

## LIVING WITH CFS

### BRIAN'S STORY

#### A Family Transformed

"Mom, do I have cancer or AIDS?"

That was 11-year-old Brian's question after being ill with what he first thought was the flu, or perhaps mono at the worst. But it wasn't long before this star soccer player and straight A student realized something was seriously wrong.

He went from being a healthy, active kid on April 6, 2005, to a sick kid with severe flu-like symptoms the next day. In fact, for the first time ever the school nurse had to call his mom to come and pick him up because he was too ill to make it through the day. Two weeks later he was still sick, with a profound exhaustion that left him confused and worried.

"My body felt like it was glued to the bed," Brian explains. "It was like something sucked the energy right out of me."

Three visits to his pediatrician didn't help. She suggested Brian might have allergies, or was exhibiting school avoidance. Next, she discussed depression with Brian and his parents.

Brian knew better. "It made me feel frustrated. I like school. I have a 4.0 GPA. I play on the regional soccer team. There aren't any bullies at my school. I knew I wasn't avoiding school and I wasn't depressed."

Fortunately for Brian, his parents are both physicians, and they soon decided to seek help elsewhere. His mother, Dr. Donnica Moore, a well-known health commentator who once had her own syndicated radio show and appeared on NBC's *Later Today*, had written stories about chronic fatigue syndrome and suspected it might be CFS. Her husband agreed.

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"Brian exhibited all eight of the symptoms from the case definition," says Moore. He had overwhelming fatigue, difficulty sleeping, sore throat, severe headaches, cognitive impairment, postexertional malaise, plus orthostatic intolerance. "My son, who since early childhood had always risen at six in the morning, could barely get out of bed. He had no appetite, no thirst. He was one of the best soccer players in New Jersey in his age group and suddenly couldn't make it to games because he was too sick."

Moore and her husband wasted no time and took Brian to see three top CFS experts.

"Fortunately, we have the medical background to identify leading experts and the financial wherewithal to travel across the country to see the top clinicians in the field," says Moore.

"We realize the situation is much harder for most families." Brian is in good hands, having seen three CFS experts. These physicians have helped treat symptoms, and just as importantly, helped their young patient deal with the social aspects of this illness.

Brian's friends and teammates try to be supportive, but it's easier for them to understand a broken limb they can see or an illness like cancer than to grasp a misunderstood illness that on one day relaxes its grip enough for Brian to go to a soccer game and the next day keeps him a prisoner in his bed.

His doctor encouraged Brian to talk to his friends about the illness. "He gave me permission in a way and said it was an obligation to tell other people about CFS and what impact it has," says Brian. "But it's still hard. Some players on my Summer Select soccer team last summer treated me like a slacker and thought I just wasn't committed enough."

Other friends are more supportive and have learned that on what Brian calls his "down" days, going outside to play is not a possibility. Instead, they watch TV or play video games with him.

But it's hard to predict when a down day will occur. "This illness is so frustrating because it's so unpredictable," Brian says. "I can have an up day where I can do almost as much as everyone else, but the next day may not get to do some activity I was really looking forward to because I can barely move. It's stressful."

There's no doubt that CFS is already having a life-altering impact on Brian, who is now 12. True to his inner optimist, he tries to cope with the new limitations. He missed five weeks of school last year, and when he was there, he often couldn't perform at his usual academic level. A boy who teachers and students all recognized as an academic achiever suddenly couldn't remember the most basic things.

"The cognitive problems may be the most frustrating symptom of all to deal with," says Brian with passion. "I would just blank on tests and not remember things I used to know. Or I would have an idea and then



couldn't get it out or figure out what word or concept I was trying to say. It was like a cat got my tongue, and he was still holding it."

Learning to adapt to regular episodes of brain fog wasn't the only new limitation. Brian also had to drastically curtail extracurricular social outings to reserve his energy for school. "I couldn't hang out as much with friends. I'd get invited to sleepovers but then had to decline. I realized I couldn't live my life the same way because of CFS."



