



Friend-to-Friend + Patient Navigation Stories From the Field



Please note: Stories from the Field were not collected until writing for the first Annual Report began. Since these stories were collected in March of 2013, they are listed under “Year 2” of the CPRIT project.

CPRIT Year 2, March 2013 – Feb 2014

East Region stories

Fear

While there are numerous reasons why women do not obtain routine mammograms, one of the most powerful reasons is fear. Ms. B called the East Texas Patient Navigator (PN) in October of 2013 to request assistance in scheduling a mammogram at the local hospital. After completing her intake, Ms. B kept procrastinating and never actually scheduled her mammogram. Having noticed this, the PN frequently checked in with Ms. B to make sure she would eventually make an appointment. It had been over ten years since Ms. B's last mammogram and she had previously been diagnosed with fibrocystic breasts. However, what scared her more than that was the fact that both her mother and grandmother had breast cancer.

The PN called her in January of 2014 and Ms. B said she still had not scheduled her mammogram because of fear. The PN told her that she would call to schedule the mammogram and call Ms. B with appointment details. The PN scheduled an appointment for that same month and called Ms. B to let her know the details and that she would call her the morning of the appointment. On the morning of the appointment, the PN called to find that Ms. B was getting ready early that morning for her afternoon appointment. One week later, Ms. B called the PN to tell her that the screening was normal. She told her that her results were read by “the best” radiologist and she felt comfortable with the reading. She said it was nothing like she thought it would be. She was so appreciative that the PN was so persistent and made sure that she got a mammogram, despite being scared.

Worried and Thankful Participant Volunteers to Give Back

The Friend to Friend Program helps women obtain screenings that will help detect cancer, but it can also provide ease of mind to women who are worried they might have cancer, but don't.

Mrs. L called and requested assistance with funding for a mammogram because she was having pain in her breast and found a lump. The Patient Navigator referred her to a doctor, who

because of her symptoms, referred Mrs. L for a diagnostic, rather than a screening, mammogram, scheduled for April 23, 2013.

On May 1, 2013, the Patient Navigator followed up with Mrs. L. The mammogram revealed that she didn't have cancer – however she has fibrocystic breasts. Her doctor explained what to expect with fibrous breasts.

Mrs. L was so thankful for the assistance that she wanted to do something to help other women. She does not have the finances to assist the program, but is willing to volunteer. The Patient Navigator invited her to attend the Friend to Friend event in Hunt County in July.

Grateful for Early Diagnosis

Mrs. R called to get assistance with a mammogram in Red River County. She stated it has been more than 15 years since she had her only mammogram. After completing the intake, Mrs. R scheduled a mammogram. About three weeks later, Mrs. R called and reported she had an abnormal mammogram and the doctor wanted to do a diagnostic mammogram/ultrasound.

A couple of days later, the Patient Navigator called Mrs. R to follow up. Mrs. R stated they had found a “knot” under her arm and she was scheduled her for a biopsy on May 22, 2013. On follow up, Mrs. R reported she was told it was a first stage invasive carcinoma. At this point, Mrs. R applied for BCCS Medicaid for surgery and treatment, but had not heard whether she was approved or not. The Patient Navigator contacted the BCCS representative and was informed that Mrs. R had been approved.

After Mrs. R met with the surgeon, she notified the Patient Navigator that the surgery was scheduled for June 7. The Patient Navigator visited with Mrs. R before surgery. Mrs. R. said if she had not gotten the screening, she would not have known she had cancer. She told her family the Patient Navigator saved her life through the CPRIT program.

Due to the limited facilities in rural Texas, many low-income women do not receive the screening services they need. The Friend to Friend plus Patient Navigation Program provides information and resources to find cancer early, when it is most treatable.

Too Stubborn

My name is Carolyn. I was diagnosed with breast cancer July 15, 2013. From that day, I have been on a roller coaster moving fast. I have a family history of fibroid breast tumors.

My journey started when my daughter (who was approved for a breast reduction) called me to say she had three tumors in her breast after getting a mammogram and needed biopsies done. I panicked because she was just 36. Fortunately, her results were benign. Thank you, Lord!

