

About Health with Jeanne Blake
Organ Donation
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JEANNE BLAKE: Welcome to *About Health*. I'm Jeanne Blake. Every day in the United States, 17 people die while waiting for a transplant of a vital organ. That's 6,600 people a year. On this edition of *About Health*, we'll talk with Nancy Earhart, who donated her son Bo's organs and tissue after his sudden death, and with Esther Scharz from the New England Organ Bank, who will give us some information about organ donation and hopefully dispel some of the myths. And then we will, a little bit later on in the program, meet a man who received a double lung transplant. Thanks so much for coming in to talk with us about a topic that I consider really important. Nancy, let's start with you. Tell us what happened to your son Bo. He was 25 when he died.

NANCY: Yes. My son was having a nice evening, he was with his friends, he had a very sudden death. What happened was, he was standing with his friends in a room, they were all celebrating him being at a new house. He might have turned – no one actually saw his face – but he dropped down onto his back without a heartbeat. His friends were not sure what happened immediately, but they got down on the floor and were able to revive him. He was brought to a community hospital, where he was evaluated, but when I was immediately notified and came to the hospital, it was evident to me he needed more intensive care. So we went to a hospital that specializes in neural injuries like this, this brain injury.

JEANNE BLAKE: From lack of oxygen.

NANCY: Yes. What actually happened – we didn't know at the time, but what actually happened is, his carotid artery in his neck, on the inside of it, on the inside part of it, had a small tear, and that tear ended up preventing the blood flow, and then it burst into his brain. And none of this was evident at the time it happened.

JEANNE BLAKE: So he was transferred to the bigger hospital that specialized in – how long was he kept alive? Was he kept alive or did he stay alive?

NANCY: He was alive for three days. Actually, my experience in the hospital, within the hospital field, working there, was very helpful in being able to handle the trauma, the information coming to me. I understood it very detailed. And there was no hope for revival. There was no hope for him to ever really have a life. After a few days. I think they were able to keep him alive, but immediately I was considering what to do to make this better.

JEANNE BLAKE: And when you say that, what do you mean by that, what to do to make this better?

NANCY: I saw him lying there as a healthy 25-year-old who had an unexpected tragedy, and yet his organs, his life, I wanted to have it have some meaning.

JEANNE BLAKE: So you thought about donating his organs before you were approached?

NANCY: Yes. Yes, I did.

JEANNE BLAKE: Esther –

ESTHER: That's extremely unusual. Most of the time, we approach a family about donation when we get a referral from a hospital when there's a potential or an impending death. But Nancy actually brought it up to the nurses and said, "I'd like some information about it. Can someone come and talk to me?"

JEANNE BLAKE: And you were the person?

ESTHER: I happened to be the lucky person to get to meet Nancy and her family, and truthfully it was an honor, and it is an honor to know her now.

JEANNE BLAKE: So you made a decision at that point to donate organs and tissue – and I think that many people don't really understand the incredible capacity that one human has for helping so many people. Those organs and tissues have helped about 50 people.

NANCY: Yes.

JEANNE BLAKE: Talk with me just a bit about – and Esther, I'd like you to help with this as well – about – most people, I think, that are going to hear this will think, How is that possible? Help us understand.

NANCY: Esther and I actually sat in a room alone together, and she showed me a list – we went down a list of all the things that could be possible to donate. And all I was thinking of was the number of people that fall, the people that don't have a chance for normal life, and the reasons that I always felt Bo would have a chance to give back in life. He was just reaching the height of his life, he had so much potential, and this gave us still a lot of potential.

JEANNE BLAKE: Esther, help us get through this list of 50.

ESTHER: They gave his corneas, and two people can see that were blind before. People can walk, because they take allograft of bone tissue and they can mold it into a specific piece of bone that someone may need that was injured in a motor vehicle accident, bone that was removed because of cancer, it prevents limbs from being amputated. So long bones go a very long way. Also heart valves are life-saving as well. It's considered tissue, still, but children that are born with heart defects and people who just don't have valves that work. These valves work, patients don't have to have constant surgery. So tremendous lives are saved. And even some skin, a tiny patch of skin can grow a whole new body of a burn victim, because burn victims die of infection because they can't grow their new skin. And it's very transparent. I don't want the viewers to think that skin that you would touch and peel off, that if you've ever had a sunburn, that tiny bit of transparent skin that gets sloughed off, a very small piece can actually grow more skin.

