



Issues faced by Young Adult Cancer Survivors

According to the National Cancer Institute, there are more young adults today being diagnosed with cancer than any other age group in the United States, making it the number one disease killer amongst the young adults. In this show we have a fun group of young cancer survivors sharing their experience with us. You may be surprised by how different the issues and challenges surrounding a life of cancer for this age group really is.

Full Transcript:

Priya : Hello, everyone, and welcome to the Cure Panel Talk Show for young adult cancer survivors. I am Priya Menon, Scientific Media Editor at Cure Talk, and I welcome all of you this evening to a discussion on how different are issues faced by young adult cancer survivors.

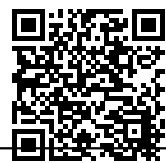
This is the 24th episode of the Cure Panel Talk Show and the show is featured on Blog Talk Radio. Before we begin with today's introductions, I would like to share the fact that in August, Cure Panel Talk Show is celebrating its first anniversary. We launched the Cure Panel Talk Show in August 2012 with our monthly series on multiple myeloma and we have grown over the year to conduct talk series on a variety of topics including prostate cancer, yoga, nanotechnology, and cancer and nutrition. Please visit our website www.trialx.com/curetalk for information regarding our shows and you can always mail me, priya@trialx.com if you would like to be featured on our show.

Today, we are launching our new talk series, Cure Panel Talk Show for young adult cancer survivors. Over 70,000 young adults aged between 15 to 39 years are diagnosed with cancer every year in the United States. According to the NCI, in the past three decades, cancer incidence in young adults has increased more than any other age group and cancer has become the number one disease killer in young adults. It will come as a surprise to many that the cancers that affect young adults are very different from those affecting other age groups and young adults have entirely different and unique needs from other age groups. The panel today will be discussing how different are issues faced by young adult cancer survivors.

We are excited to have with us young adult cancer survivors who have inspired young people all around the globe. New York Times "Life, Interrupted" columnist, Suleika Jaouad. Suleika was diagnosed with acute myeloid leukemia at the very young age of 23 years. Suleika underwent a stem cell transplant for her cancer and post chemotherapy she is getting better everyday. Founder and CEO of Stupid Cancer, Matthew Zachary. Matthew is a 17-year pediatric brain cancer survivor. He founded Stupid Cancer and advocacy support and research organization that works for survivors and care providers with the aim to end isolation, improve quality of life, provide information regarding resources to young adults with cancer, and form a community where young adults in cancer world can share and help each other.

Soccer player and the 2002 winner of the reality television show "Survivor," Ethan Zohn. In April 2009, Ethan was diagnosed with CD20+ Hodgkin's lymphoma and has undergone two stem cell transplants to control his cancer. Ethan served as the national ambassador for Stand Up To Cancer. Ethan is also a global envoy for LIVESTRONG and Movember.

We also have with us Huffington Post blogger and project manager at Azul 7, Erika Lade. Erika is a breast cancer survivor and advocates the young cancer patients. Azul 7 is a design consultancy that works to make the medical system more human. Erika also holds a masters of art in food studies at New York University, where her research focused on the prison food system and its industrial ties. I extend a hearty welcome to everyone. I would like to remind all listeners that we will be taking live questions at the end of the discussion. Listeners who have a question for our panel can let us know by pressing one on your keypad and we will



bring you live on air to ask your question.

Priya : Hello, Suleika, you are on air.

Suleika : Hi, there!

Priya : Hi! Welcome to the show.

Suleika : Hi. Thank you. I am actually with Erika and Ethan and we are currently on a boat on the Clark River in Montana. So, if you hear sounds of waves, that's what's happening in the background.

Priya : (Laughter) Suleika, let's... I think its been two years since we connected with each other. So good to talk to you finally.

Suleika : That's wonderful to talk to you as well.

Priya : Yes. Suleika, you have been fighting cancer for the past two years now, if I am right.

Suleika : Ah... That's right.

Priya : So, how did... Yeah. How did all that... How did it all begin? Can you please share your story with us?

Suleika : When I first started to feel symptoms, I felt tired and worn out. I was like so many other young adults. I was burning the candle on both ends. It wasn't until I started getting frequent infections and colds that I finally went to the hospital and realized that there was something wrong with my blood counts. It took about six months for me to get diagnosed and I was finally diagnosed with myelodysplastic syndrome and acute myeloid leukemia six months after graduating college at age 22.

Priya : Wow! So, how was your support? How was the support from your friends and family? I know that your brother was and your mom, I read a lot about your mother in your blogs. So, how has been the support from your friends and family? I am sure they kept you motivated.

Suleika : My closest friends and family were really wonderful, but I think that like a lot of other young adults, I felt incredibly isolated. I was few years too old for pediatrics but younger than the other patients in the adult oncology lab and I really didn't feel like I fit in. It is only after I started writing about my experiences regarding my story publicly that I started to get to know other young adult cancer survivors and started to feel like I was able to form a support group, not only of like-minded people but people who had these difficult experiences.