While dealing with her situation, I decided to set up my mammogram because it was time. On May 31st, I had the usual exam but the lab tech did not mark all the sites where I had benign lumpectomies in the early '70s and again the early '90s. I made a point of telling the tech where to mark beforehand. She said it was not needed. I let her do the mammogram anyway. I was called about my results and asked to come back in. I got on the offensive side and told them what had happened and that I had no money to pay for the second mammogram and will have to pay for the first one in increments. They insisted that I come back in. So, to keep from arguing, I said ok, knowing I was going to cancel it out and I did. I got called again, and again I was informed as to how important it was to me to get back in. This time I said, "Look when I say "no" I mean "no" and I'm stubborn". The voice on the other end (who was a lady named Regina) said "Yes, and I'm stubborn and I don't give up, do I have to lay my profession to the side and start telling you about taking care of yourself?" Two stubborn people too stubborn, having a standoff. So, with that, I let her reschedule me and this time I was intending to keep that appointment.

So we discussed the concerns with the financial situation. She put me in touch with a Patient Navigator Jessie Bell to help me pay for the mammogram.

I kept my appointment and was examined again, thoroughly and they got the same results. There was a tumor that looked nothing like the benign ones. So, a needle biopsy was suggested and I agreed to it. It too, was taken care of by this program. By this time, reality was setting in, this might actually be cancer. I nervously waited on my results but all the time praying it was maybe an infected milk gland.

I got the phone call from the doctor saying "you have breast cancer". I calmly asked, "what's next" and he gave me the next steps. From then on, I was on the move with paperwork approval, seeing doctors (Dr. Prud'homme, surgeon and oncologist Dr. Droder) for consultations and reporting to Jessie to see if I'm doing everything right and staying on the right track. (She was God sent!).

On August 1, 2013, I had a lumpectomy, lymph node removal and a port put in for chemo. My first chemo treatment was on August 27, 2013 and so far it has gone very well. I will go through a regiment of medicines for an entire year and if all goes well, I should be cancer-free by August or September of 2014. Looking back, I thank God for putting certain people in my path. I could not have made this journey without them.

My Journey with Breast Cancer

In April, the East Region PN (Patient Navigator) received a call from Mrs. R. in Avery, Texas. Mrs. R didn't have insurance and was asking for assistance to receive a free mammogram through the county extension office. After asking a few questions, the PN told Mrs. R they would pay for it with a grant and told Mrs. R to go have the mammogram and to call Jessie back

when she had made the appointment. When she didn't hear from Mrs. R., the PN called her back and repeatedly asked her to make the appointment. Mrs. R had her mammogram on April 29th.

Although she told her daughter that she had no lumps and felt healthy, on May 10th, her doctor's office called and said they had discovered a mass. Mrs. R said she felt like her "world hit a brick wall." She was told she needed to go have a diagnostic mammogram. This was not a good Mother's Day. She contacted Jessie Bell on the following Monday and explained the situation and she gave Mrs. R the number to the doctor in Tyler to have the diagnostic mammogram done.

On May 15th, Mrs. R. and her daughter went to Tyler and have this procedure done. At this time, the doctor told Mrs. R he's "9 out of 10 positive that it's cancer." Another blow.

On May 22nd, they traveled back to Tyler for a biopsy. Then on May 24th the phone call confirming Mrs. R had 1st stage low-grade invasive carcinoma. Mrs. R said her world came crashing down at my feet. Again, the PN came to the rescue. She made sure all the paperwork was done and on June 5, 2013, Mrs. R met with the surgeon in Tyler and on June 7th, she had a lumpectomy. With the support of her husband and family, Mrs. R. made it through the surgery just fine. After 2 re-excisions later to take out what they call DCIS, she is now undergoing chemo. She's still looking at the possibility of a double mastectomy after all the treatments are done.

