

My story:

Hello. My name is Nikki Roberts. Telling my story can be difficult at times. It feels like a never-ending story of grief and struggle. Since the age of 15, I have been through countless doctors' appointments. I have endured what seems like endless testing. I have experienced way too many hospital admissions. Truthfully, I have been in and out of the hospital since September.

I was a normal child. I was a competitive dancer and cheerleader. When I was 15, I faced a dramatic change. My entire body became stiff and I could no longer move. My parents had to carry me, dress me and feed me. I went from an extremely active, exuberant teen to a bed-ridden, helpless sick person. The doctors did tests and combined with my symptoms, determined I had lupus. At 16, this was a terrifying diagnosis. I started on medications including Plaquenil, prednisone and other immunosuppressive medications. My senior year, I was so ill that I only made it to school for nine half-days.

Finally, I ended up at the Cleveland Clinic. There, I was told I had six months to live. However, they found a medication, Methotrexate, that worked for me. Within six months I was able to go back to work and had my life back. Three years later, I suffered another setback. I got sick again. They tried another medication which almost killed me. Finally, they got my lupus flare under control and I was able to get my certificate for phlebotomy and got a job at Cincinnati Children's Hospital. Unfortunately, in 2016 I had to file for long-term disability because I was too ill to work. I am still on long-term disability. Like I mentioned before, I have been in and out of the hospital since September. In March, I was in the hospital for three weeks due to MRSA in my pic line. I finally had to have an NG tube placed. I also had pneumonia in both lungs in January. Like many patients with lupus, I also have another autoimmune disease called scleroderma. Keeping my body healthy is a constant struggle.

The past year has been a rather tough one for me. I lost my mother this past September. It has been a huge loss in my life. My mother was my biggest advocate. She brought me to the Lupus Foundation to show me that there are other people like me. She helped me get involved and connect with a community of people that helped uplift us and show us how we can fight back to make a difference. My mother and family hosted a walk in our community of Middletown, Ohio. The first year we raised over \$4,000. The last walk in Middletown raised over \$12,000. My mother helped groom the walk in our community and we quickly outgrew our town and helped the Greater Ohio Chapter move the walk into Cincinnati, Ohio.

Probably the most surreal part is my mother was diagnosed with lupus just a few years ago. Truly, it all happened so fast. Never did I think my mother would pass so soon. She was my rock and my best friend. She was the one who took care of our family. She was the one person who tried so hard to help me to just be me. My mother was diagnosed with lupus antiphospholipid antibodies. She had a massive stroke. I never would have imagined that she would be gone so quickly. My life will never be the same.

Advocacy is something I am passionate about. This is not my first time. With the help of the LFA, GOC I was able to testify on "The Hill" in Washington DC. Advocacy is an experience that provides empowerment and makes me feel as if I make a difference to others.

The greatest benefit to advocacy is learning and growing with the other advocates. I want to be a part of the education and bring the experience back to my community. I gain the knowledge that is necessary to share with others of all the cutting-edge information the Lupus Foundation strives and fights for. I know we are making a difference for all lupus patients and I want to continue to be a part of it.

I do not know what I would have done on my journey without the support of the Lupus Foundation of America, Greater Ohio Chapter. They have been an integral part of my journey. From education, to advocacy and research, they have been here with me every step of the way.

There is still so much to do in the state of Ohio. It is simply unacceptable that there is no known cause or cure for lupus. There has been only one treatment developed for lupus in the last fifty-five years. There are 60,000 patients in the state of Ohio alone and like me, they suffer daily from lupus. Sadly, like my mother, some patients lose their battle. Please don't let the patients in Ohio suffer while we wait for a cure. We need funding today and I am asking you to include lupus in the Ohio budget. I am counting on you. Lupus robbed me of my childhood and stole my mother. Ohio lupus patients are also counting on you. Thank you for your time and consideration.