

September 12, 2022

My name is Leah Williams. My husband and I live in Cambridge, MA. Both of our children have ME/CFS. Our son, now aged 26, became sick when he was 12. He had what seemed like an ordinary cold, except that he never got well again. Instead, he suffered increasingly from headaches, joint pain, unrefreshing sleep, overwhelming fatigue and difficulty concentrating. He was able to successfully complete grades 6 through 8 with accommodations from the school (partial attendance and reduced assignments). The school nurse was sympathetic and assisted with working with the school on a reasonable plan. He missed most of high school because he was too sick to physically attend.

Our daughter, now aged 23, also became sick at the around the age of 12. Her symptoms were similar and equally debilitating and gradually became worse through junior high and high school. She had a terrible experience with her school in 8th grade. In spite of a Section 504 plan describing her illness and the accommodations she needed, and in spite of letters from her doctors, the school staff made everything as difficult as possible. The school nurse said that she never believed an 8th grader when they said they did not feel well. The principal said that my daughter could not make up work that she missed in class, and I was not allowed to come on campus to drop off or pick up assignments. The school social worker told my daughter that she had to either throw up or faint before she would be allowed to leave a class. The assistant principal filed a truancy claim against my daughter in juvenile court. Finally, eight months into the school year, the school administrators agreed to the accommodations we wanted all along, a waiver of the attendance policy, partial school days and modification of assignments, and my daughter was able to successfully complete 8th grade.

I think that awareness and education about ME/CFS would have made a huge difference. If the school nurse had been knowledgeable about ME/CFS, she could have worked with us to educate the school staff. If the school staff had known what ME/CFS was and how it impacts schooling, they might have approached our situation differently. I strongly support the plan to expand surveillance for ME/CFS (and closely related long COVID) by school nurses. If it helps families avoid the terrible situation we experienced at my daughter's school, it will be well worth the effort.