Support for Yale Cancer Answers comes from AstraZeneca, working to change how cancer is treated with personalized medicine. Learn more at astrazeneca-us.com.

Welcome to Yale Cancer Answers with doctors Anees Chagpar and Steven Gore. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week, it is a conversation with Christine Frisbee of the Richard D Frisbee III Foundation, founded in memory of her son Rich. Dr. Chagpar is a Professor of Surgery at the Yale School of Medicine.

So, Christine, maybe you can start by telling us the story from the very beginning. How did your journey here start?

In September of 1988 our son, Rich, was feeling sick and we ended up bringing him up to Yale on advice from the pediatrician, and he was diagnosed with leukemia. He was 14 years old and he was treated here by Dr. Diana Beardsley who was a pediatric hematologist at that time. And, he did not do well with his chemotherapy and they decided he needed a bone marrow transplant. So, after he had 3 rounds of induction chemotherapy, he finally went into a remission and Joe Rappaport and his team had come down from Boston to start the bone marrow transplant unit at Yale and he was the first child to have a transplant at Yale in January of 1989. Unfortunately, after 6 months, he relapsed, and he never got well again and he passed away in December of 1989. So, that was our journey of coming to Yale and knowing Yale, etc.

I am so sorry to hear that. Tell me a little bit more, I mean, your son was a 14-year-old when he was initially diagnosed. You said that he did not feel well and you took him to the pediatrician. What kind of symptoms was he having?

Well, he had been away at a camp, an outward bound type of camp, the summer before, and when he came home from camp, he was acting very tired and I just assumed it was because of this rigorous camp, and he started at New Canaan High School as a freshman and after a couple of weeks, he
came home and he sat down and he cried to me, which he never did over things, and he said I could not run down the field today at soccer and I failed the French test and I just have no energy. So, I said we will stay home tomorrow and catch up on your rest, you are just tired. So, he stayed home, but by the middle of the day, he said to me, "I feel faint," and I said I don't like faint, let's go to the doctor. And Dr. Flynn in New Canaan was our pediatrician and he did tests and at the end of the tests, he said call me tonight I don't care what time it is, just call me this evening. So, we called him and he said you have an appointment at Yale in the morning, it is something serious. So, that was sort of it. It was just a simple complaint of running down the field and not being able to do it and feeling weak, but months before, he had been very achy. It was on and off. So, it was hard to diagnose as a parent that something was that serious. I just thought it was literally having growing pains.

03:37.900 -- 03:55.400
<vChagpar>Because certainly, kids get tired, kids get achy and all of a sudden you take him to the pediatrician and they do a simple blood test and next thing you know, you are at the Yale Hematology Clinic.

03:55.400 -- 03:55.900
<vFrisbee>That's exactly what happened, yes.

03:55.900 -- 04:12.600
<vChagpar>I can imagine that was rather shocking, and when you arrived at Yale that first time and you met with the hematologist, what did they say, what was that like and what were the next steps that they did in making the diagnosis?

04:12.600 -- 05:33.300
<vFrisbee> Diana Beardsley, who has since passed away, anyone who knew her, she was a lovely, charming, warm person, and after they did a bone marrow aspiration and confirmed that it was leukemia, they came out and told us, but what I heard was, maybe it is leukemia, and they said we will put him in the room upstairs on the seventh floor of the hospital. So, they brought him up and the nurse came out and she said we are starting chemotherapy right away, and I said, no. We were not really sure what it is, please do not start anything, and she goes no, we know. So, there was this parental confusion as to what we were hearing, how intense it was. We knew leukemia was serious, but we did not know really that it was a blood-related cancer, and what the prognosis was or what the treatment was, it all seemed to happen in a flash, so within hours of us stepping through the doors, he was in the hospital for a long time.
<vChagpar>So you go to the hematologist, they say okay we need to do a bone marrow biopsy and then what you heard was maybe it is leukemia, but what it really was, was leukemia and I can imagine how that must have felt. And so, when they started chemotherapy, what was that like for your son and what was that like for you?

