

Remarks for October C.F.S.AC meeting October 29, 2009

By Marilou Regan

While every child is a miracle, my daughter Elizabeth was a miracle baby in the truest sense of the word. During her premature birth in Philadelphia, 23 years ago, I nearly bled to death and she was rushed into the Intensive Care Nursery. But through the miracles of modern science, we've both lived to tell how difficult and challenging life became for my little girl.

Beth was a wonderful, affectionate, happy and vibrant child who loved life, her family, friends and school. But then at age 12 without any warning her world was shattered. One random day she suddenly became so sick that she wasn't able to concentrate or move without pain and she was exhausted all of the time. An A-student, Beth couldn't get out of bed to go to her sixth grade classes. She could barely get up to eat or function in any way. Her other symptoms, that she still suffers with today, included stomach aches, vomiting, body aches, migraines and general malaise.

Her condition was so incapacitating that we sought medical intervention immediately; however multiple trips to multiple doctors and test after test didn't provide a single clue. Beth's symptoms resembled Lyme disease and mononucleosis, but both were ruled out. The medical community was stumped. Some of the doctors even suggested that she was faking it. We trekked to major medical centers in our tri-state region and there was no conclusion about her illness for over a year. Finally, at Children's Hospital of Philadelphia the chairman of the infectious disease department gave Beth her diagnosis: Chronic Fatigue Syndrome (C.F.S.).

The doctor immediately dismissed Beth from his care, telling us nothing could be done to help her. He explained that Chronic Fatigue Syndrome had no treatment or cure and that my 13-year old daughter would have to accept "living" like this for the rest of her life. We were devastated by the news and could barely comprehend this horrible life sentence.

Beth spent most of her middle school years in a fetal position on our sofa. She was home-schooled but she could barely rouse herself from the depths of her exhaustion to meet with the tutor or do the school work. Beth desperately wanted to be a normal teenager, so she tried attending high school but she was absent for more than half of her classes. If she did manage to get through the school day she would come home and go to bed until the next morning. She had no social life or friends. Our entire family was affected and we always had to be quiet because Beth was always sleeping, which was very tough for her two teenaged brothers.

Because of her fragile health, she enrolled in a college close to home and registered as a disabled student. Chronic Fatigue Syndrome affects the immune system and can cause sufferers to be susceptible to many additional illnesses in the community, and Beth was

no exception. She missed multiple college classes because of episodes of illness or sheer exhaustion. Beth even had to accept a failing grade in a class since the university would not allow her to withdraw because of the illness-related absences, affecting her GPA (Grade Point Average).

Beth felt discriminated against by the disabilities advocate at the University of the Arts who would not support Beth's need to acquire class-attendance concessions from her professors. The University official also told Beth that she should seek psychiatric help and insinuated that her condition was psychosomatic.

Although the Centers for Disease Control categorized C.F.S. as a disease in 1994, Beth was denied Social Security Disability benefits last year, despite her six-inch thick medical file of all the failed interventions over 10 years, including alternative treatments. She is currently struggling with the rigors of graduate school and will earn her master's degree in Art Education in December. But Beth doesn't know how she will be able to function as a teacher, (or in any career), with a medical condition that constantly interrupts her life at the core level. And she will lose her desperately needed health benefits when she graduates.

Chronic Fatigue Syndrome is often misdiagnosed by doctors and health care professionals who, along with many others including family and friends, misunderstand the dire implications it has on the patients and their families. More respect needs to be given to sufferers and C.F.S. needs to be recognized as a real disease entity that merits consideration for disability and health care coverage.

Currently there is no course of treatment, although a promising new drug is waiting for FDA approval. More research funding is needed for this insidious illness that sucked the life force out of my beautiful daughter. Beth needs another miracle from modern science; please help her, and other children like her, to attain it.