2009 NJCFSA HIGH SCHOOL SCHOLARSHIP WINNER

NJCFSA is proud to announce the winner of our 2009 NJCFSA Scholarship award is Alexandra Volper. Alexandra graduated from Point Pleasant Borough High School, Point Pleasant, New Jersey. She is attending Ocean County College, Toms River, N.J. and is majoring in dance therapy.

The New Jersey Chronic Fatigue Syndrome Association is proud to support Alexandra and her efforts to continue her education. This is her winning response to the essay question, *"What do you see as your goal for higher education or career direction and has having CFS influenced your choice in any way?"*

"Life with chronic fatigue syndrome is a nightmare - always struggling to wake up, sometimes struggling to get to sleep, constantly feeling sick and exhausted. There are always headaches, stomach aches, and pains in my arms and legs. These are things that people with CFS deal with everyday. Chronic fatigue syndrome is something that most people do not understand, or they are just not willing to believe. Many think it is a non-existent illness and an excuse to be lazy. That is definitely not the case. My Dad always thought I was faking, and my school administrators thought I was just being irresponsible.

I am eighteen years old and have been dancing since age 2. I always had trouble sitting still when I was a child, so my Mom sent me to dance lessons to burn off some of my energy. My sister is two years older and I was always trying to sneak into her dance classes. In elementary school, I was always getting in trouble for tapping my feet under my desk, or for singing in the hallways. I just couldn't wait to get to 5th grade so I could be in chorus and band.

Even now, if music comes on you can see me **start** to move. I could never make myself to stop doing that. Dance takes my heart and my mind to an imaginary place that I love to be in. I never stopped moving until one day a few years ago when I was just too tired to do anything.

My Mom would take me to dance class and after about 5 minutes of dancing I would be totally exhausted, whereas before I was able to dance 6-7 hours straight. I'd tell my Mom to take me home because I was too tired to dance and I'd go home and go to bed.

I was very dedicated and loved to dance, so I would push through a class. I would come home and cry because I was so tired and cranky and wanted to dance. You know how cranky teens can get, and I was beyond cranky. I couldn't figure out why I couldn't dance anymore.

After weeks of trying to push myself and failing miserably, it just became too much. My Mom knew from the beginning that something was wrong if I couldn't even make it through dance class. So, we began the rounds of doctor visits. I was at the doctor's so much, I am surprised they didn't give me my own room. My first pediatrician said I was depressed! I'd leave the doctor's and tell my Mom, "I AM NOT DEPRESSED!!" My Mom knew that I was sick and so we went to another pediatrician.

After ridiculous amounts of blood work, nothing seemed to be abnormal except my Epstein Barr level, which we already knew was high. I was so upset that every day I cried saying, "They are never going to find out what is wrong with me." My Mom was on the computer talking to people all the time, doing research and trying to get a clue as to what was wrong with me. At my next doctor visit, my Mom brought up chronic fatigue syndrome and the doctor agreed that could be it. I finally had an answer about what could be wrong.

I went from the pediatrician to an allergy and immunology doctor, an infectious disease doctor, a rheumatologist and a sleep doctor. Low thyroid? Not it. Lupus? Not it. They tested everything and finally they came up with the same diagnosis….chronic fatigue syndrome. Not what we wanted to hear…but at least we knew what we were dealing with. The doctors all tried numerous medications, but nothing helped. I finally went to an endocrinologist who again said, "Chronic Fatigue Syndrome," and sent me to get 15 vials of blood drawn. He has given me a medication that does help with the dizziness.

On the bright side, today I can dance again. I dance several days a week and am an assistant teacher in several classes, mostly working with the tiny ballerinas and little tappers. I still have to push myself, but I am doing better. Dance clears my head of negative thoughts. Everyone needs an outlet, especially with the amount of mental stress CFS creates.

I have developed a lot of compassion for people who are sick and can't do much. I am the co-director and choreographer of a dance company. Every Saturday, we get together and work on dance numbers, which another senior and I choreograph. I love working with the younger girls and inspiring them to dance better and to use their talent to help other people. A lot of dance companies compete to win trophies, but that's not what we do. We use our love of dance to bring smiles to others (we hope.) We perform at community events and also go out and do shows at nursing homes. My favorite part is going around and visiting all the patients after our shows. They are fun to talk to and they tell us lots of interesting stories.

I would like to pursue a career in dance education and/or dance therapy. I love working with children and I love sharing my love of dance with others. Since I have loved dancing since I was 2, I can't say that my chronic fatigue syndrome influenced my decision to be a dance major. That just seems to be something I was born to do. The chronic fatigue syndrome has made me more aware of what it is like to be sick all the time, have problems functioning and not being able to live my life as a normal person. In that respect I think CFS has influenced my decision to incorporate the dance therapy into my career plans. A combination of being able to dance and to help others at the same time seems like an ideal career.”