

## Survivor Story: Lonnie Mitteis Grand Island, Nebraska, Firefighter /Paramedic Diagnosed with Stage 3 Bladder Cancer 2019

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I received my Firefighter Cancer Support Network toolbox in March of 2019. I found some useful materials inside, but the most important thing to me at that time was the phone call from a Retired Firefighter in Texas that had gone through the same diagnosis that I was going through. I wish I could remember his name, but I was in to my 2<sup>nd</sup> month of Chemo and things were a little rough. Although, he had chosen a different surgery option than I had, it was extremely helpful to hear that his outcome from surgery had been positive. The truth is, at that moment, I really needed to hear that. My story takes place over a two-year period. I am an example of why it is important to know your own body and to advocate for yourself.

I had competed in the Scott Firefighter Combat Challenge for the last 10 years and I have always kept myself in good shape. At the World Challenge in Louisville KY in October of 2017, I had an incident. I was getting ready for bed and I had to go to the restroom. I went to the bathroom drained my bladder and walked back to my bedroom. Before I got back to the bedroom, I had to urinate again. This happened over and over for the next

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five hours. I could not stop urinating. At one point I was sitting on the toilet and the urine was just running out of me. All I could think about was I am going to be so dehydrated that I will not be able to compete tomorrow. Somewhere around 3:00 am, I was about to wake up my teammates and have them take me to the Emergency Room. Then, it suddenly stopped.

When I got back home after the Competition, I made an appointment with my primary Physician to see if he had an idea on what had just happened to me. The first words out of my doctor's mouth were, "It was probably your prostate." I told him I did not think it was my prostate; I get it checked at work, it is not enlarged, and my PSA tests are always great. I did have a slight urinary tract infection, which had him thinking I had a bladder spasm. He gave me a medicine for that and said it would take about a month to start working. I have always had to get up a couple times every night, but by the middle of December, I could make it all night without getting up once. At this point, I figured we had the problem solved. By May of 2018, I noticed that I was getting up again a couple times a night, but I did not think that was a big deal. Then things started to change and by July, I could not go more than three hours without using the bathroom.

As the summer passed, my trips to the bathroom became more and more frequent. By August, I could not go longer than two hours without using the bathroom. If I tried to go longer than two hours, I would have extreme pain that would last for days.

In mid-October of 2018, we went to Sacramento CA to compete in the World Challenge and things seemed to be pretty good. After the competition, my wife, Deb, and I went on to San Francisco for a vacation and I experienced a dramatic change. I could not go for more than forty-five minutes without a restroom. When we got back home, I made an appointment with a local Urologist, taking the first available appointment. I met first with a PA who worked for the Urologist and explained what was happening to me. The first words out of the PA's mouth was, "It is probably your prostate." This is the reason you must advocate for yourself! I told her the same thing I had told my Primary one year ago, "It's not my prostate!" This turned in to a very short argument (which I won) and the PA scheduled the scoping of my bladder.

The first week in December, the Urologist, who was extremely angry with me for arguing with his PA, scoped my bladder. Inside he found that there was a mass the size of a woman's fist. Then, I was scheduled for a biopsy on the 8<sup>th</sup> of January of 2019, with a 20% chance that the mass was benign. It was not! The Urologist said, and I quote, "You are one of those people that knows your body very well. If you had not been willing to argue for yourself, we would have sent you home with a med to treat prostate problems and told you to come back in six months. In your case, that would have been way too long to wait. You saved your own life."

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From there it was on to Oncology and 3 months of Chemo. On May 20<sup>th</sup>, 2019, I had my prostate and bladder removed. The surgeon constructed a new bladder for me out of 60 cm of my small intestine (a neo bladder) at UNMC in Omaha, NE. By the way, there was no cancer in my prostate! After I healed up, I needed to learn how to use my new bladder, so I spent some time in Physical Therapy working with a Therapist who works with women's pelvic floor issues. My Therapist was an amazing young woman.

On the 9<sup>th</sup> of September of 2019, I returned back to work at Fire Station #1, full time, no restrictions. I won't lie, it has been a rough road, but I have had the most amazing support from my wife, my family, my Scott Firefighter Combat Challenge team from all over the world, the crew I work with every day, an amazing group friends and the Cancer Outreach Program.