

Tameka Nelson's Story

By: Teri Gerson

Tameka first became aware of Scleroderma when she experienced breathing difficulties and coughing when sleeping and thought she was experiencing a recurrence of bronchitis. Her doctor agreed and prescribed medication which was ineffective. Then, one day at work she noticed significant swelling of her feet and a blue discoloration of her hands and feet. The rheumatologist she was referred to, by examining her fingers, immediately diagnosed Scleroderma. The first question Tameka asked was “Will I die?” The doctor “diplomatically” told her people could die from many diseases if they didn’t take care of themselves. Seeking clarification Tameka turned to the internet and saw people who had lost limbs and who had become deformed. Understandably, she became depressed and wasn’t even able to get out of bed. She realized she needed to take constructive action. The idea of attending support groups worried her because she was concerned that she’d imagine that she had everything that they talked about. Tameka went on her first Walk for Scleroderma, and that was unfortunately not a positive experience. She met a woman with a tracheotomy who was in a wheel chair who didn’t realize that Tameka was walking for herself because she “looked great”. Seeing this woman made her feel guilty for complaining about her own circumstances and she wondered “How am I supposed to look?” At a gathering after the walk, her aunt was talking with survivors who had suffered for years with Scleroderma and some had no finger tips, or deformed faces. Crying, Tameka decided she wasn’t going to attend any more walks.

By the next year, Tameka had gained more strength and had begun using a lotion for dry, itching skin & joint pain. She immersed herself in the process and began making her own lotion which she sold and donated. Tameka had turned her misfortune into a growing business and she soon found she couldn’t accommodate the orders she received!

As Tameka continued her Scleroderma journey, she decided to forgo traditional medications (she was taking 13 pills a day) and replaced them with vitamins. Scleroderma has caused her lips to thin, and she suffers from rashes and skin pigmentation changes along with weight loss, and swollen and thick hands. Despite this, she has resumed the life she had and has put the traumatizing impact of what she saw on the internet behind her. She no longer feels fearful and views Scleroderma as a superpower given to her by her God and her purpose has become spreading awareness. This belief helps her cope.

Tameka has always felt a strong connection to music and dance. A particular song by Lyfe Jennings made her realize things could be so much worse and complaining about the manifestations of Scleroderma when others did, in fact, have it so much worse, was not the path she wanted to take. This song spoke to her in a deep way and prompted her to create a brand of t-shirts called It Could Have Been Worse in 2018. She also tapped into her contacts with celebrities and began doing concerts with them, even dancing again, herself. Tameka told her story at one of the concerts at a college and was amazed how other folks with illnesses began to tell their stories. Tameka expanded her campaign to “All Illnesses Matter” and continues to spread the word through performance and T-shirts.

Besides the physical changes Scleroderma has wrought, it has impacted Tameka’s family as well. She didn’t tell her 2 younger children about her diagnosis for the first 4 years in order to shield them from worry, but she did share her diagnosis with her oldest son. As a result he left college in order to be near her, and never went back. Tameka’s husband (a hospital worker) has coped by educating himself about Scleroderma so that he can be supportive.

Tameka hasn’t allowed Scleroderma to change her life. She continues to dance, is active with her kids, works, takes vacations, and generally, just goes with the flow. She just added educating people and spreading awareness to her repertoire. She describes her mission as learning about her body and educating herself about her disease so that she remains motivated and is able to motivate others. Tameka advocates for those who can’t advocate for themselves and who are looking for someone to provide support for what they are going through.

Tameka never imagined the impact she would have on other people’s lives. After one of the concerts she participated in, a group of 7 African American women asked her to speak to them as a motivator and to educate them about Scleroderma. Tameka doesn’t want anyone to feel sorry for her, but rather to have empathy and show support and understand what other people are going through. She believes this will make the world a better place and is proud to be a part of it. Her advice? Always remember “It Could Have Been Worse”.