JEANNE BLAKE: Some people might view this, and I think that this is part of the myth, and maybe not a myth, I think we should talk about it very frankly. I know that a concern for some people has been that the body will be, I've read the word mutilated. It sounds to me, though, that so much was taken from Bo that I'm wondering if that ever bothered you –

NANCY: Well, actually –

JEANNE BLAKE: And I'd like both of you to address that, because I know that I have some misinformation here.

ESTHER: Actually, the body is not mutilated at all. If you think of the gifts that Nancy has given in honoring her son, how would someone dare mutilate that body? This is done to honor Bo and honor the people who are going to get his organs. It's a surgical procedure. When they removed his liver and his kidneys and the heart valves, there is an incision, just as though someone is having open-heart surgery.

NANCY: I wanted to mention also that Esther assured me that there would be – we were planning on having an open casket. I had his Johnny Damon Red Sox shirt picked out that he had won at the All-Star game last July. I actually talked much with the funeral home, actually, and they told me that he was treated with meticulous care, and I really felt that. As a matter of fact, I would like to say that we also were with Bo until his last heartbeat. We went down, we were offered several comfortable – Which would you prefer? Which is most comfortable for your family? And my daughters and his father and I were able to go down and see him being prepared. We joked that we always loved to have his shaved hair and shaved chest, and in a way, being there was a choice that we were able to feel that we were kind of offered this in a transition that was the most intimate way. We were really talking to him, and at the moment that his heart stopped, what good would all these things be to not use for someone else's life?

JEANNE BLAKE: Nancy, you've written to the recipients.

NANCY: Yes.

JEANNE BLAKE: And not heard back. And you do that through the organ bank. And the people who are the recipients have the opportunity to write back and be in touch with donor –

ESTHER: When I talk to families, and my colleagues as well, we cannot make any guarantees that the recipients are going to write back or you're going to meet them. As I explained to Nancy, this is a gift that you give freely, expecting nothing in return, as you give love to someone you care about. Just to know that you're honoring Bo, you're honoring your family. And hopefully people will write back and acknowledge that. But that doesn't mean they're not grateful. I have met people that are recipients, and I think part of it is that they are so grateful and they feel a little guilty that they have life and someone like Nancy lost their son, and they quite don't know how to say hello and thank you.

JEANNE BLAKE: How would you want someone to be able to – because you would love to be able to hear from someone, and you don't feel envious that they have life where you lost --

NANCY: Oh, no. No, I don't feel that way. When you work in health care, seeing things happen, with no prediction whatsoever. I guess when I see someone older coming from a knee operation, I feel that the gift that I gave back for him, and I know he would have wanted me to do this. We had talked about it oftentimes, of all the help he had gotten, that someday he would give back. And he would always say to me, "Mom, I'm gonna do it." So I look at it as a gift that is rather anonymous. We have the idea that this spirit would go on this way. It's just a really nice way to feel that his life made a difference to many people. That really doesn't happen in many situations. It's a very rare thing.

JEANNE BLAKE: Esther, what would you say is the leading myth – what would you say is the leading reason that people don't donate? I find, as a medical reporter I covered the transplantation of every organ, and I was always amazed by it, and I saw the richness of people's lives, and the tragedy as well. But when you see people on dialysis, as I have, it's so sad to me that more people don't give when they could. The richness of one's life, the quality of

one's life that is enhanced, as we'll meet with, who we'll speak with in a minute, but also just the health care dollars that are spent that wouldn't be spent if people weren't on dialysis, and if there were more organs that were donated.

ESTHER: I think the biggest myth is that the body will be mutilated, and I think sometimes families have – it's what their idea of death is, and ethnicity does play a big part of it. But I think there should be more education through the media so that people can understand and accept that donation is a good thing, because people who are on the list are of every denomination, of every race, every age group, infants up into someone who is an elderly patient. So illness doesn't know any age or race.

JEANNE BLAKE: I keep hearing Nancy's description of being with Bo and talking with Bo, and it's beautiful, and I expect that people who would do that would have a change in attitude about it, or maybe at least it would start the discussion within the family, which is very important, isn't it?

ESTHER: It's very honorable. We even – I asked Nancy if he had some favorite music that he loved, and we could play that, and just have a moment of a minute for her family, and that was important. And we played the Beatles, remember?

NANCY: I felt very respected through the whole process. We had the Beatles' white album playing, and it was really helpful for all of us. We had a chance to say goodbye, and we had many, many friends that were there, and part of the problem was, it was very hard to tell what the reason was that he died. We know the physical reason, but why that happened. So this was a way to give a real positive way of saying there's a big thing that's happening that's great here.

