

## Testimony

### Suzan Jackson

My name is Sue Jackson, and I have had ME/CFS since March 2002. Both of my sons, ages 13 and 16 have it also – they've both been sick for seven years. I have always wanted to come to a CFSAC meeting, but I need to nap every day. I know that attending today will cause a relapse, but it's just too important to miss.

Although my own life has been dramatically changed because of ME/CFS and I am severely limited in what I can do, I want to primarily focus on my sons today because pediatric ME/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 ME/CFS just in my local area, plus several more who probably have ME/CFS but aren't diagnosed, and I'm sure there are many more. I write a blog about living with ME/CFS, and I receive e-mails every week from parents whose kids are completely disabled by this devastating illness.

Our older son, Jamie, started showing symptoms of ME/CFS when he was eight 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 ten. Jamie missed 60 days of 5<sup>th</sup> grade that year 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 three 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).

Our younger son, Craig, began showing ME/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 experts, we were fairly certain he also had ME/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 and the principal began calling, 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 are both excellent doctors with amazing dedication to their patients. They explained Orthostatic Intolerance (OI) 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, ME/CFS is still a significant part of daily life for them. They go to bed at 8 pm every night, even our 16-year old. They have to be careful not to overdo and will experience a severe flare-up of ME/CFS symptoms if they do too much. A sleepover at a friend's house can result in several days of being too sick to get up off the couch. Jamie still misses between 25 and 35 days of school each year due to ME/CFS flare-ups (a bit less for Craig). 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. As my 16-year old son said to me recently, "This illness has ruined my life. I am so far from being a normal teenager."

My husband and I worry about their futures. Our older son will be college-age in a year, 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? Neither of our sons has been exposed to the Epstein-Barr virus yet, a known trigger for ME/CFS. What will happen if one of them gets mono or is exposed to another triggering infection? 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 ME/CFS and unable to attend school at all.

Living with ME/CFS is a constant struggle. We can't escape it even for a day because we can't escape our bodies and our limitations. It is always there and we worry that it will always BE there, and there's nothing we can do about it. When our children feel bad or can't do something, we feel helpless, and there is no worse feeling for a parent than helplessness.

These kids are missing out on so much – parts of their lives they will never get back. When I was a teen, my life felt so carefree – no worries, few responsibilities. Jamie in particular constantly feels the weight of his illness and is always trying to catch up from missed days of school. Our kids deserve more. They deserve solid, scientific research and real treatment options that address the biological cause(s) of the illness rather than just masking symptoms.

After living a perfectly healthy life for 37 years, I got ME/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 ME/CFS, are not uncommon, as the 2006 New Jersey CFS Association study showed.

Although research funding for ME/CFS in general is severely lacking, funding for research into pediatric ME/CFS is practically non-existent. There hasn't even been a complete population study done on the incidence of ME/CFS in children and teens.

Most, if not all, of the significant advances in ME/CFS research so far have come from private funding, but 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 ME/CFS and can't find a knowledgeable doctor or an effective treatment.

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