<vFrisbee>Well, the first thing that Rich said actually is, I have cancer, am I dying? Because they told him, and I said, no you are not dying, they can cure this kind of leukemia now and it was a back and forth very intense type of conversation that you never think you are going to have with your child of discussing the intensity of treatment, whether they are going to live, how long it is going to take, what your chances are of living. As I said, nobody prepares you for having those discussions and thinking the thoughts you think. I remember getting on the pay phone and calling my mother in New Jersey and saying I need another opinion, I can't just make this decision as fast, how do I know that these doctors are good, how do I know I can trust them, how do I know we are not making a mistake.

<vChagpar>Right. What did she say?

<vFrisbee>She said I understand, she said let's try to see who else can answer some questions, and I did get the name of another doctor in New Jersey and the doctor said you are in very good hands, I know the doctor who is taking care of your son, she is one of the best, I think you have to trust them.

<vChagpar>And so, you got the second opinion and it was leukemia and your son started chemotherapy? What was that like for him, in terms of chemotherapy and losing his hair and suddenly the diagnosis must have become real?

<vFrisbee>Yes. It was real to him. He was quite a mature 14-year-old and he was very nervous. As an adult, it does not seem important, but to him losing his hair was one of the most serious things that could have happened to him, and when he started the chemotherapy, he was very sick. They did not have the same kind of medicine that they have now to prevent you from getting sick. He was very, very sick all the time, taking especially the induction chemotherapy, which is the very strong kind to stop the
cancer from growing. And, we were battling his depression because he was very anemic, battling the reality that he was going to feel sick to his stomach for a long time and that his hair was falling out, and he did not like that at all, and eventually, he had some of his friends come up from New Canaan High School to visit him and he was very embarrassed by the way he looked and he was a private child and it was very hard for kids to come from the high school to see him in that state when he was kind of getting this macho feel about him.

09:00.800 --> 09:19.800

<vChagpar> I was about to say that when you are 14 and you are at high school and you have got your social circles and you are learning how to drive and you have got your plans on who you are going to take to the prom and what you are going to do for college, and then cancer strikes.

09:19.800 --> 10:04.800

<vFrisbee> And he never went back to school, it all became so intense, some friends would come up to see him, but when he would go home, we had to be so careful because his immune system was so compromised, but a lot of kids came over. It was very nice and they were a special group of kids, they ran a fundraiser to raise money for childhood cancer at the high school, they wrote articles in the school paper about him, it was really an amazing thing because you do not really feel that children are able to separate themselves from their everyday life and devote it to a friend who is very sick.

10:04.800 --> 10:27.800

<vChagpar> So he got a little bit better with the chemotherapy and went into remission, and did you kind of feel at that time like okay, the chemotherapy did its job, now let's get back to life or what was that like? Or was there still the sense of any minute the second shoe could drop?

10:27.800 --> 11:43.000

<vFrisbee> Well, we were told early on after he went through the second round of induction chemo and he did not go into a remission that you have to go into a third induction round; and therefore, if they could get him in that he would have to have a bone marrow transplant. So, we began typing all of the rest of the siblings. He was the second eldest of 5, and the rest of the children and my husband and I were both typed to see if we would match him for the bone marrow process, and one of the children matched, the fourth child Meg. She was 7 at that time and she was identified as the person who would take her marrow and give it to Rich. And then, we felt like that was the cure. It was like the aspirin that was going to cure him completely. We were elated, we just thought oh! my goodness, this is the end now, we are going to do this transplant and he will be cured for life. So, that was our attitude at that time and thank god we had that respite of enthusiasm to carry us through because it is a long journey.
How did Meg feel about it being 7 years old and being asked to be a bone marrow donor for her older brother?

