

Clinical Trials Inspire Hope in Rosa's Battle for Life



The story below is from a series of articles created by CISCRP as part of their educational awareness campaign to increase public understanding that those who volunteer to participate in clinical trials are genuine "Medical Heroes."

Rosa Small knew that something was wrong.

She had always made sure to take care of her health, and had performed regular breast self-examinations. Rosa had never noticed anything unusual until one day, at age 62, she felt a lump in her right breast.

"My only symptom on self-exam was the lump, and it was not sore," says Rosa. At that point, Rosa could not have predicted that she would soon be nurturing the belief that clinical trials could help prolong her life.

Disturbed about her finding, Rosa went to her primary care physician, who confirmed the lump. They knew time was of the essence, so without delay, Rosa went to a radiologist, a surgeon, and an oncologist.

Rosa's worst fears were confirmed. She was diagnosed with invasive adenocarcinoma of the breast, which is a malignant tumor that spreads beyond where it initially developed and invades healthy tissue.

"I have Triple Negative Breast cancer," says Rosa. That type of breast cancer is considered more aggressive and less responsive to standard treatment.

Up until then, Rosa's life in Durham, NC, was happy and active. Rosa had many friends in the town, where she lived with William, her husband of 49 years. She had retired from the Durham Public Schools as a media coordinator, and now had a satisfying job as an events manager at a building owned by her sorority, Alpha Kappa Alpha. Rosa and her sorority held community service

projects in the building, and also rented the facility.

Learning she had cancer threw Rosa's cheery existence into a tailspin. "I felt as if my life was almost over, and I desperately wanted to live," says Rosa. "I felt that I had many other things to do during my journey here and services I wanted to provide to people and my community. And there were so many places to visit and see. I felt so pushed to get things done quickly."

Rosa's two adult daughters, Sheila and Maria, helped her travel to her many doctors' appointments that followed. "My life totally changed," she said. "I had a lot of medical appointments. My family was affected as they assisted me with appointments, transportation, encouragement, and delays in their own schedules."

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Harder than the logistics, though, was the effort to mentally accept that she had cancer. “I had to get the diagnosis in my mind,” said Rosa. “I had to tell my family and my mother—who was living at that time—that this disease was with me. She wanted me to take anything to get rid of it.”

As Rosa struggled with her illness, her oncologist suggested a new treatment that he thought might be promising. The treatment was part of a clinical research study. Rosa was determined to keep fighting, so she learned more about the study, and went through the informed consent process.

She knew that there might be risks involved with taking part in a clinical trial; but she also knew it might be her best bet.

“Cancer is scary and it makes you humble,” says Rosa. “I had heard about people who had been in trials and they had gotten worse. However, I felt that the researchers were suggesting a drug that might help my disease, even if it did not cure it.

“I spoke with another person who had been in clinical trials and she was very positive. I was somewhat apprehensive, but I had faith that

things would work out,” says Rosa. “I always try to become knowledgeable about my treatments. I try to know what to look for and signs and symptoms that may occur.”

The trial took place at the Morris Cancer Clinic at Duke University in Durham, NC. The treatment being tested was not yet available on the market. Rosa was one of 100 participants with a similar condition, who were going to test the drug.

Rosa participated in a number of trials, each lasting from 2 weeks to 5 months. “The first clinical trial lasted 5 months until I had some side effects that caused me to stop the study,” says Rosa. “Besides that study, I’ve been involved in 3 or 4 other clinical trials at various times.”

Taking part in clinical trials helped Rosa feel that she had some control over her disease. “I felt that I was taking a more active role in my care,” she said. “I also had more treatment options than the standard treatments. I felt that the trials might help with the future of others who may have the same disease.”

In addition to getting the best possible care, Rosa also appreciated the warm

and solicitous treatment from the clinical site staff and researchers. “The most positive part of the trial was the amount of attention that you get in a study,” says Rosa. “The health care professionals give you more attention that you would get with regular standard care. The people conducting the trials were very much involved with my care and were willing to speak to me at any time.”

Still, the clinical trials had their downsides. Rosa was aggravated at some of the lengthy tests required. “The worse part was having to undergo the treatment along with the many long exams and tests,” she recalls.

While Rosa’s most recent clinical trial has ended, she plans to enter another clinical trial when her oncologist suggests one.

“I still have metastatic breast cancer, and the tumors have moved to my lungs,” says Rosa.

Yet the positive spirit that has bolstered Rosa through a happy, industrious life is still burning fiercely.

Rosa’s strong faith also kept her hopes high and her attitude hopeful. “I try to meet challenges as a means of doing something to the alternative of dying,” says Rosa. “I’ve never lost hope because I often repeat the following Bible verse: “He keeps me functioning each and every day. Without him, I will be nothing. But, with Christ, He strengthens me.”

“I am optimistic about my future, and I feel that I will be managed for many years,” adds Rosa. “I would ask anyone to take part in research trials, as it can help you. Always remember the purpose of the treatment is to kill the cancer cells that are in the body and keep them from growing and spreading to other parts of the body.” ■



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