through their chemotherapy or it is life after cancer.

Chu: So I am just curious, what was it like running across the country and that is a long distance?

Keith: Well, we all have their odd bad days, most of my days were good. It was a long journey. You know life as a journey not a destination and I learned a lot. I met a lot of wonderful people. I raised the bar for myself personally, and for myself, it was very homely experience to be crossing the finish line to have my cruise throw me in the Pacific Ocean, I did start in the Atlantic ocean and you know it was a great experience and I visited hospitals along the way, met cancer patient’s, listen, learnt from them, they told me what their needs were, and that is why I continued today. I never forgot the patients that I took chemotherapy with they did not make it. They never had a chance to live their lives.

Chu: No again just for the listeners out there, as you said in the beginning, you had bone cancer, but I guess the official term was osteogenic sarcoma. Is that right?

Keith: Correct.

Chu: And unfortunately, it is one of the cancers that with surgery chemotherapy kind of a combined approach to the treatment, we really can cure?

Keith: Yes survivor rates I believe and you can tell if I am wrong were 25% when I was a kid and I think they are up into the 65% range right now, so the odds of surviving are a whole lot better. Survivorship today is a very, very invoked term. Lance Armstrong has done a great job of stepping out and promoting it and you know there are 12 million survivors today in United States.

Chu: Right, may be just on the topic, so there are some 12 million cancer survivors like yourself, but actually it is interesting I think people are now
taking an even broader definition of the term survivor, may be you can let our listeners know little bit about that.

Keith Great question. To someone who has gone through cancer like myself, survivorship means being given a second chance of life. To the general population, we define a survivor they are diagnosed with cancer. You know as a result of strong advocacy efforts by many organizations out there, the national action plan for cancer survivorship was written in 2004 and published by the Lance Armstrong Foundation in the center for disease and control and prevention, and in this report, the term cancer survivor was redefined to those people who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis with cancer including family members, friends, and caregiver. To quantify this number then, there are 11.5 million to 12 million survivors today and a few include the extended network family, friend, and caregivers that number could reach 100 million that is a big number. This document is my Survival Bible. I carried around with me to a lot of places because it is a public health pushing for change and for anyone who are listening out there. You can find this report by going to www.livestrong.org and click under the programs button that is Lance Armstrong Foundation, it is called Livestrong.

Chu You know it is really kind of amazing because I would suspect that everyone who is listening right now to the show has been in some way touched/affected by cancer either through a family member or friend or neighbor just down the street. It is really quite remarkable and then and then you know we just hear recently about the diagnosis of Senator Ted Kennedy now with a brain tumor.

Keith Correct.

Chu You know, so clearly cancer is unfortunately equal opportunity.

Keith Well, I mean the statistics are 1 and 3 women and 1 and 2 men will get cancer in their lifetime. So, there are few Americans whose lives have not been touched by cancer, in fact, already quote from the Surgeon General of the United States, Richard Carmona, who said the need and urgency to make cancer prevention and survivorship a national priority should be clear to all of us. You know, even beyond that there are now scientific and clinical studies that are out there that if you exercise and you follow nutritional program and you stop smoking, you reduce your risk of getting cancer by 40%.

Chu So, I think that is tremendous advice to everyone, not only to reduce the risk of cancer but just general well being to have good health. It is important to follow those steps.
Keith It is really important for cancer survivors because it has been clinically proved that you will reduce your risk but even for the general population cancer prevention is key and if we follow some of these programs, you will reduce your risk of getting cancer.

Chu Now, Jeff, you know, this whole experience obviously has you know inspired you and made you really dedicated to the cause of cancer survivorship in cancer patients. Now, I just heard recently that you and your team as you call it have raised over $50 million over the years to support cancer patients, maybe you can just tell our listeners a little bit about some of the organizations that you helped to find and you know, what is kind of kept you going in terms of this drive.

Keith Yeah, we started with the Run Across America project which was the American Cancer Society that was in 1985 and then we followed up with Swim Across the Sound which raises money for cancer programs in Fairfield County, and now, we branched into Swim Across America in the 1990s and we incubated and founded that with a friend and that is now an organization that raises $3 million a year Swim Across America and it goes to multiple programs, survivorship, research, clinical science, gene therapy, and then lastly, four years ago, we started the Connecticut Challenge which is strictly forced to advance the cause of survivorship. You know, I think what keeps me going is again you know like I said earlier that the children that never made it, I guess this memory is really created the fabric for which, you know, I made of and by launching and starting these non-profits, it is really my only way of giving back. You know, all of us need a reason to get out of bed everyday. Luckily, I found a purpose in life and once you find that purpose, then life becomes pretty powerful.

