Good Morning. My name is Carrie Hartgenger and I would like to welcome you back to rising from the ashes trauma talks. A podcast series brought to you by UB School of social work, the Institute on Trauma and Trauma-Informed Care. This series provides an opportunity for individuals to share their witness of how strength and resiliency has allowed individuals to rise from the ashes. Trauma talks follows those who have worked within the field of trauma as well as those who have experienced trauma. Here we will reflect on how trauma informed care can assist those who have experienced traumatic events to embrace a new life of wholeness, hope, strength, courage, safety, trust, choice, collaboration, and empowerment. Today I am here with Debbie Mancuso. Debbie is a survivor of breast cancer. On behalf of the Institute we would like to thank you for being here today, and sharing your story with us. Today, I'm going to let Debbie begin with sharing her story that has allowed her to rise above the event to become a stronger and more confident person.

(58.2)DEBBIE: In 2004, I went for my first mammogram at the age of 45. They ask people to go starting at the age of 40, but I had no history of any kind of cancer in my family. So I went for my first mammogram at the age of 45 after that first mammogram they told me that they saw something that may have to be biopsied. They told me I could wait for 6 months or I could have it done on the following Monday. And the day that I had the mammogram was a Saturday so the following Monday I had the biopsy. They came back to tell me within two days, they called and told me that I had breast cancer. And it rocked my world. I had been very health up until that point and never had any real issues. And again cancer doesn't run in my family so that was kind of a last thing I was thinking about. At that point I was told I had to see a surgeon and my OBGYN gave me the name of someone to go and see and I went to see him and he confirmed the diagnosis, that was in mid August and by mid September I had the surgery to remove the cancer, followed by 6 weeks of daily radiation therapy. And I'll tell you, if you have been through cancer you'll know what I'm talking about when I say once you've been diagnosed it is something that absolutely never leaves you. There were many times I thought there was something wrong with me because I couldn't get it out of my head I kept thinking about it and wondering every time you had an ache or a pain, you wonder if it was cancer in that part of your body and I had had some friends who had been through it and I talked to them and they told that I wasn't crazy that's just what cancer does to you. So it stays with you for the rest of your life.

(2:52) CARRIE: So Debbie it kind of sounds like you went through a really fast progression of things treatments and things. Were you given when you mentioned that your doctor had given you the names of certain people. Did they present that in a way that made you feel like you had choice or that you had a say in it or was it more directed that this is what you are going to do.

(3:13)DEBBIE: My OBGYN gave me the names of 3 surgeons. and told me I could chose anyone of the three and I asked her for her opinion for who she felt was the best. Um the person that she chose for me was Dr. Ronald Bower He is used to be the head of breast care at Roswell. And had since left Roswell and had his own practice and that is who I chose to go with. Against, you know you always going to hear pros and cons about doctors and I had heard some people who didn't care for him but I went to him anyways and I was very very pleased.

(3:50) CARRIE: What did you do to kind of or what did they do to make you feel like you said to have a good experience, how did they earn your trust?

(3:59) DEBBIE: Well I can tell you how Dr. Bower earned my trust. He earned my trust the minute I walked into the room. He came in he was very warm, he had great bedside manner. He told me the diagnosis he told me what kind of cancer it was. He told me that it was stage one and that it was very early and that I was lucky. And then he explained all of my options to me. What what I could do. And I felt very comfortable with him I never felt a need to go and have a second opinion, he really really earned my trust at that first meeting.

(4:33)CARRIE: Cool. So I hear you say that you know he told you everything, what you needed to hear like the diagnosis and everything else. Does that, would it be a stretch to say that helped you feel emotionally safe?

(4:45)DEBBIE: Absolutely, one of the questions I asked him which is probably where my safety point came in was one of the questions was if I was your daughter what would you tell her and it came down to either having a lumpectomy or a mastectomy. And he said if you were my daughter I would tell you to do the lumpectomy because the lumpectomy in and he had all kinds of scientific research behind him that he was very much aware of. That said the survival rate was just as good for this type of cancer whether you had a mastectomy or a lumpectomy. I chose the lumpectomy. He also told me that if it was to ever reoccur at that point they couldn't do another lumpectomy I would have to have a mastectomy. I felt very secure in his knowledge and his his ability to to portray to me what this was going to be like.

(5:42) CARRIE: Did you feel did you feel like having these choice these options for treatment did that in anyway impact your attitude towards the whole experience toward the outcome?

(5:44) DEBBIE: Well I think he gave me the choices and then me asking him what he thought, it was still my choice in the end. And he having the experience that he's had in dealing with so many people I really trusted and even though it was my choice but it was also his choice I felt very comfortable going in the way he was guiding me to go. In in in the end it appeared to be I got the best results from it.

(6:26) CARRIE: So as we know cancer I mean is a life altering situation and it can be extremely heavy, but it can be extremely empowering overcoming it. Would you say that making the decision to get treatment gave you a sense of empowerment over life?

(6:41) DEBBIE: Yes, and I i think that it empowered me because a lot of the providers that I dealt with the oncologist along with Dr. Bower along with my OBGYN provided I did what I was suppose to do that my chancer were going to be very good. One of my first questions after I woke up after the surgery and saw the doctor was what are the chances of reoccurrence and he pretty much told me that it was zero, but we all know that it can take different forms and end up in different places, but that my chances were very good because it was caught at such an early stage and the radiation oncologist told me the same thing. that when I went through the radiation I was going to achieve the best results at that point. Chemo wasn't an option at that point and there are some forms of medication you can also take after you go through radiation which they also told me I didn't need to take because of the type of cancer that I had. I felt very empowered by what they said. I really felt a sense of confidence in my treatment. My provider seemed very confident which in turn made me very confident. And to feel empowered that I made the choices that I did to get the best results I could.