JEANNE BLAKE: Esther, I want to thank you so much for coming in, and you haven't seen each other –

NANCY: No, since the hospital visit.

ESTHER: We spoke after that, but we haven't seen each other.

JEANNE BLAKE: We're going to ask you to stay, Nancy, because we're going to be joined by Lee Cohen in just a moment, who is a recipient of a double lung transplant. We'll be right back. [commercial plays] We continue our conversation now about organ donation, and we're joined by Lee Cohen, who is a recipient of a double lung transplant. Welcome, Lee.

LEE: Thank you.

JEANNE BLAKE: Tell us, please, about what required the transplant, why you required the transplant, and how long you had to wait.

LEE: Sure. I was born with cystic fibrosis, which is a hereditary disease that, for the most part, affects the lungs, causes a gradual deterioration over time, and for me, I guess the really bad part occurred when I was about 30 years old, and my doctor spoke to me and said, "You really should get listed for a double lung transplant." And that was in March of 1997.

JEANNE BLAKE: By the way, 30 years old for someone with CF is –

LEE: Old. Yeah, it's old. It's not very old, but it's old, and I had had a reasonably normal life to that point, but definitely I felt compromised at certain points.

JEANNE BLAKE: And so when your doctor suggested that, what was your reaction?

LEE: I actually was resistant at first. I was still working full time, and while I couldn't walk fast or run or expend a lot of activity, I was living by myself and still quite active in a normal lifestyle. But to be honest, I realized that they knew more than I did, and at the end of the day, is a form of cheap insurance, and it turns out they were exactly right, and about four months later my health became very much more compromised. I was so sick that summer that, in fact, I checked into the hospital, was hooked up to oxygen full time, and couldn't do hardly anything.

JEANNE BLAKE: And you had a relatively short wait.

LEE: That's correct. I was very lucky. I was only on the list for seven months, and one of the reasons why I was listed when I was in March of '97 was the anticipation that it could be as much as a two-year wait. I think my health declined even faster than the doctors anticipated, but lucky for me they acted when they did.

JEANNE BLAKE: You might not have lived for two years.

LEE: There's no chance I would have lived. My lung function was down in the fall of 1997 to about 10 percent of what is expected –

JEANNE BLAKE: Wow, 10 percent.

LEE: Yeah. You can imagine what that does to somebody.

JEANNE BLAKE: I can't imagine, actually. You were fortunate because you have an unusual blood type.

LEE: That's right. I have B-positive blood type. Some people say that works against you, for me it worked for me, because when somebody came up with a B-positive blood, it was allocated to me.

JEANNE BLAKE: Lee, we've been talking about Nancy, of course you heard our interview, and that she donated her son's organs and has not heard from the recipients. You've been in touch with your donor's family.

LEE: I have. It's actually a little bit of an interesting story. I wrote a letter to my donor's family and my parents wrote a letter to the donor's family, and my mother had particularly written down her contact information, and since it's a very confidential activity, you know, and they had blacked out my mother's phone number, which she had put on there. But the parent of the young boy that died for me saw that and felt very strongly that, Well, they want to get in touch with me, I'm going to get in touch with them, and somehow held it up to a light and they figured out the number and called my parents. So they received a phone call some evening in the beginning of 1998, and we managed to hook up that way. So I've met my donor family.

JEANNE BLAKE: What was that like for you, to meet them, and for them to meet you?

LEE: In some ways, it's a very emotional thing, there's no doubt about that. I am very aware of what they had to go through, and I can't imagine the courage of the family that makes the decision at that point in time.

JEANNE BLAKE: Your donor family lost a 17-year-old, right?

LEE: That's right, a 17-year-old boy who was hit by a car on his ATV vehicle, and donated all of his major organs. From what I recall, I was the only person that has maintained constant contact with them. I think they heard from a few people initially, but I am – as I said, I'm very aware of what has been such a rewarding thing for me personally, was very tragic for them. Even as a parent myself, I can't begin to comprehend what it's like to have that situation in front of you.

JEANNE BLAKE: So you can understand both sides, really. You can understand if a parent perhaps didn't want to meet the recipient, and vice versa.