Chu Yeah, now I think those are very powerful words that we all should to live by and as I started the show, we here at the Yale Cancer Center particularly proud of I think the relationship that we have developed over the years between the Connecticut Challenge and Yale Cancer Center because really, you know, all of the proceeds from the Connecticut Challenge go to help support survivorship programs and research at the Yale Cancer Center.

Keith Yes, you know, if I could brag a little bit from my team, you know, we are proud that we raised 1.4 million in the first 3 years for survivorship. The programs we fund are the Hero’s Clinic, which is the first and only Children’s Clinic in the state of Connecticut. The Connecticut Challenge Adult Clinic, which is the first of its kind for cancer in adults for survivorship. We are also sponsoring cancer survivor day which is a free event hosted by Yale here and open to all cancer survivors and families.
and then, you know, finally we are currently funding for Pilot Cancer Survivorship research projects at Yale and our goal will be to continue to fund new research like this every year and an ongoing effort to change and improve the way cancer survivors are cared for in the future and I cannot forget it, we are actually helping fund the Cancer Symposium, which is currently going on as we speak which is offered for healthcare professionals in the state. So, we are pretty proud of the survivorship programs that we fund. We feel like we are making a difference and we want to continue to do that.

Chu Good, terrific. What we would like to remind you to e-mail your questions to canceranswers@yale.edu or call 1-888-234-4-YCC. At this time, we are going to take a short break for medical minute. Please stay tuned to learn more information about the Connecticut Challenge Cancer Survivorship with our special guest Jeff Keith.

Over 170,000 Americans will be diagnosed with lung cancer this year and more than 85% of these diagnoses are related to smoking. The important thing to understand is the quitting even after decades of years can significantly reduce the risk of developing lung cancer. Now everyday patients with lung cancer are surviving. Thanks to increased access to advanced therapies and specialized care and new treatment options are giving lung cancer survivors new hope. Clinical trials are currently under way at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for the lung cancer and the patients enrolled in these trials are given access to medicines not yet approved by the Food and Drug Administration. This has been a medical minute and you will find more information at www.yalecancercenter.org. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Chu Welcome back to Yale Cancer Center Answers. This is Dr. Ed Chu and I am here in the studio this evening with our special guest, Jeff Keith, discussing Connecticut Challenge Cancer Survivorship. So Jeff, before the break we were talking about how you and your team have put together this extraordinary group called the Connecticut Challenge which kind of I guess symbolized each year by not a bike race, I guess we really would call a bike event and maybe you can tell our listeners out there what is this event all about, when this is going to be taking place this year?

Keith Yeah the Connecticut Challenge is a charity bike event, it is not a race. It is open to anybody. The date is July 26th, Saturday, 2008. We have a 12- or 25- or 50- and 100-mile bike ride, so there is a level for anyone. We rent bikes there on the property. If you go up onto our website at www.etchallenge.org, you can get the information. It is a fundraiser. We asked people to come in to raising some money. We have families that sign up, my daughter last year did the 25 miles, she was 8 years old and we had a kids top ride around the church.
Chu: Actually, I am going to actually ask about the kiddies event because actually that is something that I might take a part in this year.

Keith: You can follow my 4-year-old son in and out in his tricycle, he did 22 laps around the church but we want to be known as an organization that is for survivorship and the bike ride that actually helps fund that there is a direct link between what people are doing on their bikes and it is actually helping people in need. There are 120,000 survivors in the state of Connecticut. So, we think this event will continue to grow and we had 34 survivors actually participated last year in the event and that number will go up this year as well.

Chu: what really I think for those who have not either participated in the event or been there, I think, it really is a very emotional and inspirational event and you started off the event by having survivor’s kind of do a lap if you will.

Keith: Yeah. One of our colleagues came up with the idea why not before we start the ride all 400 other riders start on a line and again it is not race and we let the 32 survivors do a lap of honor around the green and it is the church bell ringing and they get their moment to ride around the church, takes about 2 minutes and it is pretty powerful to see those people out there, some are currently going through treatment and some are actually passed treatment but I think if you ask any rider that is really what inspires them for the rest of the day because those are the people who help me.

