

September 2017

Dear OT friends,

I am an occupational therapist, mom and now advocate for my daughter's condition: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS or ME). My goal is to educate all of the OTs to this debilitating condition. ME has robbed my daughter of a pain free childhood; our entire family has suffered ME's wrath. Millions are missing from their lives due to ME.

Thank you for your attention,
Sincerely
Amy Mooney, MS OTR/L

Our Daughter is One of the *Millions Missing*: Myalgic Encephalomyelitis

By Amy and Don Mooney

We asked our daughter, "If you could be well tomorrow, what would you do?" She immediately responded, "I would leap out of bed and be the first one at school. And I would stay there for the entire day!"

Our 12 year old daughter, Lizzie, has been ill for over 2 ½ years with a devastating condition. For 90% of her day, Lizzie is bedbound with fatigue and excruciating pain. She can't nap and doesn't sleep well at night. In fact, every aspect of Lizzie's life has been altered, yet there is no treatment or cure for her illness.

Family, friends and even the medical community do not understand her condition. It is an invisible illness, and for the one hour a day that she does manage to get out of bed, she does not appear sick. She so badly wants to be a regular, active 12 year old kid that she pulls herself together just to have an ounce of normalcy in her life.

The reality is that because she is so sick most of her day is spent in a darkened bedroom with very limited sound and movement. Socializing is a luxury; she does not play with her siblings or friends for longer than an hour, and maybe only once a week. Even while playing, Lizzie has a headache, ear pain (she says it feels like bees stinging her ears) and brain fog. These symptoms are due to the encephalitis (swelling of the brain and spinal cord) that accompanies her disease. Plus, all these symptoms worsen by the minute when Lizzie tries to do just about anything.

She receives online schooling at home for an hour most mornings, and attends one class period (45 mins) at school in the afternoon. But the truth is, her attendance is poor. In fact, she has never finished her lessons without having to be helped upstairs, only to

collapse in bed, crying. She spends the remainder of her day there, recovering from the exertion.

Because of how weak she is, all of her meals must be eaten in bed, too. She cocoons herself in her sheets and blankets to protect her fragile neurological system from the hyper-responsive reactions she has to any stimulation.

This is the new life of our child -- and for us, her parents -- and it is all due to a devastating disease called myalgic encephalomyelitis (ME), also known by the belittling name chronic fatigue syndrome. Because of ME, she has missed her 4th, 5th, 6th grade education -- and her condition is not expected to get better as she begins 7th grade

We have been told by major university doctors that "It doesn't matter what we call the condition, there is no treatment or cure. So the name doesn't matter." As heartbreaking as it was to hear that, it was even more so to hear another physician say, "Send her back to school. Kids with cancer still get themselves to school."

The Beginning

It began in January 2015, a year that started off rough. Lizzie was feeling worn out and just couldn't shake a bug. She was having a hard time keeping up with her 4th grade basketball team travel schedule, and was soon even missing practices.

This was unusual for Lizzie, she typically had an endless supply of pep in her step and rarely missed activities. She was always so happy to attend school, play with friends, play any type of sports and, in general, live an active 9 year old's life. Lizzie was a child who woke up with a smile and bounced down the stairs to start her day. How many times have our kids woken up not feeling well and we expect that after a few days they will simply return to their normal activities? Well, Lizzie didn't.

On February 5, 2015, Lizzie woke up with a very sore throat, severe axillary (armpit) pain and utter exhaustion. Then, as the next months unfolded into years, different symptoms emerged, each one more devastating than the next. Though we have held on to hope and have kept praying that this illness would go away and return our usual energetic daughter to our family, the reality is that nothing has improved in her -- or our -- lives.

Searching for a diagnosis

We started to search for a diagnosis. What could have turned our powerhouse of a daughter into a weak and bedridden child? We figured finding answers would not be hard, after all we live in a major metropolitan area with many top ranking medical facilities. We started out with getting Lizzie evaluated at three major medical centers and in multiple departments (infectious disease, neurology, rheumatology, gastroenterology). Each of these departments searched for a cause in their individualized field and ruled out countless conditions. Lizzie even participated in a grueling eight week pediatric pain

clinic program, focusing on physical reconditioning and psychological strategies to manage pain. It did not help.

After one year of searching for answers, Lizzie's pediatrician mentioned the illness Myalgic Encephalomyelitis (ME) and felt the condition resembled Lizzie's symptoms. In April 2016, Lizzie was finally diagnosed as having ME by a physician in North Carolina who specialized in the disease. The search for a correct diagnosis was an excruciating process but finally getting the correct name for this monster at least gave it an identity.

My=muscle Algic=pain Encephlo=brain Myl=spinal cord Itis=inflammation

To our shock, we discovered that medical and graduate schools do not teach their students about this condition. Even though 1 million to 2.5 million Americans have ME, it is not featured in medical textbooks. In fact, most doctors and therapists have not been trained to evaluate, diagnosis or even treat ME. Many have the impression it is a psychological condition, which it is not.

ME is a complex multi-system disease that causes significant immune, neurological, and autonomic abnormalities. These altered systems result in just what our daughter faces daily: unrelenting exhaustion, debilitating sensory sensitivity, cognitive impairments and muscle and joint pain. An exacerbation of all symptoms follows even trivial amounts of physical or cognitive exertion, which is why Lizzie needs help getting from her short tutoring sessions back to bed.

Our focus now is to protect Lizzie's fragile body and provide her with rich opportunities for continuing her education and nurturing her soul. But, for the most part, we must do this from her bed and within the walls of our home.

We continue to see our sweet Lizzie's personality sparkle but we know she is missing from the life she wants to live. We hope you will join us as we fight for Lizzie's life and the improved health of all the **Millions Missing** from their activities of daily living.

Please continue your education and awareness of ME.

<https://www.omf.ngo/what-is-mecfs/>

<http://www.unrest.film/trailer/>

<https://mecfs.ca/diagnostic-criteria/>

<http://www.meaction.net/resources/patient-resources/>

Sincerely,
Amy and Don Mooney