

Christine Frisbee, Day by Day: Children of a Seriously Ill Sibling Tell their Stories of Faith May 18 , 2008 Welcome to Yale Cancer Center Answers with Drs Ed Chu and Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center. 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 at canceranswers@yale.edu or 1-888-234-4YCC. This evening, Dr. Ken Miller welcomes Christine Frisbee. Christine is the Chair of the Richard D. Frisbee III Foundation, and she joins us to talk about her new book Day by Day, which documents her family struggle with leukemia. Miller You wrote a beautiful book. Tell us a little bit about Rich. Frisbee Rich was our second child, our first son. He was growing very tall and very thin and had just started at New Canaan High School right before he was diagnosed with leukemia in September of 1988. Having 5 children, everyone was very well. We were very, very shocked to hear that he had leukemia but once we found out we realized that he had had the symptoms for quite a long time, but they had not presented themselves strongly enough where one would know that he had leukemia. He was a smart boy, not number 1 in his class, but a smart boy, and he was very athletic. One day he came home from school and said, "Mom I could not run down the soccer field and I failed my French test," and he cried. Rich was not the type of child who cried easily, and I just thought he must be awfully tired from starting at New Canaan High School. I told Rich that the teachers were pushing him, that they want him to do well, that they can be very serious the first week of school to make sure you do well. I told him to stay home and catch up on his rest. He had been away at a summer camp before and I thought he might just be exhausted. So he stayed home and I was doing an antique show in Greenwich and I came home at lunch time to check on him. He said he felt faint and I did not like the sound of that so we went to the doctor's office immediately. The doctor did many more tests than a pediatrician would normally do and he said to call him that night. This pediatrician, Dr. Flynn, had 9 children and he never really spoke like that. It was of great concern that he would act in such an imperative way at the time, and so we called him that night and he that we had an appointment at Yale in the morning, that it is serious. Miller It has been many years, but do you remember that phone call as if it was yesterday? Frisbee I do. I remember where I was standing. I remember where my husband was. I remember him saying to me, "What he did say, what he did say, what he did say?" And I told him he said it is serious. He asked what else he said, and I said I could not ask anything else. I knew he meant it. I told him we had to get to sleep because we have to be at his office at 7:30 in the morning with Rich and a bag packed. 3:28 into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 Miller How did you share that with Rich himself, that something was serious and that you needed to go to the hospital. Frisbee I told him calmly. I knew that the doctor meant it, but I still thought that maybe he made a mistake. So we were going very fast up 95 the next morning and there was a song playing on

the radio that was popular then, "Don't worry be happy", and Rich turned to me and he said, "Don't worry mom, be happy, it is not bad." But within a few hours he had chemotherapy infused into him to start treatment right away. Miller Can you tell us a little bit about that first day? How did they make the diagnosis and what was that experience like for all of you? Frisbee My husband Rick and I went into the emergency room. It was the old hospital then, they did not have the new Children's Hospital at that point, and Dr. Diana Beardsley was waiting for us. She said that she had to do a couple more tests so they brought Rich into a procedure room and they did a bone marrow biopsy and aspiration. Then they asked us to leave the room and she told us that Rich had leukemia. I asked if she was sure and she said they were pretty sure, so I left in my mind the hope that maybe they were not sure. She told we could check into our room and Rick and I were crying and completely in shock. We did not really know what leukemia was and we thought that something had to be wrong. I mean, he was not that sick. He was just tired. How could he be that sick? I immediately got on the phone in the emergency room and called my mother and tried to say what was going on. She said we have to get other opinions and all of this commotion that so often happens when somebody is diagnosed with a serious illness. Miller We were talking earlier that in our family, we got a similar shock when my wife was diagnosed with leukemia. There is a sense of disbelief because life goes from being pretty normal one day to being very, very abnormal the next. Frisbee It does, and I often talk about it as being the first day of the rest of my life. It changed our lives completely, that illness, and Rich did pass away, but even if Rich had lived it would have changed our lives forever. The reality of those harsh moments in life really does zap something out of you, and into you, that makes you look at life differently. Miller I want to talk about what zapped in and what zapped out. What made you decide to share this story now? Frisbee I ended up working in the field after Rich passed away and I found that there was such strength in the families that I worked with. I searched for unrelated donors for families and sometimes we would work for over a year with these families and 7:10 into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 I watched the children come into the clinic and leave the clinic, month after month, and I got to know the children and the families very well. I felt such a bond with them and eventually it came to me that I wanted to know how my children felt about all of these experiences that they had been through. I asked Meg and Mary Jane, the two youngest, to write stories for me with the idea that I would love to get stories from many children because I felt that I really did not know how they felt until they put it down on paper. You talk about things, but you do not talk about things in as much depth sometimes as you should. They put things down on paper that I never knew they felt. I had this as an idea that I wanted to work on, but I did not know how it would develop and it has taken a long time to reach our goal in getting the stories together. It was very hard to get stories from other people, it was very hard for them to write down on paper how they felt, a lot of people would not. Miller Because it was too painful? Frisbee Because it was too painful. They