(7:57) CARRIE: Did you feel that they there was a good collaboration between providers that you were going in and they were each telling you the same thing over and over. You know I hit this nail on the head so many times. You know that can also influence a relationship too. You don't want to go in hearing the same everything every time. I know this.

(8:16) DEBBIE: Right and and Dr. Bower was the one who recommended the oncologist that I went to he had also worked with him at Roswell. They worked very good hand and hand. My oncologist was very in tune and very receptive to you when you went with him. He asked you a lot of questions. He sat with you, he talked with you, he wanted to know how you, you didn't seem him every time you went for radiation on a daily basis, but I saw him once a week. They worked, they worked hand in hand they each had reports and they passed reports back and forth to each other so their definitely was a collaboration and I felt I was included in that collaboration. It was also about me and how I felt psychologically, emotionally they talked to me about all of that. So there defiantly was a collaboration between the three of us.

(9:06)CARRIE: That's great. So it's it sounds like what I'm hearing is you have touched on a lot of what Fallot and Harris call 5 guiding principles of trauma in formed care. Safety, trust, choice, collaboration, and empowerment. Would you say that there, it sounds like to me that they have been using somewhat sensitive language, I mean if they gained your trust. Would you say that their environment was is welcoming as well?

(9:31) DEBBIE: Yes, in some senses I would. I don't know if there is any welcoming environment when you actually go through radiation. um I found it very, and this is for me, um your in a room by yourself in the end with machines going over you administering the radiation. And I can only tell you for me it was an extremely lonely place to be. A lot of things went through your head. I think a lot of things do go through your head when you are diagnosed with cancer I think it changes a lot of your perspective on life. The offices that I saw these providers in were great. The experience I had going through radiation every day was a little tougher. You realize you are in this your in this yourself. it's you and that machine or that chemical and if you have a belief in a higher power you have that going for you too. you know it's a really tough place to be in. I think it plays a lot on your psyche.

(10:30) CARRIE: How would you say that this experience has empowered your journey overall?

(10:34) DEBBIE: I think its definitely changed my perspective on life. You know I'm not saying that every day that I have the greatest attitude in the world, but I'll tell you what when I hear people complain about trivial things and I think back to that time, there is really nothing to complain about. How I feel today that every day that I am alive I feel is a bonus. Because had I not gone for that initial mammogram which was encouraged by a friend, who had gone for her first one. I don't know where I would have been. I had an aggressive form of cancer so I don't know where I would have ended up. I might not even be here talking to you to be able share my story or my experience. but I just it has definably changed my perspective. To the positive, but on the other hand, it has also changed me in a way that like I said before, once you are diagnosed it's with you every every little things that happens. I certainly go for a mammogram and an ultrasound and an MRI every 6 months or a year depending on if they see something. I have had numerous numerous biopsies for stuff that has come up on anyone of those test. It's a scary place that never leaves you. You have an anxiety that you get before you have to go for your yearly exam. Its just a scary place to be. There is a group of us that hang around ad there are 5 of us who have had breast cancer. Some of them more than once and so I know that the possibility for it to come back is there and it can come back in a different form and a different strain. It's scary and it changes you for the rest of your life because you can't it never leaves your mind. The days that I don’t' feel good and I don't know why or I have a pain and I don't know why, I go right to that place and no matter how strong of a person I am mentally or emotionally it's still happens. So you know I talk to other people which as been a huge help for me is to have people I know. I was also was part of an online program through Roswell where you can talk to other people who have been through tit and that was a great help to me. You can get all kinds of information from people who have gone through different types of cancer and they are along and their also our medical professionals monitoring that site who also give you that site and give you different kinds of ideas and help on there so. I used the resources that were out there. I wanted wanted to beat this and stay on top of it. It changed my life in a positive way and it's also changed my whole perspective in life in some ways in a fearful way.

(13:16) CARRIE: Can you um kind of add this is there anything that you would like to say to others that may be experiencing the same you know to kind of give them that instilled hope and confidence that will help them rise above the ashes as you did?

(13:33) DEBBIE: I think what I would say to people is obviously go get your mammogram when you are supposed to. And then keep on following up with it. I don't miss any of my appointments when it comes to my cancer follow ups. I even went as far as to have the genetic testing done. I do not carry the gene and that was important to me because I have three sisters and I have a lot of nieces. And that um my mom was still alive too and I don't carry the gene so that was a relief to my family. So I’ve done as much as I can to stay on top of this. And that is what I have done. I would encourage other people to do. Get the testing done go through it talk to people. talk talk talk don't keep it in the feeling that I had that made me feel like something was wrong with me and it definitely was a trauma that I have in my life that has changed me but I'm willing to talk to other people. And I know by talking to other people that I’m ok. I'm where I'm suppose to be. My thoughts are crazy this is this is just what happens when you have been diagnosed with it. You know for anybody whose going through it there's a ton of hope out there. I've gone so far as to be involved in races, Susan G. Colman, um I've been to fundraisers, I've had people fundraise in my honor um through walks or whatever. I am not afraid to talk to people about it and I'll end with this. I knew who to call because I had a friend who had gone through this at a very young age. As soon as I talked to her she had no qualms about it. To say to me this is what it's like, showed me her scars, said this is what it's going to be like and this is what is going to happen to you. And you know I've been able to be there for other people in that same way . Friends who I know or people who’ve known people who have directed them to me. And you know I am more than willing to talk about it to people and you know it's reality, it's what happens and I know that my greatest help came from other people. So that's what I would share with you. If you’ve been diagnosed uh, don't be afraid to talk about it to other people because there are a lot of other people who are suffering silently.

(15:41)CARRIE: Well Debbie we would like to thank you so so much for sharing your story.

(15:45)DEBBIE: Thank you