That realization really hit home when Brian had to give up his beloved soccer. "Sports are the central core of his identity, not unusual for a boy his age," Moore explains. "It was important to him to remain on the team, still be on the roster, even if he missed most games or sat on the sidelines when he did feel up to being there. He's a typical seventh-grade boy, and he just wants to be like everyone else."

Brian feels the loss keenly. "I feel sad because soccer is my life. I started to feel like this illness will never end. I wondered, why me? Out of all the people in the country, why was I unlucky enough to be in the 2% of the population who gets this illness?"

Encouraged to learn about CFS, Brian had absorbed lots of facts and statistics about the illness. But he was still unprepared for its almost unrelenting impact on his life. About three months into the illness, he became depressed, both saddened and angered at what CFS was doing to him. Although he has been dealing well with the secondary depression caused by the illness, CFS is taking a toll.

The illness is also having a significant impact on the rest of his family. Brian's 10-year-old sister, who is empathetic and has taken on the self-appointed role of cheering her brother up when he's down, doesn't really understand the changes in family dynamics and lifestyle. "She doesn't always get as much attention as Brian since we've been adjusting to the illness," says her mother. "We don't go out to eat very often now, vacations have been curtailed, and a lot of decisions about what we can do as a family revolve around how Brian is feeling. It's hard to find a good balance."

The balance is even harder this school year because Brian is sicker than he was last year and has already missed 15 weeks of school, only able to attend school one or two periods a day. For

Moore, this has meant professional and personal changes, and she has eliminated all but the most essential social obligations and reduced professional speaking engagements and travel.

Both parents feel a burning need to help their son as they witness firsthand his daily struggle with CFS. Even though they're physicians, they feel the same sense of helplessness other parents of kids with CFS feel, and they vacillate between calm deliberation and the impulse to do anything, try anything, go anywhere to find effective treatment strategies to help their son. "My husband and I sometimes have to remind ourselves that we're on the same team and have the same goal because we can have very different points of view on how to handle this," reveals Moore.

Both parents also struggle with the changes they see in their son. "The number one challenge is keeping our own sanity," says Moore. "We feel like we're in the Twilight Zone and that aliens came and took over our son's body. He's a shell of his former self."

"My whole career has been spent as an advocate for increased funding for women's health research, so I should be able to do something to help my own son," Moore adds in a poignant refrain.

This professional expertise makes her passionate about addressing deficits in CFS research. "Often, when there's no drug company behind a condition, it gets little federal attention. But the government should focus more, not less, on illnesses the pharmaceutical industry isn't taking on. The NIH and CDC should be at the forefront of CFS research. This is a public health issue and not the sole responsibility of private industry."

To keep Brian grounded, they "try to treat him like a normal 12-year-old boy who happens to have CFS instead of like a sick child," she says. "That means we have to allow him to be a kid and to sometimes engage in activities we know he's going to have to pay for the next day, or the next few days." Allowing him to go to school dances or hang out with friends when he needs to conserve his energy for school is hard, but they know social interactions with friends are as important as academics in developing a well-rounded and happy child.

Using language characteristic for him, but advanced for a typical 12-year-old, Brian sums up how he feels about CFS: "Chronic fatigue syndrome is not death, but it takes your life away. It's very limiting. It engulfs you in uncertainty because it's so unpredictable. I'd rather have a bacterial infection that can be treated with antibiotics. With CFS, there's no quick treatment, and you never know what the outcome will be. It can change your life forever."

Nevertheless, thanks to the encouragement of his family and doctors, Brian says he's not scared he won't recover. But he's still looking for the answer to the why me question and hopes that telling his story to advance understanding about CFS may help him find some meaning in enduring this illness. So this very private boy, who in spite of his academic and athletic gifts hates being the center of attention, is stepping into the limelight to try to help others understand how CFS changes lives.