Priya : Okay. Hi, Matthew!

Matthew : Hello there.

Priya : Matthew, you are a... Yeah. How are you, Matthew?

Matthew : I am great. How are you?

Priya : Fine. I think its been a year since I spoke to you last.

Matthew : Been a while but I missed you.

How have you been doing?

Matthew : Really fantastic. My kids are healthy. I am well and the organization is thriving and its a good day



to be alive.

Priya : Yeah, great. Matthew, you are a 17-year cancer survivor. What is your cancer story?

Matthew : I was a classically trained concert pianist for 10 years. By the age of 21, an undergraduate, I was planning to go to grad school to be a film composer and study at USC Film School until my left hand started experiencing symptoms with fine motor coordination. I wasn't diagnosed for six months and was also only diagnosed with pediatric brain cancer and given just a few months to live because they had never really seen something like that in someone my age before. They also told me they were plenty, so neither of those came true. I am celebrating 18 years this September. I am still playing piano, but I had a major course correction at a very early age and was unable to become a professional pianist. I wound up working in the advertising agency Universe for 10 years and rehabilitated my left hand to play again five years later and then finally started meeting some other young adults who had gone through similar experiences, which was transformative, then inspired me to start a non-profit organization that raised awareness for young adults and their unique needs in the world of cancer.

Priya : Wow! Ethan, I will bring you on air now. I would like to connect with you, Ethan. (Pause) Can you hear me? (Pause) Hi, Ethan!

Ethan : Hi!

Ethan, you are a soccer player, a reality show winner, and a cancer crusher. How did you cope with your cancer diagnosis?

Priya : Ethan, could you please be a bit more louder? I am not able to hear you.

Ethan : Can you hear me now?

Priya : Ah... Yes. Better now definitely.

Ethan : I just said before I get started, I want to give a quick shout out to First Descents because we are all flowing down a river at an outdoor adventure (okay) camp for young adult cancer survivors, though. Its pretty exciting and that's one way that we have all been able to manage our diagnosis and manage our survivorship because we are just connecting with other young adult cancer survivors right now.

Priya : Okay. That sounds great. I think... I do... I can't see Erika. Erika, if you are on air... If you are dialed in, please press 1 on your phone so that I can...

Erika : Hello. Hi, Priya! I am here. We are all steering across.

Priya : Okay. Fine. Great. Great. Hi, Erika.

Erika : Hi! Thank you for having me.

Priya : Oh, thank you for dialing in, Erika. Its great to have you. Erika, what was your initial reaction into your diagnosis and how long has it been?

Erika : You know, its been about a year and a half basically, as you can imagine the shock. I didn't have a genetic history of breast cancer in my family and I only found out when it spread to the lymph nodes, though there was a lump in my armpit. I didn't have any suspicion of disease. I felt fantastic. So, for me, it was a great surprise to be diagnosed and, you know, a horrible surprise to be diagnosed of cancer at age 28.

Priya : Okay. Okay. So, how was your support system that you received in your friends and family and what are some of the things that had kept you motivated?



Erika : Yeah. You know, I felt like I didn't have a ton of connection to the young adult cancer community until I found Suleika and Stupid Cancer. So, for a long time I felt pretty isolated in my disease and I think that's a common issue among young adult cancer patients because it is at a strange time to have cancer in your life. You really are up to eight packs and all of your friends are max'ing out on life, having kids, getting married, you know, eating, and their careers and to be at risk such an disease its really isolating, but I just feel supported, you know, in my family and friends.

Priya : Okay. So, I guess that we are all here now and the topic for today's discussion is how different are issues faced by young adult cancer survivors. Matthew, Stupid Cancer must be coming in contact with young adult cancer survivors from all over. What is the most worrying aspect that you have encountered about young adult cancer survivors?

Matthew : I would have to say that there's a lot of us and...

...we don't know there's a lot of us and those that don't get to know that there are a lot of us are in for a major life transformation when they discover that and its truly a transformational, I said that word twice on purpose, because it really changes your life when you realize that you are not alone and you have peers that even know its like. As much as your friends and family are wonderful, its not the same and its never the same as meeting somebody who got diagnosed in their 20s and 30s and I think that's the most tangible and meaningful thing that we offer and that is necessary to talk about in the world of young adult cancer and that is the basis under which I started the organization.

Priya : Okay. And, do you find something which is hopeful and optimistic about the cancer population that comes to Stupid Cancer?