did not want people to know how they felt, but I hope that the book will show those people who found it so hard, that there is a common thread between all of these people. It is not a bad thing to feel pain or anger or embarrassment. They should, it is normal. Miller Along those lines, talking about Rich, I think a lot of people would say they are afraid to bring it up with you because it is going to be painful, but let me ask you, is this okay to talk about, it is okay for people to ask you about it? Frisbee It is, and I think for me it is part of who I am now and I am proud that we were able to survive it and be happy. Our family is very, very happy. We acknowledge that this happened, it is painful, but you can stand up and move forward and be very happy in life and I look at everyday as a joy. Everyday brings new things to me and that is one of the things I wanted to show by having these stories written by the children; they are inspirational. They write about how they are not sorry that this happened to them, that they see good things in life and they want to help other people that they respect all the differences in people. This is what I hope to achieve from the book because it is really what I feel. Miller With your children, you mentioned that what they had to share about their experience with their brother was different than you might have expected. Frisbee Yes. Miller In what ways? Frisbee Some of them expressed a lot more anger at what happened and how I handled things at the time. They did not express to me then how angry they were that I10:29into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 could not be there for the soccer games, that I did not give the right response when they asked to go to the dance, or why I wouldn't buy them that dress. Often I would be exhausted and I would snap at them and I would be rushing around trying to balance everything out and I thought they sort of understood, but then I realized that they did not and it made me very sad to think that I was not able to be all things to all people during that time in our lives. Miller The way I look at this is in many ways a process. You now have more years to look back on this experience. As I listen to what you say, you are just a person doing the best you can with a very, very difficult situation. Is this something you are able to feel comfortable with, or is it still a sore point? Frisbee No, I am able to feel better about it. I know that you have read the book and just recently actually I gave it to my children to read. One of my children wrote me what she felt about it and she had very strong points. She realized how hard it was for me for the first time, she realized that I felt I was incapable of being all things to all people and she felt compassionate about it. I thought "wow" we still are going through our own healing process as a family. Even though I think we have done well, it was Meg who actually wrote this to me, and she said "Wow mom, this is amazing, I never realized that you felt that way, all I realized was how I felt." She said that now she knows how hard it was for me and that she thinks it is so wonderful that we are all going to understand each other better. It is going to be a wonderful story for parents and a wonderful story for children too, and again our healing process is ongoing so that was so nice for her to say. Miller When people are in the midst of a crises, or have lost a loved one, a son or a daughter, a spouse, a sister or a brother, there

