

**Public Comment**  
**Anonymous #1**

We've all heard the myths. Ulcers are caused by stress. Cold mothers cause autism. Bad parenting causes ADHD. MS, or hysterical paralysis, is a faker's disease. Except for ulcers, none of these illnesses have a simple "germ theory" explanation. And yet, these myths have thankfully been retired. And patients are treated respectfully, compassionately, and sanely. It's time to do the same for patients who are ill, but diagnosed with the myth that is CFS.

In the fall of 2008, my older daughter was diagnosed with a mono-like illness; my younger daughter was diagnosed with viral meningitis. After a proper medical and psychological evaluation, we were referred to a Pediatric Infectious Disease Specialist and received a diagnosis of Chronic Fatigue Syndrome. My daughters were diagnosed right away, and I'm grateful to our pediatricians who've known my daughters since birth. Our problems began when the High School found out that my daughter was diagnosed with CFS.

The PedsID doctor had recommended a gradual return to classes in order to prevent relapses. But the school incorrectly informed me that that couldn't be done. The doctor found out about a 504 plan for me, to have her transition back into school. Despite repeated crashes and an increase in symptoms that this caused, the school removed the 504 in June.

In September my daughter attempted the first day of school, optimistic after the summer. But she collapsed for two days afterward, hardly able to stand. No one had told us about post-exertional ...not malaise really ... but crash, or collapse. I realized that the school employees had a very different impression of this diagnosis than what I saw in my daughters. A search for CFS in children yielded stories about how it "may be," "is thought to be," or "some researchers feel..." that it develops because of depression and other psychiatric reasons. My daughters had all these other physical symptoms that were not listed. And despite the insistence of school employees who didn't know my daughters, they did not have any depression or social phobias. According to them, CFS is just fatigue, and everyone experiences fatigue... she still needed to go to school. We were coerced into pressuring my daughter to ignore her diagnosis and just push her to attend school. My daughter became more exhausted and very discouraged as her physical condition worsened.

At school, the psychologist, social worker, and guidance counselor had started telling my daughters they were "not sick" when they saw them. They said they could tell by looking at them. They said they simply did not believe that my daughter was at home exhausted, sleeping, unable to stand or shower. The school psychologist suggested that I drag her into the car in her pajamas, and he would get her out of the car and into the school building. Scary.

By March, the district created a petition requiring my daughter to attend family court diversion. They had claimed that her "medically excused" absences were now truancy. The counselor we met with did her research and found that my daughter had a legitimate illness. Unfortunately, the school didn't listen to her either.

Next September the guidance counselor and social worker again refused to discuss the illness, but spoke only of behavior and attendance issues. The guidance counselor asked my daughter when her birthday was, so she could determine when they would no longer be responsible for her under compulsory education laws, so my daughter would drop out. She then told me I needed to home-school my daughters or else child protective services would be called, because the district was never going to provide services for my daughters. They claimed that the doctors' letters did not have a valid diagnosis or prognosis. The nurse from the school called the doctor to challenge him to see if he had any proof that he was correct.

Later, the district consulting psychiatrist challenged the validity of the diagnosis. She used the CFS pages on the CDC website to question my choice of treatments and then decided that the school should not have to provide any services because I did not have my children in CBT and GET to "treat" their CFS. Additionally, the district psychiatrist told the family advocate that they were focusing on discrediting me, and went on to make several claims, including Munchausen's-by-proxy, to Child Protective Services. Luckily, the CPS caseworker was extremely thorough and fully investigated the illness.

The PedsID doctor, out of frustration, asked me to bring my daughters to be evaluated by another doctor who had experience with adolescents with CFS. After a very thorough evaluation, he said they had what he called "classic" CFS and said he would get the school to provide fulltime home tutoring. Instead of providing a written plan to start the tutors, the school made more CPS complaints. We signed our daughters out of school under threat of continuing CPS complaints, and started them on an online program that they could start from the beginning and move at their own pace. We made a complaint of harassment and bullying to the superintendent but it was ignored.

Except for the fact that I filed a complaint with the U.S. Department of Education, Office of Civil Rights, I am certain that my daughters' school district would continue to refuse them an education and they would have no future, because of the myth that is CFS. As it is, OCR accepted the school's excuses for bullying and harassing my daughters because the district claimed that they believed I was doing harm to my daughters, since they did not believe the doctors' description of illness.

After we signed our daughters out of the school, we brought them to a CFS specialist. He was the very first person to fully explain the symptoms of an illness that matched my daughters'. He did additional medical testing to pinpoint physical abnormalities, and started the girls on a treatment regimen. The science is there; it's just mixed up.

In my opinion, CDC should establish guidelines for pediatric specialists, school districts and child protective investigators to help them understand this illness. There is a real illness, which has been historically described, and which still occurs in men and women, children and adults, whose symptoms still fit those described in the past. Current medical research supports the fact that groups of people diagnosed with CFS have real, physical abnormalities. And yet, most people believe the myth that anyone with a diagnosis of CFS just needs therapy.

The name CFS and the description of the diagnosis are just plain damaging, in my experience. They are used to mock, harass, and humiliate patients, some of whom are too young to defend

themselves. It has been several years since the Pediatric ME/CFS, the Canadian, and the International Criteria have been published. Why aren't they in use?