Matthew : There have been three very significant sort of sea changes in oncology in the last couple years and I would like to take pride and credit in having the young adult cancer movement sort of mobilize, influence those changes, the first of which is that there is now a clinical journal of adolescent and young adult oncology out there which produces real white papers, real publications, and real research studies. Unique is this age group, unique biology, unique outcome. That's a huge step in the right direction. The National Comprehensive Cancer Network which is the de facto gold standard by which all primary care physicians, some specialists, hematologists, oncologists are delivered standard of care, now have a young adult cancer protocol that was released last year and that is incredibly significant to the movement and third, that the American Society of Clinical Oncology has launched a campaign for CME programs to focus under 40. So, those three things in the clinical world are ridiculous. To say that they actually happened in such a short period of time, but they have been so heavily influenced that I can say with confidence that in 2013 young adults affected by cancer today is much better off than they were five years ago.

Priya : That's really great. Do we know what percentage of cancer patients, young cancer patients, young adults?

I am sorry. What was the question? How often?

Priya : What percentage of cancer patients are young adults?

Matthew : I am sorry. I am just... Its breaking up a little bit.

Priya : Yes. Okay. What percentage of cancer patients are young adults?

Matthew : We define the age range based on Public Health Policy brought forward by the CBC and the National Cancer Institute which defines young adults as 15 to 39.

Priya : Okay. What are some of the common cancers in that age group?



Matthew : And that's a really important question to ask because cancers change based on age. We don't see a lot of the traditional cancers, colorectal, prostate, and lung in young adults. Breast cancer happens in young adults but not nearly at the same proportion as it does in older women. Young adults get like Suleika blood cancers, ovarian cancers, sarcomas, thyroid cancer, melanoma, and cancer and its very important to recognize the significant differential that young adults get different cancers than every other age group.

Priya : Suleika, what is your opinion regarding the distant issues that are faced by young adult cancer survivors? What according to you are the two most important issues that young adults face today?

Suleika : I think some of the things that were most difficult for me was that I was inpatient in isolation for a combination of six total months leading up to my transplant, so I really didn't have much of an opportunity to go to young adult cancer events or to support groups and I think that made me feel even more isolated. I found myself looking for a voice in Namibia, that I couldn't relate to and I really didn't find that. Many of the people who are writing about their experiences were writing from the perspective of being in remission or were authors who are many decades older than I was. So, I couldn't relate to a lot of what they were saying, but one of the things that prompted me to cope with the isolation was writing. I had always wanted to be a journalist and right around the time that I was diagnosed I had been hoping to go and report on the revolution taking place in Tunisia, which is where my dad's from and with the isolation and with the diagnosis, I really felt like there wasn't much for me to write about, that there is no air, I was trying to get on a plane to travel up to some grand revolution until the day that I had at the Tiffany and realized that I could report from the frontlines of my hospital bed and that I could write about the revolution taking place inside of me and that's how my New York Times Life, Interrupted was born. So, one of the things that was really important to me in writing dotcom was trying to be as brutally honest and as raw as possible. I think often times when we talk about cancer, we talk about the silver linings and there is the emphasis on staying positive, but I didn't probably feel that way and I really wanted to write from and to report not only on the good but also on the bad and to talk about topics like infertility and sexual health and things that we don't often hear discussed in the news.

Priya : Oh, yes. Ethan, what are some of the hurdles that you had to overcome with regard to your career and maintaining your energy levels post your cancer diagnosis?

Ethan : Hi, everyone! What's that? I am having trouble hearing you.

Priya : Ethan! what are some of the hurdles that you had to overcome with regard to continuing your career and maintaining your energy levels post your cancer diagnosis?

Ethan: the public. You know, its one of those things lot of stigma is still associated, you know, with people diagnosed with cancer and so somehow I realized I needed the details of my life, had the opportunity to help others out there. You know, like Suleika said, its a very isolating experience. Everyone goes through cancer alone, in their own separate way and I felt that, you know, by, you know, having a video blog and, you know, sharing my story on, you know, television and with my friends and family and people.com, I really felt that, you know, people could relate to me in some strange way and in that sense if you are staying on your couch in the middle of, you know, nowhere, feeling alone that all right, well maybe this guy, you know, I am like this guy. This guy has issues too and this guy is going through cancer. He is doing okay. I can do okay as well and for me, it was, you know, a tough decision to go public with my diagnosis because its really gross, ugly, disgusting time of your life and I didn't know what would happen if I opened up my life to complete strangers all over again, but for me, it was the best decisions of my life and I was overwhelmed with the support of everyone out there, you know, all the fans and, you know, people at Stupid Cancer and people at First Descents and how welcoming they were and how generous and selfless they were towards my fight and, you know, seeing that gave me the strength and gave me the courage to go out there, continue with fighting and to, you know, get through this with the help of everyone.

Priya : Oh, that's really positive. Ethan, what according to you is the most important problem that young adults face today, young adult cancer survivors?



Sorry. I am sorry. I didn't hear you.

Priya : Ethan, what according to you is the most important problem that young adult cancer survivors are facing today? I think we dropped Ethan.