Well, she did not know what it was going to really entail. So, that was good in a way because she did have to have bone marrow aspiration from her hips and it did end up being somewhat painful, but she was excited. She thought she was going to be the one who saved her brother and she was very enthusiastic and happy that she was the chosen one so to speak.

And how did you feel? I mean, certainly, there was the elation of okay this could be the cure, but this was now the time when the bone marrow unit was just starting at Yale, and so, was that somewhat, did that give you some trepidation that this was still novel at that time?

It was very novel and you had to sign off on a protocol, the protocol being this was what we are going to do to your son, this was what the expectation is, these are the ramifications that can happen and reading it, it was a very, very scary thing. And we did not have anyone else really to talk to at that time. We were the only family undergoing the transplant and the unit was not even finished. So, he was transplanted in an adult room on the oncology floor and it was really such a scary experience when it happened because you are basically told that your child is going to have his immune system taken down to zero and a new immune system is going to be infused and the whole concept is a frightening one when you think about it. So, we were very nervous the whole time, we were very excited when the marrow arrived from Meg and started dripping into Richie’s veins which knows how to go to your bone marrow. It is an amazing medical procedure, but we were elated on the day thinking this was it.

And we are going to learn a lot more about what happened after we take a short break for a medical minute. Please stay tuned to talk more with Christine Frisbee.

Support for Yale Cancer Answers comes from AstraZeneca, working to eliminate cancer as a cause of death. Learn more at astrazeneca-us.com.
This is a medical minute about genetic testing, which can be useful for people with certain types of cancer that seem to run in their families. Patients that are considered at risk receive genetic counseling and testing so informed medical decisions can be based on their own personal risk assessment. Resources for genetic counseling and testing are available at federally designated comprehensive cancer centers. Interdisciplinary teams include geneticists, genetic counselors, physicians and nurses who work together to provide risk assessment and steps to prevent the development of cancer. More information is available at YaleCancerCenter.org. You are listening to Connecticut Public Radio.

Welcome back to Yale Cancer Answers. This is Dr. Anees Chagpar, and I am joined tonight by my guest Christine Frisbee. We are talking about the work that she has done with leukemia that really stemmed from the experience that her son had with this disease. So, right before the break, Christine, we were at the point where you thought this was it, your son had a bone marrow transplant courtesy of Meg, your daughter, who ended up being a great donor and this happened to be one of the first kids to be treated at Yale with a bone marrow transplant. And there was hope and then what happened?

Well, 6 months after Rich had his transplant, we were on vacation in Cape Cod.

He got better and was healthy and able to take vacation and did he go back to school at that point?

No, he had not been back to school yet because after a transplant, you are so immune compromised for a long time that you cannot be out in public. So, you really have to be protected. He never went back to school. But we were able to take a trip to Cape Cod with great warning that everything had to be done just so, so he would not get any germs or infections. So, we were quite happy about that and we took the trip to the Cape, and in the middle of July, he was due to come back for a visit, a checkup. So, there was a flight, a puddle jumper so to speak, between Cape Cod and New Haven. So, we flew back and went into the clinic. Everything seemed fine, and Rich over the time and I do not know if they would do it now, but they would let him go to the computer and look at his blood counts and he went in and took his visit and was trying to find his blood counts but they would not let him this time, and we went back to the Cape and I called the doctor and I said oh! how is he doing, how
are his counts? And he said, well I have to call you a little later, all the counts are not in. And so, he
called us a little later and he said he has relapsed. And that just hit us so hard I did not know how bad it
was, but I was just, my heart just dropped knowing here we go again. So, we thought okay fine, we will
do more chemo, we will do another bone marrow transplant, but this time his sister Meg said, no I am
not doing that again, she said no way. I said, Meg just be patient let's try to get him into a remission.
So, we had to bring him right back to the hospital.

18:00.500 --> 18:04.400
<vChagpar>And he felt fine though?

