

Staying Brave and Positive

Nichole's Scleroderma Journey

By: Teri Gerson

Nichole is now 26 years old, and it's 10 years since her diagnosis, which she received when she was in the 10th grade. Nichole developed what appeared to be bruising on her right thigh, and as a cheerleader, she thought the bruising was a result of that activity. When it didn't go away when the cheerleading season ended, and because her grandmother had suffered from Scleroderma, her mother took her to a dermatologist for a skin biopsy. Although initially Nichole's diagnosis was Localized Scleroderma, she is now somewhere between localized and systemic because she has symptoms of both.

Upon learning of her diagnosis, Nichole felt unsure of what it meant or what to expect. Her mom had always told her how much like her grandmother she was, and having the same disease that her grandmother suffered from and that contributed to her death, she feared she would have the same fate. She began researching the disease and describes what followed as "growing up very quickly like my childhood was taken away". A regimen of drug therapy followed, and in 10th grade, she missed 80 days of school. The couch became her classroom and she lost out on many of her friends' activities due to the side effects of her medications. Nichole describes the experience of both the disease and the medications as never really feeling like herself. Despite her disease, today she feels "pretty healthy", although there have been times where she "got in a funk". One year ago, Nichole made the decision to deny traditional treatment and switched to a holistic approach and currently feels good about the decision.

When looking for tools to help her to cope with the uncertainty of her disease, Nichole turned to writing a personal blog. She described feeling alone and invisible, because her disease wasn't necessarily obvious, and people, including some doctors, left her feeling that she wasn't believed or taken seriously. She even wrote a college essay on the experience of being diagnosed. Putting her thoughts and feelings on paper provided affirmation and gave her a voice.

Between her writing and the strong support she has received from family and friends Nichole has come to feel thankful because Scleroderma has taught her valuable life lessons which have made her who she is today. As a full-time alcohol abuse and addiction counselor for adolescents, Nichole was able to translate these life lessons and the example of her mother's career as a social worker into a career to help others. Although she must always be mindful of her body, she plans to ultimately become a State Trooper and join the SWAT team.

Throughout her journey as a Scleroderma warrior, Nichole has found a way to adapt and achieve. When she stopped being able to run for exercise, she took up rollerblading to stay active. Caring doctors and loving family and friends have been there to help her cope with her fear of the unknown although new symptoms still scare her. When first diagnosed, her biggest obstacles were learning to accept that she was sick and couldn't always do what her friends could do. Now, her struggle has shifted to coming to terms with giving up control and not knowing what is going to happen. Talking about it and her strong relationship with her mom keeps her positive and moving forward.

When asked what advice Nichole would give someone newly diagnosed, she said that the Internet, although hard to resist, got her into lots of trouble and caused her to overthink things. For the most part, she felt it was negative and somewhat scary. She suggests that not holding anything in and asking questions would help people to understand their diagnosis and remain anchored to what could still be. Nichole urges others to never let Scleroderma define who they are. She believes that although there are limitations, people can grow around it and live their lives fully even though they may have to do things differently.

When she was 18, Nichole got a tattoo of an anchor with the infinity sign to signify that she refuses to sink. The tattoo is on her foot because feet keep you grounded, and it reminds her that she won't allow Scleroderma to take over what she is supposed to do with her life.

Determination to live fully, a refusal to be silenced and an investment in others keep this brave and positive woman moving through and on!