Suleika :I think I... Oh, sorry. Ethan [00:22:15] _____.

Priya : I think we just dropped Ethan's call now.

Erika, are you on line, on air?

Yeah, I am here. This is Erika.

Okay. All right, Erika. Does the fact that you are an young adult cancer survivor affect the attitude of your buddies at work?

Erika : You know, it's interesting because when I was diagnosed I was working for a company that was almost like a family to me and I felt very lucky to be supported through my diagnosis, though everyone at work, out of a hundred people know that I was sick. I felt very supported and when I left that job, sort of just after finishing treatment, I was really nervous to re-enter the work site and, you know, I sort of highlighted the insurance risk and you know, its just a risk in general for a lot of the players. So, I was very fortunate to find a company that was interested in actually making the medical system more human and empathetic and was therefore open to me having gone through the experience I had gone through because I have sort of been in the transit and they have seen that side of things, but I think a lot of people that are post treatment deal with a lot of needing to hide what they have been through and already needing to hide that they are a cancer survivor from their prospective employer because its seen as a risk instead of a positive aspect of their resume. I didn't have a choice because I had chosen to go public with it, I have written about it, but I have heard many award stories about people, you know, getting rejected for a job with no other reason than, you know, probably they are survivors, so I have been, like I said, very, very lucky, but I think its a huge issue that the young adult face as survivors.

You know, that's a really positive story actually because mostly, you know, I will show you the... We have people saying how they are discriminated against and there was a cancer diagnosis come out, so this is certainly very inspiring.

Priya : I would like to now introduce our patient panel. We have with us Karen Crowley. Karen is a stay-at-home mom who was diagnosed with multiple myeloma in 2005. She chronicles her cancer journey in her blog, has been cured of cancer though. We also have with us Heather and Cameron Von St. James. Heather was diagnosed with mesothelioma in 2005 just after three months of giving birth to her daughter. Heather together with her husband, Cameron, embarked upon a site against mesothelioma. Today, Heather is a seven-year mesothelioma cancer survivor and continues to provide unending inspiration to mesothelioma victims around the globe. Welcome to the show, Karen, Heather, and Cameron. Karen, you are on air. Karen, you were diagnosed with multiple myeloma and you have a little girl.

Karen : Yes.

How was it when you heard about your cancer diagnosis and how have you been coping?

Priya : Umm... My cancer diagnosis came... I just went for a regular checkup to my doctor. I felt fine. I didn't have any symptoms, but my blood work came back that there were some abnormalities and the diagnosis came from that and it was multiple myeloma which is something that typically much older people get. There are very few people in their 30s that ever get it. So, I have never been in remission all this time, but I take a medication everyday that keeps the cancer stable and its still working for me and I have been hoping to... I guess to my writing on my blog and trying to find other survivors my own age. Its kind of hard but. (Laughter).



Priya : Karen. Karen, you can ask your question to our panel now.

Karen : Okay. Umm... Yeah. Well, I have been able to meet other cancer survivors my own age online, but I would in the real world, people that I am friends with, you know, most of them don't have cancer, so sometimes it hard to have conversations about it or know when to bring it up or if I should bring it up. So, do you have any tips on how to approach the topic with non-cancer people?

Matthew : Okay. One of the biggest challenges that I have seen, not just as a survivor but as community is that while there actually are legitimately 800,000 Americans that are still under 40, who have had cancer or living with it, God knows where they are...

Uh hmm...

...and its been very difficult to cast a net to bring them together, but between First Descents and Stupid Cancer, which I consider two of the more dominant brands in our sector, we have been able to build a huge alumni network of people who benefited from our programs and services and when combined, its a significant amount of people. If you go to an FB retreat, which Ethan by the way I am going next spring, so ha ha... (laughter) about that, you know, that kind of like open bar night for a week in Idaho on a river. Stupid Cancer has 14 regional chapters on Facebook with about 3,000 or 4,000 people combined and we host live in-person meetups in, I don't know, maybe 30 cities or so around the year. So, that's the way that you can connect with survivors in your region that you may not even know are there, but as far as what I understood you were saying, having to act "normal" around your, we call, non-survivor citizens...

...is really how you wanted to find what that relationship means to you. I am not a therapist, but you have to decide what role you want to play in your life. Are they your caregiver? Are they your therapist? You just want to go out and drink with them and if they don't really understand what's going on, I would encourage you to tell them to visit First Descents website and our website and learn why you are a distinguished individual in the cancer world.

Suleika : Yeah. I was just while there's a lot of meetings, organizational, happening, so I think this is unlike a personal on personal level but this is the young adult people but also like, one other thing is I think that Suleika and I had to we can do in kind of research center and then really angry at the world and its about sort of trying to transcend some of that. You don't understand that nobody is going to get us in public.

