The Faces of CFS

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Like most speakers, I must begin by thanking the organizers of this program, and by saying that I am happy to be here. *Unlike* most speakers, however, I **REALLY** mean it! At this time last year, I was often unable to *attend* a lecture, let alone stand up in front of an audience to give a presentation. I'm not crazy about being invited here because I have a severe, mysterious, and poorly understood illness, but I am happy to provide some insight into CFS and how my family and I have been dealing with it.

My illness began in the textbook fashion for 90% of people with Chronic Fatigue Syndrome. I was 100% well until April 5, 2005 when I developed flu-like symptoms - severe headache, horrible cough, fevers, chills, no appetite, nausea, sore throat, and overwhelming fatigue. My mother and sister had similar symptoms, but got better within two weeks; I did not. After 4 weeks, I was tested for mono. After 8 weeks, I was tested for *everything*! And yes, I was tested for Lyme disease several times, using the most reliable labs.

When all the tests came back negative, my pediatrician suggested that I might have bad allergies or that I was exhibiting "school avoidance" or depression. But I knew something serious was *physically* wrong. First, I loved school. Second, my body felt like it was glued to the bed. I felt as though something had sucked the energy right out of me. I lost 10% of my body weight in the first few weeks. I didn't have any appetite or any energy to eat and drink. I needed help getting up to go to the bathroom. I felt so sick and weak that I asked my mom if I had cancer or AIDS.

Fortunately, my parents are both physicians and they knew that I was severely ill. My father had also been diagnosed with CFS several years earlier, so they feared that this was the diagnosis. They took me to several top CFS specialists to confirm it, including Dr. David Bell in upstate NY, Dr. John Oleske in Newark NJ, and Dr. Peter Rowe at Johns Hopkins University. I had all 8 of the symptoms from the case definition, plus a myriad of others: persistent, overwhelming, incapacitating fatigue; unrefreshing sleep; sore throat; severe headaches; cognitive impairment or "brain fog"; severe photophobia; postexertional malaise; and muscle aches and pains. When tested, I had significant orthostatic intolerance. In addition, I had weird rashes, new food intolerances, stomach problems, and horrible indigestion.

After 5 months, I started to improve a little, but within a month of starting 7th grade, I had a severe relapse which was worse than the original illness. This was no longer "chronic fatigue syndrome." This was "*crippling* fatigue syndrome!" Not only could I barely move, but I couldn't even read for 10 to 12 weeks, and even watching television was an effort. My memory was seriously impaired. I was socially isolated and I was unbearably bored. Worst of all, I did become clinically depressed.

My friends and teammates tried to be supportive, but it's easier for them to understand a broken limb they can see than an illness that relaxes its grip enough for me to go to a soccer game one day, but keeps me a bed-ridden prisoner the next. Dr. Bell encouraged me to talk about CFS. He gave me permission, in a way, saying it was my obligation to educate other people about CFS and its impact. But it's hard. Some players on my soccer team treated me like a slacker and thought I wasn’t committed enough. Most of my friends are athletes, so if you can’t do sports, they’re not interested. But, a few of my friends were very supportive and hung in there with me, either watching TV or listening to music or playing video games.

After 12 weeks into my relapse, my parents realized I wasn’t going to be able to go back to school. They suggested taking a year off or switching to an easier course-load, but I was committed to excelling academically despite CFS. They arranged for home-schooling tutors and I did an online honors algebra course through Johns Hopkins University. My mother also started what she called “The TiVo Curriculum,” taping a wide variety of television shows that were educational as well as entertaining.

I have tried numerous experimental medicines and therapies; most didn’t help. What did help? Time; patience; a medicine to stimulate my appetite; forcing myself to drink fluids even when I didn’t want to; sleeping medications; headache medications; a regular sleep schedule; socializing even when I didn’t want to; vitamins and supplements; and gradually increasing my physical activity. Playing Scrabble helped organize my brain fog before tutoring. Physical therapy was too grueling, but we knew that CFS patients can improve with regular mild exercise.