18:04.400 --> 18:57.100
<vFrisbee>Yeah, he was not complaining, he was not complaining at all. We even let him have a little
private tennis lesson and he would ride his bike up and down the street, he would not mingle with
people very much because that was not allowed. He was not supposed to be in the sun too much, but
we let him do a few things to feel normal, to feel like a well person again, and so it was a complete
shock, and the doctor kept saying, well we will try to get him into remission again, we will try to get him
into a remission and then one day, I said to the doctor, how many people who relapse after bone
marrow transplant actually go into remission again, and he said, well Christine, I have to tell you I h
ave not had any and that was the night I knew he would not like it.

18:57.100 --> 19:26.800
<vChagpar> And so, you are left with this feeling in the pit of your stomach like this is not going to end
well. But you still had a little bit of hope that maybe, just maybe he could end up in a remission and
tried to convince Meg, his sister, who did not really want to go through the whole bone marrow
donation thing again to go through it again?

19:26.800 --> 20:12.800
<vFrisbee>Well, you constantly went through that, but as they gave him more chemotherapy and it
went on and on, he would go and he would read his counts, and he knew he was not getting better, the
cancer was winning. And then, finally one day, he said to me, mom am I going to make it? And we had
all discussed that he was not and we all knew it. And it was the question of are you going to stop the
chemotherapy, at what point. They begin to get pneumonia because they are so compromised and so
finally we had to decide not to start the chemo and when they told him that, he said I am dying aren't I
and I said yes, you are.

20:12.800---> 20:17.300
<vChagpar>Oh my gosh! What was that conversation like?

20:17.300 --> 20:44.800
<vFrisbee>It was so hard and I just tried to be strong for him because the next thing he said, well what happens when I die, where do I go? And I said the angels are going to come down from heaven to take you. And you will go up to heaven and I will be here with you the whole time until you go.

20:44.800 --> 20:49.100
<vChagpar>And was he at peace with that or was that incredibly scary?

20:49.100 --> 21:35.500
<vFrisbee>He talked about it, we are quite a religious family but of course you never think you are going to have that conversation, and he was actually quite good with it, he was okay. About a month later, he died and it was a funny thing because we were both, Rick and I were both in the room and I had promised him I would be there at the end, but I fell asleep and Rich was there and he woke me up and he said, Rich is gone and it was very good for Rick too to be there because he was so afraid of it and yet he got a lot of strength from being there when Richie died. And I think we were so tired at the end of it, we were happy to see him be peaceful.

21:35.500 --> 22:20.000
<vChagpar>Yeah. Were there services that helped you at that time because I can imagine what a difficult time it is and there must be many parents who have children with childhood cancers, who ultimately have to face that fact that some children are not going to make it and are going to pass away and it must be the most difficult thing in the world to lose a child, but were there services that helped you, pastoral services, palliative care services, people or things that were particularly helpful for you that helped you through that difficult time?

22:20.000 --> 24:03.100
<vFrisbee>I can't say that there were specific services, there were friends, I think that people at the hospital became our new friends and I come from a very large family and of course I did have that support system. But I think the doctors and nurses who took care of him were so special to him and we were sort of a unique situation at that time and they really gave us a lot of TLC and they were a great support system. And when we had a wake for Rich, they all came down and we stayed in contact afterwards and they were sort of my support system because they knew where I was coming from. We had a lot of good friends in New Canaan who were very wonderful and supportive at that time. And as I said, we are quite religious, but we did not go to any support groups. So, there was not any pastoral care in particular who helped us. Months later, we did go and speak to somebody who helped us as a couple because it is very stressful as a couple to go through this because you do not always react the
same way and you do not understand that this person whom you love very much and we spent so much time with is totally reacting differently than you, so that was very, very hard and I think we found somebody who was very good and helped us through that. And of course, we had 4 other children we were so lucky and it was something that we used to try to keep everybody very close together because they were all suffering very much as well.

