##### Your Stories: Conquering Cancer

“Clinical Trials & Tribulations”

Episode transcript

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Intro: A clinical trial prolonged Jane Coulbourne's life, allowing her to work tirelessly for others before she died. Jane was a fierce patient advocate and a champion of research whose legacy is still impacting the quality of care patients receive. In this episode of *Your Stories*, Jane's husband, Bill, talks to Jane's friend, Susan Braun, about how Jane used her illness to help others. He recalls the joys and heartbreaks of loving and caring for his wife in sickness and in health.

Susan Braun, MA, FASCO: I remember her diagnosis was a very serious breast cancer diagnosis.

Bill Coulbourne: It was.

Susan: And they didn't expect her to make it that long.

Bill: Yeah, her treatment almost killed her. It was a stage three breast cancer. She knew a good friend and they thought there were some clinical trials that she might be eligible for. And so that's when she went to the NIH to seek treatment and they accepted her in this program. Living with her at that point was pretty scary.

Bill: I mean, she couldn't work anymore because the chemo really took her down. I don't remember now exactly what the regimen was, but it was like a chemo treatment every three weeks or something like that. And she's supposed to have ten of them. And there were a few that got postponed because she was really sick.

Bill: So, the whole time was really scary.

Susan: And I remember, too, as other people who had been on the trial with her died, she kept wondering, ‘am I next?’

Bill: She and one other woman were the only two that survived that clinical trial.

Susan: It's pretty remarkable because they were treating her with experimental drugs then. And in fact, her tumor disappeared before surgery. That was pretty extraordinary.

Bill: Matter of fact, she never even had surgery.

Susan: She had a tumor. But like you said, the chemotherapy and the radiation shrank it so that there was never a need to take it out surgically.

Bill: It was pretty amazing. I can remember her losing her hair. One day she was taking a shower and all this hair was falling out in the bathtub. It just freaked her out. And she said, all right, I'm going to go have this hair cut off. And she wanted to have it done at some haircuttery place or some hair shop.

Bill: We didn't have any place really around us. So, she decided she wanted to go to some mall to have it done.

Bill: So we go to the mall. And, of course, every haircuttery place has got glass windows that face out to the mall. And she's like, I can't do this. I can't sit. And I said, come on, let's go home. I'll cut your hair out. I can't screw it up any.

Bill: She said, okay!

Susan: So you did it?

Bill: So I did it.

[laughter]

Susan: Oh my God. That must have been a real memorable moment, I mean in a funny and a difficult way.

Susan: Because that's a real outward indicator of what's going on… when you lose your hair.

Bill: Exactly.

Susan: You think you know somebody pretty well and then adversity hits and you go through a struggle for your life. And it changes everything.

Bill: Oh, it changes everything. And you really don't know very much about each other until there's some event that happens that forces you to learn a lot more about each other and how to deal with it.

Susan: Right.

Bill: I learned how strong she was. I mean, I already knew she was a strong person. That's one of the things that attracted me to her.

Bill: But I didn't know how she would deal with something like this. And she was incredibly stoic. I mean, there are a lot of nights, a lot of days when she was just really, really sick. I mean, chemo would just create incredible amount of nausea. So that exacerbated the problem with having the chemo. But she would power through it. Sometimes she powered through it in a stupor or in a fetal position, but she powered through it and she didn't really give up.

Bill: She was gonna try to beat the odds any way she knew how to beat the odds.

Susan: And then after her diagnosis and treatment, she went gangbusters into patient advocacy. I remember working with her as an advocate. And at times when we were in different organizations we always seemed to have the same point of view about what was right and about what patients really need and about what research is meaningful. She was so incisive in looking at the data and looking at treatments in what we would really need to cure breast cancer.

Bill: She was also pretty impatient. She was not very patient with solutions that didn't seem to be getting people anywhere.

Susan: There are so many things that Jane would ask of people to come along and be a part of that really were so meaningful from training patient advocates – Project LEAD, that she helped create – which was the first training program of its kind for laypeople who were survivors of breast cancer and who wanted to take part in the research all across the country.

Susan: She really created this program that taught them not only enough of the science to really be able to talk intelligently and understand, but also how you evaluate the science, and how do you take your seat at the table and hold that seat with a great deal of dignity.

Bill: I think she wanted people to be knowledgeable about the process so they could be strong, credible advocates.

Susan: She had created not only a name for herself, but really a reputation of a lot of intelligence, a lot of thoughtfulness, not being about the drama, but being about the end game. And that was always, always who Jane was and what she did. Is it okay with you if I talk about that day when she died?

Bill: Sure.

Susan: We were there in the hospital room. I got there just after she died. But you were there, and Jane had a last wish that her body be used in what they call a ‘rapid autopsy,’ so that they could take tissues from all parts of her body to study the cancer.

Susan: And you had told people she wanted that. And the coordinator for the autopsy came into the room and said, ‘I'm sorry she didn't sign the papers before she died. So we can't do it.’ And you said, ‘excuse me, I'm her husband. And she said she wanted to do it, and we're going to do it.’ And they still said no. So, I went out in the hall and called people I knew. And about a half an hour later, that poor woman came back and said, ‘I guess we're gonna go ahead and do it.’

Susan: So we were all waiting there, with Jane there with us, for them to come, because we weren't about to give her up. Because she wanted this, and we were fiercely defending her right to have this rapid autopsy.

Susan: And the nurse would come in and say, ‘are you all done yet?’ Very gently. And we'd say, ‘no.’ And she'd come back in. ‘Are you done yet?’ ‘No.’ Finally, the nurse came in and said, ‘you know, we're not going to do the autopsy here in the room, right? We have to take her to be able to do it.’

Susan: We laughed at ourselves because we were guarding her fiercely because we weren’t gonna let anyone take her until we were sure that she was going to get that autopsy done that she needed and wanted.

Bill: That’s patient advocacy at its strongest.

[laughter]

Bill: It was a pretty awesome experience.

Bill: And I was sort of on the sidelines. I was watching you guys and really, it was awesome.

Susan: You and I talked about the backpack story that she told me.

Bill: Right.

Susan: And it was a recurring dream that she had for years where she would be out hiking with a friend. And each dream, the friend was different. And in each dream, it was someone she knew who had been diagnosed with cancer. And they were hiking, and a shot would ring out from somewhere surrounding, and the companion would be killed. And she would go over and get that person's backpack and be searching through it frantically because she knew there was something in that backpack that she needed to find.

She decided that what was in that backpack of each person was their essence and that it was incumbent upon her to ensure that that essence did not get lost. So she carried that with her. And in fact, she would put it in her own backpack. And I can tell you, by the time she died, she probably had the heaviest backpack in the world because she carried the memories, the essences of so many people who cancer had taken.

Bill: So, does your backpack feel heavier now? I know you were gonna pick up the essence of Jane's and yours must be pretty heavy, too.

[laughter]

Susan: Just from her alone, it's heavy, because she has such a huge essence. But I do. I carry that with me.

Bill: She just had a huge heart, just a really giving, big heart.

Susan: She did indeed. And that's the part that lives on.

Bill: Yes, it is. It certainly is.

[music]

Outro: Around the world right now, there are patients participating in clinical trials for cancer research. They are taking experimental drugs and testing therapies in hopes of curing their own disease. Like Jane, they are also playing an important role in helping other patients. What researchers learn in clinical trials inform decisions doctors make about treatments for decades to come. Learn how you can help patients with cancer at CONQUER.ORG.

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