Priya : Erika, would you like to add something? (Pause) Erika, is on air?

Erika : Yes, I am there.

Priya : Yeah. help Karen out here?

How Karen... Karen was asking about how to connect with young adult cancer survivors—.

Erika : Yeah, I was just going to say I think, you know, yeah... I'll... I don't know, I don't know but some of the organizations are just absolutely amazing and I have been so lucky to be part of them, but on a person to person level, I mean this has been like an incredible experience, but on a person to person level, I think just being honest with people and at the same time realizing that cancer can make you like, you know, a really, you know, sort of different version of yourself and make you angry at the world, so its kind of like towing that line between being able to be honest and open with everyone to the point that you can but also like being forgiving and allowing people in your life to make mistakes because they are not going to understand what you are dealing with...

...probably hopefully ever, so, you know, that's the weird sort of dance that we all do as survivors, figuring out how to, you know, acclimate them but also, you know, not be angry.



Yes. Karen, I hope that has...

Yeah. Thank you.

Priya : I think we have a couple of more questions for our panel, which I will go ahead and ask them.

Karen, if you have any more questions, you may ask them.

Oh! Yes. Are you still on me?

Priya : Yes. You have couple of more questions... Yeah.

Karen : Yes. Well, I have a question. Every month when I have to get my medicine, I go through a lot of bureaucracy like with the pharmacy and insurance and medical stuff. I don't know if any of you have any tips on how to deal with a lot of that, just bureaucracy and up on it. (Laughter).

Matthew : There is an organization called Triage Cancer sort of free consulting to help you. I mean they are going to make a random reference in the most incredible play like an insurance salesman and you would like all the secret back doors and got in trouble for telling that client what to do.

Uh hmm...

They are like those people.

(Laughter)

...and I am glad you got weird, but that group is kind of like that person where they know the world and they can tell you what to do and how to say things and get things done and there is another (right) group, I am not sure how effective they are, but they are called the Patient Advocate Foundation. They are in DC and they work, checking out even to see if they might be able to give you advice or help you and I think they also have attorneys, like Erin Brockovich kind of attorneys, that just scare the Jesus out of insurance companies, that actually do something when you threaten them.

Okay. (Laughter)

Priya : Thank you, Matthew. Here we have with us Heather and Cameron, her husband. Heather is a mesothelioma survivor. Hi, Heather!

Heather: Hello.

Priya : You are on air. Yeah. Hi! How are you?

Heather : Hello. I am good. I am good. How are you?

Priya : Fine, Heather. Great to talk to you finally.

Heather : Yes. I am glad to be on here.

Priya : Yes. Heather, why don't you share your mesothelioma story with everyone?

Heather : I was diagnosed in 2005 just 3-1/2 months after the birth of our only daughter. Throughout the whole pregnancy, I never really gained any weight and after I had her, the doctor said, you know, you are a little anemic, you might want to keep an eye on that and I just never really recovered and I kept losing weight and getting sicker and sicker and sicker and finally 3-1/2 months after her birth, we got the diagnosis of



malignant pleural mesothelioma which is a cancer that's always, almost always, associated with asbestos. So, when we came to find out, I was exposed to asbestos as a child and there is a 20- to 30-year latency period between exposure to asbestos and the onset of the disease. It usually affects much older people, mainly men, who worked with the products, you know, back in the day, so being 35 or 36 at the time, Mayo Clinic had only heard of one other young woman being diagnosed at my age, so I was thrown into a very uncertain world and at that time they had given me 15 months to live if I didn't do anything and I just had a baby. So, needless to say, we sought out the world's leading specialist in the disease in Boston and I had surgery to remove my left lung and followed that up with chemo and radiation and I am still here 7-1/2 years later, cancer free! No evidence of disease anywhere! So...

Priya : Well, that's certainly great.

I am happy. (Laughter)

We are happy for you. Heather, if you have questions for our panel, you may please go ahead and ask them.

Heather : You know, I deal a lot with other patients, like you guys do, and the mesothelioma community is very small. Its only about 3,000 people a year get diagnosed with it. So, its really rare and I lose a lot of friends. Do you guys deal with that, the loss of... I am sure you do. You get close to people by, you know, being their advocate or just being a friend they sought you out and then you lose them. How do you deal with that? The summer has been particularly devastating in our community and I am reeling from the loss of friends and do you have any tips or, you know, just maybe encouragement of having handled something that... that's obviously a part of our lives, you know, and will be.

Matthew : Yeah. I mean there's no good answer. It never gets easy. Its interesting you brought up that specific topic today because just today we have a team spokesperson, her name is Lauren Scott and who was diagnosed with a sarcoma, like a and she was in that treatment for years and years. She just turned 16. She came to our conferences and she passed away today and its been horrible and devastating for tens of thousands of people whose lives she changed, including my own, and I am in a strange position. I lost my brother-in-law to cancer. I lost my mother's best friend, my aunt to cancer, and my grandfather and myself and we lose people here in the organization every week, every day. I had thick skin to it, but its not the same for other people and it never gets easy and you are allowed to grieve and I think its okay to give yourself permission to accept that its horrible and it happens, but you are still here and how do you want to choose to use that information to live a great life.

