

Testimony

Rachel Smith

Thank you for allowing me to speak to you today. My name is Rachel Smith. I am 27 years old and I have been sick for over 20 years.

Please allow me to remind you of what 1989 was like. Chicago and Bobby Brown held the top Billboard spots. Indiana Jones and the Last Crusade scored big at the box office. The Berlin Wall was just months away from being torn down. I was 6½, normal and healthy.

Twenty years later I have very few memories of being healthy. The few I do have I treasure. I remember my 4th birthday party. I got a purple and pink big wheel. I remember the Halloween when I was five. I went as Tinkerbell - complete with plastic wings. I remember playing soccer in the hot August sun. I would run the field from end to end because I just loved to run. My last memory of being healthy is my favorite. It is of my friend's seventh birthday party. I remember running and swimming and dancing and playing games until the summer sun set. And just like that, my memories of health were over.

My next memory is of a horrible illness that I never really got rid of. My throat hurt and my body ached. I was too sick to move. I watched *The Secret of NIMH* and I wondered if I was in danger of dying like Timothy the mouse. I gradually got better from the fever and some of the pain, but I never recovered my strength. When my friends knocked on my front door, I would hide in my room and say "Mommy, tell them I can't play. I'm so tired." Just after my seventh birthday I was diagnosed with having Chronic Fatigue Syndrome. I attended grade school sporadically. My mother (an accomplished R.N. and licensed teacher) quit her full time job in order to provide full-time care for me.

I began a new life. My new friends were middle aged doctors. My new social activities consisted of doctor's appointments and watching the world pass by my window. My mother recognized that I needed an age appropriate social outlet. So, she did what any desperate parent would do. She bribed me. The only thing that piqued my interest enough to crawl out of bed was horses. She found a woman willing to give me 15 minute riding lessons.

As time went by, I watched the kids in my neighborhood grow into teenagers. They went on first dates with first loves. They went to homecoming and prom.

They fretted over finals and graduation. I too, became a teenager. My friends were still doctors in their 40s and 50s. I never went on a date. I have never had a first love. I have never been to a school dance. I have never gone shopping for a dress. I didn't fret over finals – I was on home and hospital. My 'graduation' was being handed a diploma by a secretary trying to close up the school for the summer. I continued to ride horses whenever I could for a few minutes.

More time passed and the neighborhood got quieter as teenagers turned into young adults and left for college. I was still here of course - watching from my window as always. I didn't mind the first wedding invitation my family received, but after the 15th I felt genuinely despondent. It is said that time heals all wounds, but I would like to add that it usually brings new wounds as well. The wedding invitations turned into baby shower announcements.

I gradually deteriorated over the past 6 years and now I can no longer ride or even go out to the barn. The neighbors have grandchildren who are nearly the age I was when I first became ill. Everyone has traveled full circle except me. Now I wait for the day when I can be healthy and have a life, an education, a job and a family of my own.

It is my most fervent hope that in hearing my story today that you do not think that I am unhappy nor am I unhopeful. Rather, it is my express desire to impress upon you the devastation of this disease - perhaps especially when it strikes the young. Those years that are lost can never be reclaimed. We can move forward though. This great country of ours claims many triumphs in history. We built the first computer designed for business. We built the first cell phone. We even put the first man on the moon. It is entirely within our grasp to solve CFS/ME. We can and should promote more research, more funding and more hope for the future. Let us all as a community of patients, doctors and researchers work towards this goal and one day soon we will be able to say "we have done it." Thank you all for listening.