

Testimony

Kathleen Rogalla

My name is Kathleen Rogalla and I have 3 sons with CFS/ME.

Every morning when I wake up my son for the last 8 years, He says to me “Mom, I’m in Pain.

My response: “I Know Buddy.”

That’s why I’m here, to bring this devastating disease to light. To put a face on this disease, to raise awareness and to have the voices of the afflicted heard.

I’m their voice today, because they can’t be here for themselves to share their stories of pain and alienation.

I have 3 sons Myles, Albert, and Bill who are all affected with this disease.

My youngest son Myles is 18 years old and has been sick since age 10. He doesn’t go to school, he has no friends, and he is socially isolated. He lives in constant pain every day. Every day.

Not only is he in pain everyday, but when he does go to school he is always an outsider. Because the public does not officially recognize CFS/ME, the support structure and sympathy of people is not there. It’s not like Heart Disease, which doctors and the public encounters everyday; my mother died of heart disease, and I know personally that it is a devastating condition. CFS/ME is something under the radar, it’s not well known. ... We need to get CFS/ME to the level of awareness of these other diseases. As Myles reaches adulthood and attempts to assimilate into society, his struggle to be “normal” only gets harder.

My adult son Albert is 26 years old and has been sick since the age of 17. He was able to finish high school and some college, but has struggled since and is in constant pain. His sleep is poor, he has gastro-intestinal issues and he is unable to sustain employment all due to his CFS/ME. Albert is a perfect example of how without a better understanding and recognition of CFS/ME, more and more people are being left behind in the shadows of our society.

My oldest son Bill is 28 years old and has been dealing with CFS/ME since he was 15. Bill struggled through high school and college with little help from the administrations. He is in pain everyday, yet has still managed to blend into society without being noticed as a person in constant pain or someone with CFS/ME. However, that's all he'll be able to do...is "blend in". CFS/ME is a lifelong illness and Bill battles life everyday in pain. However, he's been lucky. Bill is happily married, employed full-time and just recently had a baby girl.

CFS/ME affects real people. Myles, Albert, and Bill are just 3 examples; there are thousands more just like them that need help. We need support from the government to raise awareness and help find a cure. We must support effective treatments to improve the quality of life for the thousands in need.