My first “exercise” was video games! My parents then got me a punching bag to take out my frustrations. At first, I barely had the energy for a weak punch! Gradually, I built up a little stamina; eventually, I broke the bag! Then I started playing ping pong…while sitting in a chair. Eventually, I could stand and play for a few minutes at a time, then for a whole game. This summer, I will be traveling to Houston TX as a participant in the Maccabi Games playing table tennis. Last summer I started playing a little water basketball in the pool; gradually I progressed to shooting free throws in the driveway. This past semester I was able to play part-time on my school’s B team as a point guard. When I was able to walk around the house, I started kicking a little soccer ball. Then I tried juggling. Occasionally I would kick the ball for a few minutes with friends. Now I have returned to indoor soccer, although I still miss more practices than I attend.

Video games are still a good outlet when I’m bored, fatigued and frustrated. Another physical help was the game “Dance, Dance Revolution.” When I first started, I could barely do the easiest levels; now I can get a work-out doing more challenging levels for 10 minutes. I still haven’t been able to convince my parents to get me the new Wii system though!

Interestingly, the inactivity imposed upon me by my illness motivated me to develop my interests beyond sports. When the most physically demanding thing I could do was to watch television, I became an ardent fan of the History Channel. I also became a fan of comedy shows during that time. Comedy is well known to have medicinal benefits; laughter has been shown to boost the immune system. Humor is also an effective tool to overcome adversity. I not only watched funny movies and sit-coms, but stand-up comedians as well. I learned that humor is simply looking at everyday events with a different perspective. I needed a lot of humor to get me through the “everyday events” of the past two years! Unfortunately, there’s nothing funny about CFS! Since this past September, I have developed the skills I once only watched: I am currently a performer in the Improvisational Comedy Troupe at the Morristown Community Theater.

I started back to school the same way I started back to sports: slowly and gradually. I could only do this because I live across the street from school and because my school's faculty and administration were extremely supportive and flexible. I started back last April with 1 period a day, then 2 and gradually 3 on a really good day. Often, this would give me a 3 to 4 day set-back, however. I also had trouble meeting with my tutors if I also attended classes. Somehow, I finished 7th grade with straight A's, although a few weeks later than the rest of the class.

I was determined to return to school this fall. While it was extremely difficult, I started with an "everything but gym" schedule. What's most frustrating now - for me and for my teachers - is that I may have an "up day" where I can do nearly everything, but the next day I may not be able to do *anything*. It's still very stressful. While I say that I am back at school "full time," I've still missed the equivalent of 4 weeks this year due to illness. I've also missed activities like the 8th grade trip to Washington DC, school dances, most sporting events, and other activities like sleep-overs. While I have been able to overcompensate and maintain straight A's, I still have cognitive problems - where I just space-out on tests. I may have an idea and then can't get it out. I still have word blockages or forget what I was trying to say. It's like a cat got my tongue and kept holding onto it. It's a good thing I have a script today!

Ironically, we focus on the physical symptoms and limitations of CFS, because that's what we can see and, frankly, that's how medicine works. For me, the cognitive problems - the brain fog - may have been the *most* frustrating symptom of all to deal with…or maybe it was the boredom...but also the depression. While CFS is not a *fatal* illness, it does take your life away. As most of you know, it's very limiting. It engulfs you in uncertainty because it's so unpredictable...and it can change your life forever.

Overcoming the limitations of CFS, both physical and mental, has been the biggest challenge of my life. It has helped that I was able to help others by serving as the national pediatric spokesperson for the Chronic Fatigue and Immune Deficiency Syndrome (CFIDS) Association. I want to thank Ms. Kimberly McCleary and Ms. Marcia Harmon for giving me that opportunity. My role has included giving interviews for different publications, posing for the traveling poster exhibit, and giving this speech. While it may not sound like a lot, it was a lot *for me*. It has also been gratifying to have received emails from people around the country who said that they were inspired by reading my story. My parents have also heard from several of their physician friends that they diagnosed CFS in a few patients only because they knew of my situation.

Having overcome CFS-related limitations, I have discovered a new perspective and a new level of determination. Each day, however, is still a journey to establish a "new normal" for my life. While I wait for researchers to decipher CFS, I try to balance my energy demands with limited energy units. The most important way to do this is to remind myself when it's time to sit down! *It's time!*

Thank you again for inviting me here to share my perspectives and for encouraging me to do what I can to manage this illness in the meantime.