24:03.100 --> 24:24.300

<vChagpar>I was about to ask how did the other children take it? Because I can imagine with Rich being one of the older children, how it must feel to have a younger sibling watch your older sibling pass away, must have been very scary for them. How did they take it and how did you help them through that?

24:24.300 --> 25:51.600

<vFrisbee>Well, they each reacted very differently. The oldest one, our oldest daughter was the most devastated because she was already a freshman in college when it happened and it was very hard for her, she was in Pennsylvania and was very hard for her to be even that far away from him when it all happened. And I wanted her to stay home for a while after Rich died in December and she wanted to go back to school. I think she felt she could forget it a little bit more being at college, and then the younger ones really did not understand for a while what the separation was going to be. They did not understand not having their brother around, what it was going to mean for them. So, it took a little longer but they all reacted totally differently, some acted out more than others, some were mad at me because it was just somebody to get angry at. So, it has been a long journey even now it is 30 years later and it is still a journey talking about it, figuring it out, why did this happen, why did that happen, would it be different today, what would Rich be like now, would he have kids, would he be married. So, unlike some families I have heard, they try not to talk about the person who passed away, we talk about him all the time.

25:51.600 --> 25:55.200

<vChagpar> Yeah. And part of that might be part of your healing process?

25:55.200 --> 25:57.200

<vFrisbee>Definitely.

25:57.200 --> 26:03.800

<vChagpar>> And since that time, you wrote a book, Day by Day, tell us a little bit more about that.
Well, after Rich died, I actually went to work at Yale. I became the coordinator of the unrelated donor program in the early 90s and I worked with a lot of families who had children who are ready to go for a bone marrow transplant, and I would see the siblings doing the same thing our children did, sitting in the room, being patient, coloring, waiting for the office visit to be over, and my heart really went out to them because I knew what it was like for them because I would often be dragging my younger ones up to Yale while Rich was being treated. And I thought I would begin to ask the siblings how it was for them and I started of course with my other children and then we went out to children who had had siblings who had had lots of different illnesses from cancers to diabetes and brain tumors and all kinds of different illnesses, and it was very hard to get them to write stories but some of them were very enthusiastic and my goal was to have the book written by the siblings more than written by professionals. And some of the professionals said, well, we can write it really well and I said but it is not your story, it is the story of the siblings. So, we got 40 children of varying ages to write stories. I did not edit them, I just put them together, but we clustered them according to the reactions that they were having and there was a definite pattern there. And I wrote the entry to each of the group of chapters and the exit out of it. And I think it is a lovely story because there was a common theme there amongst the siblings that although they were shocked and upset, that they found inner strength in dealing with these issues and they were prepared for life and they viewed the friendships and the relationships totally differently from their friends, which I think is a very interesting thing to learn from these children.

Yeah, and certainly their experience I think is one that needs to be captured. Tell us a little bit more about the other things that you have been doing since this journey. You started an art-bag project, tell us about that.

Yes, we started a foundation in memory of Rich with the help of our friends from New Canaan and we used to have big fundraisers and do many different things from providing fellowships at Yale to nursing scholarships to lectureships at Yale as well for the medical school. Aside from the book, personally I started a project called art-bags for kids, and I want children who are sick and who cannot go to school along with their siblings to be able to be remembered with art projects. I am an artist, I love to paint, and I thought if we could provide art supplies to children who cannot go back to school or at home with their disability or illness of any sort, we would raise the funds by the art supplies. We have designed a bag and we give out these bags of art supplies which have about 15 different supplies in them from crayons, to clay and rulers and paints and we give them to the families through the hospitals, the Ronald McDonald Houses, through hospice, through other organizations, even schools. A couple of years ago, we did a big project with the New Haven School System, they run a camp for disabled children and we provided a lot of bags for them.
Christine and Richard Frisbee founded the Richard D. Frisbee III Foundation in memory of their son, Rich. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. We hope you will join us next week to learn more about the fight against cancer here on Connecticut Public Radio.