As Mrs. R says, "I am here as a witness; PLEASE go have your mammogram. Words can never express the gratitude to Ms. Jessie Bell and my daughter for pushing me to have mine. The doctor said, MY HAVING THAT MAMMOGRAM SAVED MY LIFE...or my tumor would have kept growing. Please go and have your mammogram; you just never know what's going on inside of you. My Tyler medical team has just been wonderful and with all of them and My faith, I AM A SURVIVOR!"

CPRIT Year 3, March 2014 - Feb 2015

East Region stories

"What am I going to do?"

Ms. P received a mammogram in January of 2015. Her doctor notified her that the results of her mammogram were abnormal. Her first thought was, "it was cancer" and her second thought was, "what am I going to do?" She began calling various programs and applying, but soon after, she was denied from everything. A women's health program that denied Ms. P gave her the name and number of the East Texas navigator to see if she could be helped through the Friend-to-Friend program.

Ms. P called the navigator and was scheduled within two weeks. Following her diagnostic mammogram, she was told she needed a biopsy. "This is cancer," she thought to herself again, and called the navigator for help. The navigator scheduled the biopsy for the very next week. There were complications with the results, so Ms. P needed another diagnostic mammogram. She went back to thinking, "this is cancer" and "what am I going to do?" Ms. P soon found out that even though the "suspicious" growth was benign, she needed to have it removed. Even though Friend-to-Friend cannot help her with the surgery because she thankfully does not have cancer, Ms. P is nevertheless grateful for the service that the East Texas navigator provided. She is most thankful because the navigator and Friend-to-Friend program were available when Ms. P had no idea what to do. She is now in a place of empowerment to take on her women's health issues and receive the services she needs.

So Overwhelmed and So Grateful

Ms. T was scheduled for a diagnostic mammogram and ultrasound. The doctor helping her gave her a name and phone number to call before she had the tests done. The name and phone number belonged to the Friend-to-Friend East Texas patient navigator (PN).

Ms. T called and talked to the friendly, supportive voice on the other end. After a few general questions and finding out that Ms. T did not have insurance, the PN told Ms. T not to worry and assured her that everything would be O.K. Ms. T did not understand how she could not worry, but did exactly as the PN said and focused on her health.

Ms. T had her test done and was shocked to learn that she had breast cancer. She felt that everything was happening so fast and all she could think about was the invasive ductal carcinoma growing in her body. She worried about how she would tell her husband, family and friends, and of course, how she was going to pay for treatment. She was completely overcome with fear and in her words, "so overwhelmed." As instructed by the PN, Ms. T called back once she received her test results. The PN gave Ms. T a number for Medicaid for Breast and Cervical

Cancer Treatment (MBCC). She reminded Ms. T, again, to not worry about a thing, except getting better.

In a follow-up call, Ms. T explained how relieved she was for the PN's help because without her, Ms. T would have had no knowledge of how to handle her diagnosis and find treatment. The PN then revealed that she, too, was a breast cancer survivor. Ms. T was immediately put at ease because she was talking to someone who truly understood her situation and had been on the same journey.

The PN has continued to check in with Ms. T as she goes through the journey to recovery. Ms. T. is so grateful for the East Texas PN and expressed her gratitude to the Friend-to-Friend + Patient Navigation program by thanking the PN "for helping so many in their time of need and for having the other PNs to help others like me."

Thank you notes

The East Texas navigator receives many letters of thanks from the women that she has helped, on a daily basis. She receives handwritten, typed, and emailed letters from women who want to thank her for being present and providing guidance during the stress of receiving breast and cervical cancer screenings. In their letters, women share their initial fears, concerns, and how the navigator supported them from start to finish—and in many cases, thereafter. Women often write that they would not have received a mammogram or Pap test if it was not for the persistence and dedication of the navigator. In addition to worrying about finances and locating a facility to obtain a screening, women write about how the emotional support was the most needed form of support. It is clear that these navigators serve in various ways, wear multiple hats, and are tasked with balancing hundreds of unique needs for each Friend-to-Friend participant. The service that the navigators provide is truly appreciated by women throughout the state of Texas.