Chu: Yeah, absolutely, again pretty much all of the proceeds from this event go to support survivorship programs at the Yale Cancer Center, which is phenomenal.

Keith: That is it.

Chu: So, again on behalf of the cancer center really thank you really so much for all that you and your team, you know you have done on behalf of Yale Cancer Center. So, now maybe lets talk a little bit about what the funds that you raise go to help support and specifically I think one of your main goal initially was to see an adult survivorship clinic that will be opened at Yale.

Keith: Yeah, I mean our goal for the clinics is simple. It is to educate each patient that walks through the clinic, it is to give them an extent of assessment of their health condition and provide each patient with a knowledge and power to go back out into the world and live their lives to the fullest and maintain the quality of life that they deserve. We really want to provide them with a roadmap for the rest of their life to follow nutrition and exercise and wellness and beyond to give them the tools to live their life to the fullest and not is what the goal of the clinic.
Chu So just for the listeners out there, actually my co-host who is not here this evening, Dr. Ken Miller, is in fact the Director the Survivorship Clinic, the Director of the Survivorship Program. He also does a phenomenal job and kind of overseeing the supportive care program here at the Yale Cancer Center and may be just tell us a little bit about the services that are in fact provided by Adult Survivorship Clinic.

Keith As you know and for the listeners out there, cancer survivor faces numerous physical, psychological, social, spiritual, and financial issues throughout their diagnosis and treatment for the remaining years of their life. More specifically, there exist long-term effects of the drugs used to treat us and dealing with these issues. Many survivors 5 to 10 years out do not know the issues they may be facing, so it is important to go through a survivorship visit at least every 2 years if not annually depending on the person. At the Connecticut Challenge Survivor Clinic, each individual is evaluated by a team, which includes an oncology practitioner, nutritionist, a physical therapist, and a social worker. Throughout the visit, cancer survivor is guided through the program by a program coordinator, an APRN or volunteer, throughout their visit and followup consultations. Upon the completion of the visit, each survivor received a written report teller to their specific needs, providing wellness plans, nutritional expertise, and exercise and activity regimens and then followup appointment reminders and then a copy of this plan is sent out to the referring physician or primary care giver.

Chu Now, who is eligible to come and, you know, seek the services of the survivorship clinic.

Keith Anybody in the state or across the country is invited to come to the clinic. You do not have to have been treated at Yale to come here. It is open to all. We also have a, you know, pediatric clinic, the Hero’s Clinic for children, run by Dr. Nina Kadan-Lottick so the Yale Cancer Center and Institution have a service that is really the only service that is offered in the state of Connecticut and I would encourage all survivors to take a look at doing this because it will help you live your life, it helped me by going through the survivor clinics. It is given me a roadmap to follow, listen, I am not perfect either and there are issues that I face from the drugs that I took when I was 12, 13, and 14 from the high dose of adriamycin and methotrexate, their longterm effects on your organs and people need to be aware of those. I do not want to scare people because it is not life-threatening but it is something we need to be aware of, and as I emphasized earlier, we need to follow a strict nutrition plan, strict activity plan, I call, because not everybody can go out and do 25-mile bike rides but we called it activity and then there is also psychosocial support. There is many groups that are starting up around the country that help you with this, you know, I would always defer default to Livestrong because they
done a great job in helping survivors even the American Cancer Society has the great American challenge out there that if you go a [www.cancer.org](http://www.cancer.org) you can go and follow some general advice on how to live your life and also I would direct people to the Yale Cancer Center webpage which is the most important because what is unique about the Yale Cancer Center and the clinic is you have expert advice from professionals and now we are integrating the science of survivorship in the medical research with the clinics which I think is going to be powerful some day.

**Chu**

I will get back to that in a second but just curious when, you know, you are going through your cancer experience, finish your treatments, were there such things as survivorship clinics back then?

**Keith**

No, they cured you, and they sent you on your way, you know, unfortunately, we do not blame the doctors like yourself, the oncologist, they are not trained in nutrition and wellness and back then they did not understand that there were going to be long-term effects from the drugs we took. Also the psychosocial issues that are, you know, prevalent and then there are other areas that survivors need to know about that we did not back then like, you know, we were more prone to fatigue, some of the survivors were prone to chemo brain during the treatment and there are tools out there now to help you deal with these things. There are companies popping out there across the country, they are doing studies now to the cognitive impairments that cancer survivors go through during treatment. You can reverse that by doing exercising your brain just like exercising, you know, your body. So, there are social entrepreneurs that are emerging out there in this country that are trying to serve the needs of cancer survivors.

