



We Are Not Alone

Congressional Directed Medical Research Program: The Honor of a Single Chair

Years ago I lived life like millions of other people in the world. I worked long hours, took care of my family and pursued my passion to help build our world. Then three years ago I was diagnosed with “triple negative breast cancer” and my life changed. Not only did I have cancer, I had an extremely aggressive breast cancer that with no known cure.

I learned three critical lessons through my new journey:

1. DO YOUR RESEARCH
2. ASK QUESTIONS
3. TALK

This was how I met the vivacious, energetic and inspiring leader Leslie Williams. My nurse navigator Joe Darling (my life line) said Leslie was a person I had to meet. Leslie was a cancer patient who was intent to Survive on Purpose. Her mission was to be a support for women with triple negative breast cancer, to get the word out and to learn and share about what was going on in the fight against this dreaded disease.

In 2013, I was honored to be one of the featured speakers at Baylor's Pink Pajama event where I was introduced to Leslie. Not only did she have me exited regarding her vision for a new Triple Negative Social Network group "Survivor On Purpose", she also intrigued me with information about a special research program she participated in the year prior with the CDMRP.

CDMRP stands for Congressional Directed Medical Research Program. THIS is a truly impressive, yet confidential, research group that focuses on the cure and the treatment of cancer.

After researching the organization I became more impressed. They select the best scientist and doctors to research and submit proposals for cutting edge science or medical treatment. However, what is most impressive is that a consumer reviewer is selected to partner with these specialists to ensure the patient is taken into consideration.

After going through an interview and selection process I was selected to participate in the 2013 CDMRP program.

There are several steps required to prepare for the event. But everything was worth it. I was so nervous preparing for the panel review. The best and the brightest oncology doctors and scientists in our country would be part of the panel I sit on. I could remember my heart racing, thinking "Will they listen to my opinion?", "Will I make a fool of myself? "Will my concerns be creditable?"

I arrived at the hotel early awaiting the sessions to begin. During our orientation, we were told our opinions mattered and it was important for us to share our comments, questions and concerns. Our leader informed the consumer advocates that our voices mattered. We were selected to represent the voices of cancer patients' family members everywhere. So speak up and don't be intimidated.



Can you imagine the weight that lifted from my shoulders? Shortly after the orientation I went to my dedicated session. My name appears in front of a laptop with information on each study. Imagine sitting in a room amongst the country's best medical and engineering professionals and your voice matters.

For the next few days we discussed every research program we were asked to review. I was able to share insight on proposals that only we as cancer patients would think about. One of the days, I was emphasizing a particular point and when I finished one of the oncology surgeon leaned over to me and said, I should just change my ratings to reflect yours, you bring up excellent points for us to consider."

I chuckled and said thank you, but inside I was shocked and overwhelmed by the honor of his statement. My voice really did matter. The patient experience mattered to the CDMRP. At the end of the event the leader of the program spoke with us (consumer advocates) and asked for our feedback. She wanted to know what they can do to make the program even stronger. Further proving how much our voice really does matter.

As I reflect back on those few days, I know that those were significant times that will be forever seared into my memory; a time where I was able to speak on behalf of the patient experience and have an impact on which programs would be funded to support the fight against breast cancer.

It's hard to believe that it was less than three years ago when I received the call from my doctor that altered my life forever. What I didn't know then was that my journey would help touch the lives of so many others.

That became my take away from that moment forward. In everything that happens to us, use that to help someone else. These are the things that help shape who we are and what we each represent.

Respectfully,
Latrice Collins