Suleika : Hi. This is Suleika. I can really, really connect to what you are saying. One of my very, very best friends who I met in treatment 2-1/2 years ago and who had the same disease as me and passed away on Valentine's Day and she didn't have family around. I was her caretaker and I was with her when she passed away. Its been really difficult I think there isn't an easy answer as to how to deal with that, but I know that one thing that helps me has been finding the small ways to pay tribute to her and to honor her memory. She supported rescue and and we took a trip up there the other weekend in memory of her and just last week, right around the time that she was transferred to hospice, she had talked to me about how badly she wanted to spend some time on the beach and just fly away to a tropical island and I had the opportunity to go down to the curvy end and I thought about her a lot and I read about her and I think these small acts of remembrance and fighting little waves to kind of keep her alive in my memory, that it helps me. Also talking to other people who are great in dealing with loss.

Good. I mean, yeah, that's all really, I mean, kind of overdoing, you know, and its just comforting to know that people go through it, means (yeah) that yes, I am not alone or you know, so...

I think the other thing that happens for me was when disease when she ended up not doing well, I started to write that I was also going to relapse and...

Yeah.



...I think that when you serve the role, when you are both a cancer patient and a caregiver, these two very different and equally difficult roles and I think its easy to feel like this is or this was going to happen to me and dealt with a lot of survivors.

Yeah.

...where I wonder why her and not me and that's something, but I think once again there is this easy cure and easy solution to talking about it and giving yourself permission to talk about it and to grieve have been the most helpful things for me.

Thank you. Thank you.

Priya : Yeah. Thank you, Heather. I am sure diagnosis of cancer must be one of the most painful moments in anyone's life. Suleika, what motivated you through this moment?

Suleika : What motivated me to...

Yeah. To get through...

Sorry about that.

Priya : To hang on... What motivated you through these moments of being diagnosed with cancer at such an young age and I am sure at the time not knowing what future holds for you? What was that one pillar of strength that you held on to?

Suleika : I think for me the thing that gave me the most strength was not only finding but creating a community for myself. One of the best things that has come is going public, is getting through the other young adults and other people who are going through the same things and I really cherish those friendships. That's part of the reason why right now I am out in the middle of the world doing 14 other young adults and I think that, you know, even though we don't talk about cancer all the time, just knowing that you can go there in your shoes, you can at least have different diagnoses provides a lot of comfort and a lot of strength. I know that for me coming here was a big step. I still do chemotherapy and I didn't know if I was going to be strong enough to travel by myself and to get in to a kayak and spend the whole day on the river, but just meeting those kinds of personal challenges and that really wonderful. I think we are all stronger than we realize and this has been extra strength that comes from realizing that.

Priya : Yeah, definitely. Right Erika, you are a breast cancer survivor. Breast cancer at any age will be very traumatizing, but definitely more so when you are very young, in your teening, in your 20s and 30s. What kind of support is available for young adult girls who are diagnosed with breast cancer?

Erika : What kind of support? Umm... Yeah, you know, what I thought was really interesting about getting breast cancer at a young age was that I didn't necessarily need to really people that also had breast cancer. I just needed to really people that or young adults with cancers, so for me I think the breast cancer community is mostly oriented at the maybe 40, 50, 60 plus range. So, for me it was about and I know there are great organizations like the Young Survivor Coalition and others that do cater to the younger breast cancer community, but for me it was like more effective to just talk to other people with cancer and then also meeting people through Stupid Cancer and First Descents has been pivotal than any sort of specific breast cancer organization. I will say that having, you know, breast cancer at a young age and having to have mastectomies, having to under those circumstances is incredibly difficult and without having anyone of us come through that at a young age would have been very, very difficult, but I have some certain people within, you know, the more generally young adult cancer community that have been through those things and have helped me through them.

Priya : Okay. Yeah. Matthew, I have been reading there is q lot of, like, there is low participation of young



adult cancer survivors in clinical trials. Can you tell us why is this so? Is this because there is a general lack of awareness with clinical trials amongst young adults or are there no clinical trials which take in young adults specifically?

Matthew : This is more of an issue with not unique to young adults. Trial of option is around 3% to 5% for everyone that isn't in pediatrics. Pediatrics has a mandate for trials and that's because they are minors and they have no choice, but it has proven over 35 years that trials actually improve outcomes and that's why something like child leukemia which was a death sentence 30 years ago now has a 95% cure rate for these kids. Trial of option in older adults, my working theory is that people don't understand what it is. They think they are guinea pigs. They are going to get placebo. It sounds scary and there is a need to destigmatize it more. From an actual implementation perspective, patients don't know they exist, doctors forget to think about them, and they are usually only considered for late stage disease and again, that's not unique to young adults, that's pretty much anyone over 21.

