

My name is Sue Jackson, and I have had CFS since March 2002. Both of my sons, ages 12 and 15 have it also. I have always wanted to come to a CFSAC meeting, but I need to nap every day, and I know that attending would cause a relapse.

Although my life has been dramatically changed because of CFS and I am severely limited in what I can do, I want to primarily focus on my sons today because pediatric CFS is rarely talked about – and even more rarely researched – and it is a much larger problem than most people understand. In addition to my two sons, I personally know seven other kids with CFS just in my local area, and I'm sure there are many more I haven't met or who haven't been properly diagnosed. I write a blog about living with CFS, and I receive e-mails every week from parents whose kids are completely disabled by CFS.

My older son, Jamie, started showing symptoms of CFS when he was nine years old and in 3<sup>rd</sup> grade. The symptoms came and went for a couple of years, then become suddenly much worse when he was eleven. Jamie missed 60 days of 5<sup>th</sup> grade and was bed-ridden about 50% of the time. When he started middle school the next year, we didn't even bother counting the days' absent. After some intense battles with teachers and administrators (which left me much sicker), the school finally agreed to waive all attendance requirements and all non-essential courses. Jamie took two classes with a homebound instructor and took the other three required classes in school. He made it to those classes about 60% of the time, with me driving him back and forth to school several times a day so he could rest in between classes (on the days he was able to go at all).

My younger son, Craig, began showing CFS symptoms when he was just six years old, in 1<sup>st</sup> grade. We recognized the sore throat, flu-like aches, and exhaustion after mild exercise, but his frequent chest pains and back pain scared us. After many doctor's visits, tests, and conferring with some CFS experts, we were fairly certain he also had CFS, though milder than his brother's. We didn't want him to think of himself as a sick kid at such a young age, but when he missed 35 days of school in 3<sup>rd</sup> grade, we knew it was time to have him officially diagnosed.

We were very, very fortunate to be able to see Dr. David Bell and to confer with Dr. Peter Rowe. They explained Orthostatic Intolerance (OI, a condition of low blood volume and low blood pressure) to us and worked with our sons' local pediatrician to treat it. Kids often respond well to OI treatment, and we were fortunate that it worked quite effectively for our kids. Both boys were able to return to school full-time.

Although we are grateful for this treatment that allows them to live more normal lives, CFS is still a significant part of daily life for them. They go to bed at 8 pm every night, even the 15-year old. They have to be careful not to overdo and will experience a severe flare-up of CFS symptoms if they do too much. A sleep-over at a friend's house can result in several days of being too sick to get up off the couch. They each still miss between 25 and 35 days of school each year due to CFS flare-ups. They both take a lot of medication every day, and we know if they stopped the medications, they'd go right back to being bedridden much of the time.

My husband and I worry about their futures. Our older son will be college-age in a couple of years, but will he be able to leave home? Even if he does make it through college, will he ever be able to handle a full-time job? What if the medications don't work as well for him as he gets older? What if he gets worse? These unknowns are frightening, but we know that we are the lucky ones, that there are thousands of kids across the US who are completely bedridden with CFS and unable to attend school at all.

After living a perfectly healthy life for 37 years, I got CFS in 2002, and each of my sons became ill within a couple years of that. We are living proof that this illness has both genetic and infectious roots that need to be further investigated. Families like ours, with more than one person with CFS, are not uncommon, as the 2006 New Jersey CFS Association study showed.

We need more research into the biological basis for CFS and into effective treatments. We need more education for doctors so that the estimated 80% of patients with undiagnosed CFS can finally get some answers. Although all of major advances in CFS research so far have come from private funding, we need the involvement of the CDC and NIH in order to help the millions of Americans, including kids and teens, who are disabled by CFS and can't find a knowledgeable doctor or an effective treatment.

Specifically, we need:

- The CFSAC's charter to be renewed.
- The committee to meet four times a year rather than just two.
- CFSAC replacements for outgoing committee members to be filled in a timely fashion.
- The agendas to be posted early enough to allow input from people who are often disabled for long periods of time.
- Video live-streaming of the meetings to be embedded in the charter to allow more participation from disabled CFS patients.
- Status of the CFSAC's recommendations to be posted

Suzan Jackson