is a feeling that you cannot go to the next day, you cannot make it to the next day, and it is interesting and reassuring to hear that the healing process goes on, and it is okay that it takes a lot of time. Frisbee It is okay, I mean this all happened almost 20 years ago. It was a long time ago and I really do feel that we will be healing for the rest of our lives, but everything that happens in our lives is a process and I do not think that everybody realizes that everyday, everything that happens to you is a process that you can take and help develop your character and make you stronger and more positive. It is all in the way you look at it. Miller We would like to remind you to please feel free to e-mail your questions and thoughts to canceranswers@yale.edu. We are going to take a short break for a medical minute. Please stay tuned to learn more information about coping with cancer and your family and about some of the processes of recovery afterwards with Christine Frisbee. 14:10 into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller, and I am here tonight with Christine Frisbee who is Chair of the Richard D. Frisbee III Foundation and author of a new book that is about to be released entitled Day By Day. Christine, we have been talking about your son Rich. Let me ask about your other children, how old are they now? Frisbee Kristen, the eldest, is 36; Rich would have been second; Jim is 30; Meg is 26 and Mary Jane is 24. Miller It is impossible to know how life would have been different if Rich had not gotten sick, but how do you think your children may be different than they would have been otherwise, in good or bad ways, and how are you different for that matter? Frisbee Well my eldest daughter goes through life treading very carefully. She has 3 children of her own right now and anytime one of them is sick she is very fearful that something very serious will happen to them. It has affected her very, very much, and she was very angry for a long time. Between the two of us there was a lot of anger and it took years and years for her to realize that I did the best I could. She had to just be angry at me for whatever she needed to be angry at me about, and eventually she got over it. Jim missed his only brother. His brother used to be the more aggressive one and used to beat up on him when they were little. He talks about that in the stories. I think it made Jim very shy. He had a hard time going through school. He was the quieter one of the boys and probably the most quiet of all the children. I do think that he reflects back now, and it gives him great strength. He is a wonderful, kind individual, married for a year and a half and is an architect and he is quite remarkable. Meg was very difficult at first. She was acting out at school. She was only in second grade when Rich was diagnosed, and she was Rich's donor. He had a bone-marrow transplant, and she was his donor. She writes in her story about how all she wanted to do when she 17:35 into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 was his donor is be wheeled around in a wheelchair, even though she did not need it, and be considered a queen because she was so sick of everybody giving Rich the attention, and she wanted a little attention of her own. She was very difficult at the time and I was talking to a friend about how it has really affected Meg. She suggested putting her in the swimming pool and letting her swim

year around. Well, we did, and Meg ended up becoming a fabulous swimmer, a nationally recognized swimmer, so something good came out of her eagerness to show me how she felt. Mary Jane, she was the youngest and she does not really remember it that much, but they say the youngest actually are the most affected. I think it is true because for Mary Jane her memories of growing up were always of a family that had lost a brother, and the others knew Rich better, she was so young, she was only 5 when Rich was diagnosed and died. That is an awfully young age to try to remember everything about Rich. Miller For you and for your children having the opportunity to write about this, and also for the other people that contributed to the book as well, is there a sense of healing by having shared the story? Frisbee Yes. Most of the children who contributed, and young adults who contributed, were so thrilled to write their story. They are so excited for the book to come out. They thought it was such a healing process to tell people how they felt and what it was like for them, and although some people were afraid to contribute stories, I do think the ability to voice what they felt is such a healing process for everyone. There is a common thread in the stories amongst all of them, even though all of the siblings had different illnesses. They are not all about cancer, although there are many that have brain tumors and leukemias. There are also stories of children with an autistic child in the family and many different things. There still is a common thread in that they have been asked to be soldiers and be strong and make something positive out of a difficult situation. It is really remarkable that not even knowing each other, they all told the same story and were very grateful to tell their story. Miller It is wonderful to have an opportunity to read it because I learned a lot by reading those stories. Let me ask you, as an oncologist and for physicians that are listening, how can we better be of help to families going through this experience? Frisbee When an oncologist, hematologist or any doctor is dealing with a family that has a sick child, they need to also ask the parents how the other children are doing, how the family is doing. Ask if anyone else needs attention, if you need to bring in help, a social worker or a religious person to come and support you, do your schools need somebody to talk to them? The Leukemia Society had a program for schools when Rich was sick and one of the teachers, actually two, came up to it and it made the world of difference that all of a sudden they knew what the whole family was going through. I really do think that if the doctors, nurses and21:33into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 physician's assistants could pay attention to the whole family it would really be helpful. Miller Very well said and I think it is an important reminder for all of us. Aside from writing the book, which has been a huge commitment and a wonderful gift to all of us, you have been very active in supporting cancer research and children who are going through this experience. Can you tell us about the Richard Frisbee Foundation? Frisbee As I said earlier, when Richard was diagnosed, I was an antique dealer and I was doing an antique show in Greenwich. The people who ran those shows, Diane Wendy and her daughter Meg, said to me, "Why don't we do a fundraiser to raise money for Yale?" We had gone to an antique show to buy a painting for the new bone