Priya : Okay. So, does Stupid Cancer extend support and help to people, to young adults, who would actually like to take part in clinical trials? Do you connect them up with studies that do take in young adults?

Matthew: No, that's not really part of our mission.

Okay.

We do talk about it on our radio show and we do several workshops throughout the year called the Bunking Clinical Trials, but we are largely an organization for people who are kind of beyond that point or if they are going through it or beyond it and they wouldn't necessarily need to know about trials, but they like to know that if they can pay it forward in any way, that young adults would benefit through trials. The work around that's been going on these days is that given the lack of adoption in Americans over 21, if you are a young adult diagnosed with cancer and you happen to get treated in pediatrics, instead of adult oncology, there would be much higher likelihood that you will be option for trial if you qualify.

Priya : Okay. Thank you. Thank you, Matthew. At this point, I would like to remind our listeners that if you have a question for our panel, you can press 1 on your keypad and we can bring you live on air to ask your question. Meanwhile, we have received questions via email and we will just go through them.

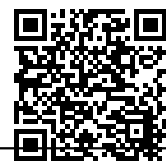
Ethan, this one is for you. Has being a sports person helped you, given you an advantage to fight cancer? (Pause) Ethan is with us? (Pause) I think Ethan's line has...

Yes, Ethan.

Yeah, good question though.

There is a question for you which states has being a sports person helped, given you an advantage to fight cancer, in terms of stamina, endurance?

Ethan : I mean I think, you know, being... One thing I was discussing with a bunch of people today was stamina, endurance to beat cancer. I think leading a healthy lifestyle in general is a great way to beat cancer because if you are leading a healthy lifestyle, you are eating well, you are exercising a lot. If by chance the horrible thing happens to you, you are in a better shape, you know, to get through what you are about to face. You know, for me exercise and fitness is my way to get through cancer, you know, like we did set little many goals for myself and accomplished those goals. It built my confidence and that's what helped me get through, you know, the most difficult times. You know, some people use meditation, some people use acupuncture, some people talk to other people reassuring, but, you know, there are plenty of organizations out there that offer great services for people that are recently diagnosed or who are going through cancer or who are survivors and that's really what this is all about. That's what this radio show is all about. Its connecting with everyone else there who has been touched by cancer, you know, whether you are going



through yourself or you are a caretaker, its really important to, you know, find your motivation and whatever aspect of the disease is to you.

Priya : Ethan, you are running marathons I think, just before almost 10 months after your stem cell transplant and we had MLB coach, Don Baylor, with us in our show in June and he too was back on the field, I think, in three weeks of his stem cell transplant. Do you think that this quick recovery is something to do .

Ethan : Umm... You know, getting through, like I said, you know, running a marathon that quickly after my transplant and actually ran marathon while going through treatment and then I ran the Boston marathon after my second transplant. Everyone's making fun of me because I am bragging right now, but, you know, it feels good to say that. You know, it feels good to be able to accomplish those goals and, listen, running isn't for everyone and I hate running as much as everyone else, but for me it was my strength. It was what, you know, allowed me to focus and it helped me, you know, clear my mind and I think, you know, everyone needs that in their life, especially when they are going through such a horrible situation like cancer.

Priya : Thank you very much. Suleika, I think you are also training for a marathon. How did the training go? (Pause) Suleika is on air?

I am sorry. What was that? I am having trouble hearing you.

Yeah. Suleika, yeah, last time I think we connected you were training for a marathon and you were going through chemotherapy at the same time, so how did you manage that?

Suleika : I actually had a very different experience from Ethan and so I did training for a marathon about nine months after my transplant and my big running dreams lasted about only 20 days actually. I ended up back in the emergency room on emergency for non cancer related reasons and with a running injury. So, I think that for me I really wanted to be one of those cancer survivors who finishes their treatment with a sword and who climbs the mountain or runs the marathon, but I just wasn't ready for that yet and it was a really important lesson in knowing to listen to your body and learning that change only really happens in small incremental changes. You can't go from 0 to 100. So, right now, I am going to start off with going from 0 to 20 and taking it easy and learning and remembering to be kind to my body, which is often easier said than done.

Priya : Yes, that's right. We have a caller who would like to ask a question. The caller calling from 212, please ask your question and... (Pause) Caller... Yeah. You are on line. Please ask your question.

