

SCOPE

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[Defying a diagnosis and continuing to dance](#)

[Inspire Contributor](#) on December 13th, 2012 [No Comments](#)

We've partnered with [Inspire](#), a company that builds and manages online support communities for patients and caregivers, to launch a patient-focused series here on Scope. Once a month, patients affected by serious and often rare diseases share their unique stories; the latest comes from college student Leanna Scaglione.

Five years ago, I was training to become a professional ballerina. Continual pain in my thigh while dancing brought me to an orthopedist who discovered a tumor the size of a melon in my lower spine, and I wound up being diagnosed with [Neurofibromatosis Type 2](#) (NF2). I was 16 years old.

The removal of the tumor caused enough nerve damage in my right leg where I couldn't stand without my leg collapsing, thus ending my ballet training and my dreams. I was bound to a wheelchair for almost four months and had to re-learn how to walk. At the time of the surgery, it was explained to me that there was a chance I would not be able to dance again.

Now, at 21, I have defied fate by still dancing and re-obtaining almost all of the nerve responses that were lost. Granted, if I wasn't so stubborn about continuing to dance this probably wouldn't have happened. I couldn't stand being told, "You can't do it," because it made me feel less than average, less than human. I would not let myself be defined by my disease.

When the tumor on my left auditory nerve was first discovered, at age 17, the neurosurgeon who removed all of my previous tumors pointed me towards finding someone who specialized in hearing and brain tumors as this was not his field of expertise. I was a bit disappointed because he was such an excellent surgeon: He had the ability to remove the tumors with minimal nerve damage, he had always taken the time to know me as a person and he was extremely supportive through all the procedures from beginning to rehabilitation. However, I appreciated that he didn't try to be a superhero. I met with four other specialists who gave options of radiation therapy or removal of the tumor, both of which would automatically result in deafness. My mother did extensive research on alternative treatments, and we decided that chemotherapy would be the better choice.

I'm currently on the RAD001 chemotherapy drug trial, run through NYU Langone Medical Center, to treat the tumor on my left auditory nerve. This is the second trial that I've participated in. The first one was for Lapatinib, also run by NYU. I was one of four people lucky enough to have had success on Lapatinib but unfortunately, it was only a temporary control of tumor growth.

Tomorrow, I will compete in the Miss Connecticut/USA pageant. My original reason for competing was simple: I felt like it. As time went on, I realized it was for another reason: I wanted to prove myself as a person. To prove that despite having NF2, or any other disease, a person can be more than what society expects of them. I want to show that having NF2 isn't going to stop me from doing anything I desire. I feel like I showed the doctors when I was told I wouldn't be able to dance again. And now I want to show the public that having a disease shouldn't stop a person from achieving goals, like competing in a pageant.

Regardless of the outcome of the pageant, I look forward to graduating college in the spring. I feel ready to take on the world. **And I am not defined by my disease.**

Twenty-one-year-old Leanna Scaglione, of Connecticut, is a senior at Endicott College, majoring in creative writing. She is also an intern at the advocacy organization [Neurofibromatosis Northeast](#). Scaglione has continued her various interests in dancing and performing arts with dance solos and the starring role of the "Emcee" in her school's production of "Cabaret." She plans on pursuing a career in the theatre arts.