marrow transplant unit and they said let's not just buy a painting, let's have an event. They decided to run an antique show, which was held in Coxe Cage here at Yale, and another friend of mine said, let's have a dinner dance as well. All of a sudden we started the foundation. It was not my plan to start it but there it was. I'm one of those people who feel that the door opens, you make a decision. You either walk through or you don't, and I decided to walk through that door. For the last many years, we have been running different events and the money goes to support cancer research, education, direct patient care, everything from therapy for the children in the hospital with different illnesses to housing for patients who come from afar to get treatment at Yale and research at many different institutions and nursing scholarships, which we have provided about 25 of now.

Miller It is very exciting. How long has the foundation been in existence?

Frisbee We established it in 1990, just a year after Richard passed away.

Miller We were talking earlier about how the book will be out very, very soon. Who are some of the people that you think is the audience for this book?

Frisbee The audience is very wide actually. I hope that the book will be read as an inspirational book, and as you know, some of it is a very hard read.

Miller Yes.

Frisbee The stories are very, very touching, but I do want people to take away from it that it is applicable in many different situations, not just children with cancer or children with other illnesses. I hope that schools will provide this book so that all of the children in the school can be sensitized towards what these children go through when somebody has a sick sibling in their family. I hope the doctors will read it and nurses will read it. I hope teachers will read it and in the best world, it

24:48 into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 will be a book that many, many people will reach out to read for inspiration, for knowledge and to help them understand the world and that we all go through bumps, but we can hopefully take those bumps and smooth the road out for each other to make life a little easier.

Miller I just want to share with you that I got a real sense of hope reading the book. Looking at people sharing very odiously very tough situations that they have been in, and how hard it was many times, and also the sense of resilience.

Frisbee The resilience is amazing. Children can share their resilience with adults and adults need to be reminded that they can bounce back like children do.

Miller This may be a tough question perhaps, but is there anything that you would have done differently as you look back? We now are looking back 20 years ago, but is there anything you would do differently, or any sort of words of advice for other parents going through a tough situation like this?

Frisbee Yes, a few things. I would have spent more time discussing things with my other children, not assuming that they understood everything that I was doing or everything that was going on. That is the one thing that is so clear to me in their stories. They said I did not communicate enough to them. I would communicate more. I would also try to communicate more with their teachers to make sure they were okay in school. Those are the most important things that I would change if I were to do it all over again.

Miller Perhaps another difficult question, but if Richard was here reading the book as an adult, what would have been his comments?

Frisbee

He would say, "It is good mom. It is really good." Miller It is a wonderful feeling. In reading the book, I did not know Rich, but it made him alive for me. Frisbee Thank you. Miller This is a wonderful book and I want to recommend it and thank you for writing it. I want to share that the proceeds from the book will go to support other projects at the Yale Cancer Center, which is very, very wonderful. Christine, I want to thank you for being with us tonight. Frisbee Thank you so much for having me. It was a treat. Miller Yes, and for me too. I want to send you our wishes from the Yale Cancer Center 27:37 into mp3 file http://www.yalecancercenter.org/podcast/Answers_May-18-08.mp3 for a safe and healthy week. We hope you will join us again. If you have questions, comments, or would like to subscribe to our Podcast, go to www.yalecancercenter.org where you will also find transcripts of past broadcasts in written form. Next week, you will meet Dr. David Leffell who joins us to talk about skin cancer prevention.