LEE: I think it depends on each person individually. It's hard for, I think, the donor family, because it's something that they've lost, and I know for a lot of transplant recipients, they feel very guilty about it, and sometimes the experiences aren't so positive on the transplant side. There are almost always some positives to it, in life extensions. My experience has been overwhelmingly positive, and I'm certain that's made it even easier for me. But nonetheless, I think it's a reality of the situation. It's obviously very tragic that this boy Joshua died for me almost nine years ago, but at the same time, that happened, and there's nothing that can be done about that, and he has made a tremendous gift to me and to others as a result of that. I would feel comfortable thanking the family, and I do thank them, as a rite every year and informally throughout the year.

NANCY: That's very nice. I looked at it as a gift I was giving. It just seemed so apparent to me that his life would not – it was very unexpected, and at the moment you just have to say, What do I do about this now? I see his life as going on, walking down different

streets. Everyone has a fate that just is something I'm not that sure I understand, but at the moment that it happens, I know what is possible, and I do think it takes thought beforehand. In my job, I've dealt with the organ bank in my job, working in the laboratory. It gives you pause to think about what you might do in that situation. But he has two sisters very close to him, just slightly older, and they arrived on the next Jet Blue flight from California, and they were very much with me that we want Bo to make a difference. We want his love and heart he has to go into another body. We want his eyes and the love we saw in them to be used for another person. We almost donated both his lungs, and the night before – we withdrew his support. After I talked about giving his organs, Esther and the people from the organ bank said, "When would you like the service?" Which, it was very helpful for us to time it, making them, and the night before, the University of Wisconsin was going to fly some doctors out to look at his lungs, and I could tell how important this whole, everything was, the orchestration of this. The people who received his kidneys were brought into the hospital the night before, and then we were in the room as they were preparing him, I knew there were two people in two other rooms waiting for his kidneys as soon as they came out of his body, and we saw him. He was treated so well, that it was like we were feeling the gift as it was happening.

JEANNE BLAKE: I understand. So it helps to mitigate the fact that you've not heard from the recipients, in a way.

NANCY: Right, yes. It does. I do look at it as an anonymous gift, and I may or may never know about the recipients.

LEE: There are, obviously, thousands of people like me out there, though, that have benefited from this, and in my particular case, the boy himself had actually signed up to be an organ donor. I can't imagine some 17-year-old having that forethought, but he did. Nonetheless,

the parents still had to make the decision to comply with his wishes, and they went through something very similar to you and wrestled with it, but ultimately said that's what he really wants, so we're going to do it. There's no amount of gratitude that I can show to that family or to other people like yourself, because that's just such a wonderful thing, and it gives life to me, it gives life to my children. Things that never would have happened without that. There really isn't any way to measure that, I think, and regardless of the fact that you haven't heard from your donors, that there's certain to be stories that are similar to mine out there. There really is no way to thank anybody, because it's such an immense gift.

JEANNE BLAKE: Lee, what was it like for you to wait and wonder, knowing that organs that could be donated aren't?

LEE: It is frustrating, and when you are very sick – I was confined to a hospital bed, so I was very sick. You just sit there and watch the hour hand go around on the clock and hope that something happens. It's unfortunate, because you also know that nothing good is going to happen to make your life be extended. This doesn't happen because somebody just decided to give – at least in my case – lungs out of living donors. That's very unusual, less popular, I guess, than just cadaver donors. So it is very frustrating to think that there may be people that have met a tragic end that didn't donate their lungs, that could have saved me. But you just kind of hope and wait, and it's a very difficult thing to do, no doubt, but it's also one of the most gratifying things when it actually does happen, which, as I said, I don't lose touch of the fact that it's definitely a hard time for somebody else, but that happened, and the benefits to me are, in some ways, just as immeasurable as the grief that other people experience.

JEANNE BLAKE: I want to thank both of you for – did you have a last comment, Nancy?

NANCY: I just wanted to say that we all feel, all of Bo's friends, that his spirit has gone on. We feel so grateful for the ability to say that this has been a wonderful gift and that many people will discover it in the future in their health, and it's the spirit that we've said goodbye to.

JEANNE BLAKE: I know that he would be glad that you came here to talk about it.

NANCY: Yes, he would be.

JEANNE BLAKE: And I hope that others will hear your stories, both of your stories, and talk about it within their family, really talk about it, because I think that does make it easier to make a decision, to know what your loved one wanted. So thank you both for coming in and sharing.

NANCY: You're welcome.

JEANNE BLAKE: We'd like to thank you for joining us on this edition of *About Health*. I'm Jeanne Blake, and I'll see you next time.

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