Caller : Yes, hope you all can hear me. I am very happy to hear all these stories and such motivation just hearing everybody's story here and I have a couple of, sort of questions, and, you know, all of you can, maybe Matthew can and Suleika can address some of these, but its open to everybody on the panel. One is a little bit more on like, when you heard the diagnosis and how much, you know, how many months or years did your doctors give you and, you know, hearing everybody here, it sounds like, you know, totally hope and wish that you all totally live beyond that initial period that they said. So, my question is that what did they tell you and is there an online database that tracks, you know, what was the initial life expectancy at the time of diagnosis and what people are... How much they have outlived that initial diagnosis because I think that's very useful information for a new patient to see that, no, the diagnosis is not the final... the life expectancy is not the final word and there are so many people out there who have outlived that initial expectancy assessment by their physician. So, my question is around that, like what did your doctors tell you and is there a database that tracks this?

Matthew : Well, this is Matt. There are thousands of cancer registries in the country and none of them talk to each other. So, any stat any doctor gives you is based on his particular assessment of which registry makes the most sense for him to quote from.

Uhhmm...



I just tell people don't listen to your doctor.

Uhhmmm...

I mean, listen to them for what medicine you take, but I was told I would be dead in six months 18 months ago. So, my position is... I am not a statistic, I am myself, treat me like me and I am going to ignore Dr. Google where I can research the ugly stuff on my own.

Uhhmm...

I was also diagnosed during so it was 18 years ago and there really was no attention to pay to doctor communications with patient's sensitivity, social work. You are really kind of a bit of a piece of meat and that changed today. The narrative changed, the dialogs changed, and there is a lot more appreciation for the individual [00:56:07] _____ the person, but also patients are smarter now, especially younger patients and I would say if you are not happy with the way your doctor is talking to you or thinking about who you are, get a second opinion and leave. They are your customers and if you are not happy with them, then fire them and find someone who cares about you.

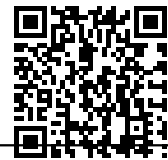
Caller : Thank you. Thank you. If anybody else can describe their experience, that will be helpful, but I did have another question and that was discussed more in relation to the emotional stress or trauma that happens. Are there any data or studies that have looked at the correlation between emotional and traumatic stress in addition to the cancer diagnosis and what kind of correlation – Is it 10% or 20% of patients who have emotional stress in relation that is documented and do insurance companies support emotional related care and is there..., I mean do they support, so I am trying to understand what's the occurrence of this correlation between emotional trauma and the diagnosis and do insurance companies really support such supportive therapies?

Matthew : The answer is just going to piss you off. Umm... No. Haha. On occasion, insurance companies will cover sort of a psychologist or a therapist, but usually there is a free therapist in the cancer center. Only recently some insurance companies in this country, and they all suck, are in charge of making sure that they do some good for patients and they are now covering like acupuncture, but they won't cover nutrition, your wellness, your well being, your physical therapy and it really just depends on who you are, where you are, where you treated, what your carrier is. From the perspective of research outcome and published white papers on the relevancy of psychosocial well being as a marker of quality of life, there are dozens of studies about those in the last 10 years. I am not a researcher. I don't know what they are, where they are, but you could find them probably on and everything that you think it says, it does. Where your quality of life is quality of care and vice versa and the more mental clarity they have during treatment, the better outcomes we have long term.

Oh, thank you. Thank you.

Priya : Thank you. Matthew, what are some of the main events or functions that a young cancer survivor is focused? I know Stupid Cancer conducts Oh My God (OMG), media get-togethers and what are some of the other events that are planned with your...

Matthew : Well, we do... We now produce two OMG cancer summits every year – one in the spring and one in the fall. The one in the fall is on September 28th, here in New York City at the New York Law School. The website is east.omg2013.org and we produce our 7th annual OMG summit in Las Vegas next spring which is OMG2014.org. Those are two principal programs. They take up a whole lot of time. They take a year to plan and they become incredibly successful and again going back to emotional well-being, we conducted a research study on emotional well being before and after our conference and we have now been able to do scientifically quantify that patient engagement with our programs meaningfully improves quality of life, which helps improve outcomes at the same time. We also produce a live radio show once a week for the last seven years. We host social meet-ups around the country and we partner with cancer centers to produce what we



call boot camps which are sort of regional workshops that cater to these different topics that young adults care about most, like fertility, insurance, dating, parenting, bereavement, fear, anxiety, self-image, reconstruction, and career planning.

Priya : I am sure that's very helpful. I think we have almost completed our showtime. We launched the young adult cancer survivor panel discussion today. What we aim to do with this program is to address issues that are specific to young adult cancer survivors and thank you, everyone. It was great to have you all here, timeout. Suleika, Erica, Ethan, and Matthew, it is absolutely great to have all of you together on the show.

I thank all the people who are listening and look forward to having all of you join us for the next Cure Panel Talk Show. We are discussing diabetes cure on August 12th at 11:30 a.m. eastern time. For more details of our upcoming shows, please visit trialx.com/curetalk. The link for today's show will be sent via email to all participants. Thank you.

curetalks.com