

Testimony

Joan Militello

My name is Joan Militello, I am the mother of a bright and beautiful, 17 year old daughter, whose life has been greatly affected by the lack of knowledge in both the medical and education field regarding ME/CFS/Fibromyalgia.

Janine became ill in October of 2007 after a bout with shingles. Her Pediatrician at that time misdiagnosed her because she had never seen a case of shingles. It was the doctor in an urgent center who immediately diagnosed and started treatment. Her pediatricians sent her to specialists because they did not accept the diagnosis. This was only the beginning of our nightmare with medical professionals who did not have an open mind to look outside the box. Janine was not able to return to school until February and it was short lived. Her doctors insisted she had school phobia as did her school. They pushed her to the point that all she could do was cry. This resulted in turmoil in our house as we argued about forcing her to go to school or letting her stay home. Friends were quick to interject their thoughts. Needless to say we lost faith in our doctors and turned our phones off to unwanted advice. After watching Janine be forced to attend school for 3 days with threat of failure, it became evident to our family that there was something seriously wrong with her. We decided then and there that she was not going back until she was well.

I spent my nights surfing the internet for someone to help my daughter. I even wrote the Center for Infectious Diseases. They wanted to speak to her doctor, but her doctors refused. One pediatrician actually stated, "Janine has her own agenda."

We never gave up and went to see many specialists, who really weren't so special. She was told by a pediatric rheumatologist that she had Fibromyalgia and that she could not stay home from school but must go. We followed his advice for a therapist who took no insurance and after 12 weeks and no improvement we stopped. Upon

receiving copies of his letter to our pediatrician, it was no wonder no one wanted to believe her it was filled with inaccuracies as to her illness.

I have over 10 pages documenting each doctor we have seen and treatments we have tried and to go into detail about them all would take a good day. I am willing to share our journey which I update after each visit without adding personal thoughts. They aren't always very nice!

What I want to share with you is the need for educating the medical professionals about ME/CFS/Fibromyalgia, especially in young people. Most doctors who deal with young children and adolescents have no idea what is going on in these children and teens. The frustration is so bad that there were times I was worried about my daughter's mental health and her ability to keep having people say it was in her mind.

We have gone full circle and are back with the first person who nodded and agreed it was Chronic Fatigue / Fibromyalgia and understood her symptoms and our frustration. I didn't want to hear there was no cure and that there was not sure fired way to make her better. We have spent endless amounts of time and money trying to cure our daughter and we have come to realize it is only by working with this illness that she can keep sane.

Janine has so many different symptoms that we continue to seek out specialist who can help improve her quality of life. We have met a few who have helped, but for the most part we get the look of being completely insane.

I implore you to create a center of excellence or at least make the funding available to teach doctors and educators alike about this cruel and debilitating illness.

Janine is my hero, she always does the best she can, and makes no excuses for what she can't. She doesn't need to hear people tell her

what she can and can't do; she knows her limitations but will not let them keep her from being the best that she can be.

Her goal is to go away to college because she did not have the high school social experience, as her friends all left her when she was not able to go out with them. We do not discourage her but tell her to try and we will regroup if necessary. She does not need others to tell her what she can or cannot do...she will decide what is best for her. She is stronger because of this journey.

Thank you for this time and your efforts to help all those who suffer.

Special thanks to Dr. Levine and the parent and teen members of "Speak Up About Me" for their support and encouragement to allow Janine and our family to continue to face the challenges that are placed before us.