

## Testimony

### Julie Ann Farnham

H. was born in 1989. My first of 3 sons, he was a cute blond and extremely active. We dubbed him “Flash” due to his speed and bright personality. He bounced off the walls and the playground, but also had a sensitive, loving spirit. By 8<sup>th</sup> grade, his P.E. Teacher had pulled me aside, suggesting he would be a great asset to the high school track team... It was not meant to be.

In April of that year 2003, H. got a mono-type virus. School had been pushing the kids pretty hard with homework, so we thought it would pass. At his 14 year check up, he complained to our wonderful family doctor that he was still having deep fatigue, muscle weakness and brain fog. The doctor pulled me aside. “Depression”, he said. I was not fully convinced, but there had been many challenges in our family relationships and with school that year. H. was given a prescription that made his heart beat “out of his chest”, and other symptoms got worse. He promptly discontinued it.

Countless sore throats, colds and strange rashes ensued. Two more years somehow marched by. In May 2005 the same family doctor noted “severe fatigue, etiology undetermined,” in H 's ever thickening chart. We moved to a home in the country and changed health care systems, thinking that might help. It was hard to let go of the primary care doctor who had brought him into the world. But H. was not getting better, and that old HMO system just wasn't helping.

We checked out the new high school. Narrow hallways packed with rushing students and rigorous schedules convinced him that it was not a match for him. We discovered a program where he could work at his own pace, and he was able to complete his GED at the local community college. He obtained amazingly high scores, which lifted his spirits. Finally something was going well, fatigue or not! A few months later, the ad for a part-time job at a charming Mexican restaurant came up. He was able to work for about two months, and paced himself. Then life got worse...again.

Despite craving salads and consuming the healthier foods his entire life, H's blood work came back with flags. High cholesterol, high triglycerides, strange anomalies. His new health care system kicked into high gear. He was also quizzed as to lifestyle choices. Was he eating at the fast food joints constantly? Smoking pot or other recreational drugs? Binging on liquor? Having wild intimate relationships? After knowing H. through his little boy days—his shy, mature personality—his more conservative pattern of beliefs--such insinuations became comical and offered much

entertainment to our family. We understood that the doctors did not really “get” that H. was virtually house bound. We also understood that many young people are high risk folks-- it's just that H. had no energy for such escapades, even if he had wanted them.

His new doctors did try. CFS/ME is a mysterious, cruel disease—one that really needs a legion of medical detectives in my opinion. At the point of the medical test irregularities, new tests and treatment trials began. H. saw a naturopathic physician. This was a very nice lady with both traditional medical training and training in Eastern viewpoints on health. He was prescribed fish oil and mega-nutrients of all sorts, some of which he still takes, but with few improvements. He also saw an internist and an endocrine specialist. The endocrine specialist checked him very briefly and intimated that he was probably “just depressed.” She ordered no tests of any sort, but did collect a hefty co-pay.

H.'s journey for answers continued. A liver ultrasound showed nothing, but the sleep study put him on a CPAP machine. The CPAP machine did not seem to improve his fatigue, but at least could do no harm. By the year 2009 , we had liquidated my husband's retirement account in order to catch up on medical bills, but we were happy that his employer had switched to #3 insurance. The co-pays would be much smaller than in our previous two health care systems. There were more new physicians and specialists. New hope.

By this time, H. had developed very sore feet. His face, his hands and his formerly ectomorphic ankles and calves had swollen. He gained weight, but was still eating light and healthy. New doctors were concerned about the liver enzymes and other lab irregularities that were still showing up in blood screenings. He was screened for viruses. He was found to have had EBV and CVM in his system. Finally he was diagnosed with CFS/ME in 2010.

In 2010, #3 health care system's resources for CFS were exhausted, so H. was sent to a new N.P. physician for 3 visits. He had to take the light rail downtown with mom and little brother—really fun when you are twenty-one years old! The end result was an increase in exhaustion . Light rail? What were we thinking? This new N.P. suggested that H. had a Hepatitis type trend, although blood work did not show Hepatitis specifically. H. felt that the N.P. was both thorough and kind, but H.'s health made little or no improvement.

Now it is 2011. H. needs hope. His life consists of shuffling around on sore feet, half awake, in our large country home. He must lean and prop himself on counters and furniture to maintain a comfortable upright position while conversing with family and the few friends we have left.

He hasn't driven since age 17 –his own choice, due to brain fog and slow reaction

times. Holidays are “iffy”. H., like many CFS/ME people, experienced relatives, acquaintances and former close friends who became puzzled or judgmental. H.'s humor remained, hidden in his sleepy sub level. There are books, DVD's, video games and online friends. There are no jobs, college classes or dates. His bedroom is looking pretty dull.

The last new primary care doctor H. tried out was curt and honest. He joked that if H. had cancer or diabetes—diseases which have had millions of dollars of research allocated toward cures—now then he could help H.! But CFS/ME? H. would have to wait a decade or two.

Almost the whole family was there in the room—dad, mom and little brother. I'm the mom. I stalked out silently as H. patiently took the sterile leaflet handed to him, stating “CHRONIC FATIGUE TREATMENT” in bold black print. H. and I are both known for our patience, but I'm ashamed to say I did not shake the doctors' hand that day. I just shook my head. It wasn't the doctor's personal fault—but it's just been so long!

14, 15, 16, 17, 18, 19, 20, 21---and now 22. Gosh, I would really like to just give H.—and all these young kids-- something. Now, I believe in God—and I really think there is a lot we human beings just have to accept. But if the United States of America can put a lot more research money into CFS/ME—it would sure give beautiful, suffering young people like H. a brighter hope.

Thank you so much for your valuable time. H.'s own words and testimony follow.

Julie Ann (parent) May 2011