**Chu**

Again just for listeners out there, you have already mentioned our pediatrics survivors’ clinic, which actually has been ongoing already for a number of years and really have led very, very capable by Dr. Nina Kadan-Lottick. She has done terrific job in running that Hero’s Clinic.

**Keith**

Yeah, Nina, is a pioneer in the field of the survivorship. There are very few survivorship/oncologists out there across the country, it is new and emergent term, but we are excited. Thanks to the people like Nina and the folks at other areas at the Dana Farber Center. They were the first to start a survivor clinic some 12 years ago and the pioneers of this field, you know, their attachment to their will to see this need and we thank him for as a survivor.

**Chu**

Yeah. Absolutely, and I think in large part why probably started in the pediatric world was because still many of the pediatric cancers are curable whereas still you know what I think we have made tremendous advances
in the adult cancers were not quite there yet and so that is where I think why the whole issue of cancer survivorship was able to begin?

Keith Yeah, I think, leukemia has 90% survival rate so it is absolutely there are more survivors at younger ages that need support. It is really a support system for the rest of your life.

Chu Yeah, absolutely. And so you mentioned now that in addition to the clinical services that our survivorship program here at Yale is offering really a lot of resources that you are putting together are now being shifted but also having a focus on the research component. May be tell us a little bit about that.

Keith Yeah, I mean, we are excited that we are funding for research grants, I do not have the documents in front of me, one of them done by Dr. Nina Kadan-Lottick, also Melinda Irwin who has an expertise. She is a scientist in the field of exercise physiology and she is doing a study on the impact of exercise with I believe its breast cancer survivors but you know survivorship needs to continue to expand and grow outside the current parameters of the clinic and we say clinic it is a concept it is not a place. You know, we are listening to our survivors today and what they want. We are doing this through, we have an online survey, which people can fill up by going through our webpage at www.ctchallenge.org and filling it out. The survey is anonymous and no one has to reveal their name. We just want people to take 15 minutes of their time to go through this exercise and what it will do is enable us to better serve the 120,000 survivors in the state of Connecticut and 11.5 million in US. The areas of need that are emerging are helping survivors with financial advice, insurance expertise, during their treatment and after, hardship cases in which the patients need assistance to pay for chemotherapy or daycare during chemo while getting their treatment or simply finding a job 4 years later. These are some of the needs we are currently reviewing. We will try to find a way to address them over the next year and one thing that is become more crystal clear is survivorship is and continues to be massively un-refunded and the Connecticut Challenge exists to try to fill this gap and make a difference in the lives of survivors. We have also even formed a survivorship committee of 12 survivors on the Connecticut Challenge Board now and we are going to meet 2 to 3 times a year and that is going to be our sounding boarding. They are going to tell us what survivors’ need out there. So, again if people could go to our webpage and filled the survey out at the end game it will help you folks.

Chu Great. Well, the fact, is you have made a huge difference. I think for everyone associated with cancer survivorship. May be before we close Jeff, if you could announce the date again of the Connecticut Challenge event.
Keith  Sure, it is Saturday, July 26, 2008. If you go to www.ctchallenge.org and you can sign up. You can also sign up as a volunteer. We had over 200 volunteers last year, they signed up online, I can tell you first hand, some of them raised money, they had a wonderful time, dedicating their time for the day. So, if anybody wants to get involve but they can ride, they can certainly come down, they can go up on the website and look at the areas of volunteer, the areas that we need for help and we will welcome your participation.

Chu  Well always Jeff it is tremendous having you with us here on Yale Cancer Center Answers and we look forward to have you come back and talk more about your own experience, the Connecticut challenge and cancer survivorship.

Keith  I want to thank Yale for being a partner with us for forming an alliance because it has really been a unique partnership that has really helped both entities learn more about survivorship and pushing the envelope.

Chu  Again, as I said, you know, you are an inspirational figure and someone. It has been tremendous honor and privilege for us to work closely with. So until next week, this is Dr. Ed Chu from the Yale Cancer Center wishing you a safe and healthy week.

*If you have questions, comments or would like to subscribe to our podcast, go to [www.yalecancercenter.org](http://www.yalecancercenter.org) where you will also find transcripts of past broadcasts in written form. Next week, we examine the history of chemotherapy with Dr. Vincent DeVita. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.*