Public Comment
Joan Militello

My name is Joan Militello and I am the parent of a beautiful and intelligent 18 year old daughter who has suffered with ME/CFS, since 2007. The unpredictable severity and symptoms, makes each day a challenge for all of us. It always weighs heavy on our minds whether she will be able to do the things she planned. I had the opportunity to address this committee via phone conference in November of 2011. I hope not to repeat myself, although, I don't think you can hear too often how this illness has robbed so many young people of their carefree, happy years. I would like you, for a moment to step into the shoes of the young adults and families who face so many challenges in both the medical and education field due to uninformed and ignorant medical and educational professionals.

Now as you walk in our shoes, and hear our experiences dealing with the medical and educational professionals, I would like you to take a moment to imagine the emotional turmoil this illness has caused Janine, a teenager, in horrendous pain and exhaustion, frightened and unsure of what is wrong. Then to add insult to injury, have doctors and educators alike say you are not physically ill, at times causing your own family to doubt you.

Janine's illness began in October of 2007, when at 13, she developed shingle. She was very sick and developed postherpetic neuralgia. She was treated with Gabapentin and Topamax, in addition to Viacoden for the constant pain. She suffered from terrible headaches, body pain, nausea, vomiting extreme fatigue, inability to adjust her internal body temperature, intolerance to smells, loud sounds, lights and even small groups of people. All she could do was stay in bed. She looked terrible and felt worse.

Her pediatrician did not believe her and kept taking me outside the exam room to tell me she needed psychiatric help.

She had teachers who insisted she complete all work, even, busy worksheets.

She had tutors who refused to believe her when she said she was too exhausted to do any more work. One actually tried to follow her to her bedroom, until she was told to leave and not come back.

-In January, her school demanded she return to classes or fail, insisting she had school phobia.

-She saw two highly recommended Rheumatologists; the first diagnosed her with fibromyalgia, but said she needed to push through it and refused to write a letter stating she could not return to school. The second rheumatologist did not see us, but had her resident's exam Janine. They were unimpressed and said there was nothing wrong with her and she needed to go to school.
It wasn't until I requested copies of their reports that I found out, not only were they plague with inaccuracies, but the second rheumatologist had diagnosed her with Chronic Fatigue Syndrome. Both doctors noted in their reports that she had to push through the pain and exhaustion, while recommending psychiatric treatment.

We were very happy when our previous pediatrician accepted our health insurance again; but our joy was short lived when after discussing the length of her illness, the doctor stated, “Janine has her own agenda.”

Meanwhile, her school forced her to see their psychiatrist, who used a bullying technique of having her talk about future plans and then telling her there was no way she would accomplish her goals because she refuses to go to school.

This was so traumatizing to Janine. I saw the light dim in her eyes and I realized that they were leading my daughter down a long dark tunnel, to which she was slowly succumbing. It came to mind that they were going against their oath, whether they knew it or not of “Do No Harm!”

She went to the psychotherapist who specialized in fibromyalgia. Unfortunately, the fibromyalgia that is related to school phobia. She was an ally in some ways, as she wrote the appropriate letters for school and home tutoring was reinstated. However, each session ended up with Janine leaving very angry and depressed.

The psychotherapist insisted we see a psychiatrist for medication.
A Pediatric psychiatric nurse practitioner put her on Effexor and kept increasing dosage when her health did not improve until she was on 250 mg of Effexor and then wanted to add Prozac. In addition, she told her that she had to push through this or she would waste her life in bed. Once again we were disappointed by the medical profession and it took almost 2 years for Janine to get off the Effexor.

The next therapist told us that Janine was one of the most grounded teens she had ever met and that although she was unfamiliar with her illness, we should continue to believe her and we should stand our ground with the education and medical professionals.

School kept threating to pull home tutoring if she didn’t attend a class a day. After three days, Janine was totally wiped out and the school nurse was dismissive of her and refused to call me. At this point her father and I decided there was no going back to school until she was well.

I met with an Attorney specializing in Education Law, who told me we had a case, but it would be costly. He suggested I give them his card and offered to write a letter if they refused home tutoring. The card worked and they re-instated tutoring.

I purchased Wright’s Educational Law books to read up on how to write letters and document what the school was doing.

We were lucky to find an education advocate, Steve Newton, who drove from Delaware on several occasions to attend Janine’s CSE meetings. His presence and knowledge made a great deal of difference making the school understand her illness, as well as informing them of the many laws they were breaking by not providing Janine a “free appropriate education”

We did not give up our search for someone or something in the medical field to help. We tried all sorts of treatments including: Myofascial Release Therapy, Massage Therapy, Chiropractic care,

Yoga, Biofeedback, Acupuncture, EECV treatments, gamma-globulin shots, B12 shots, a cocktail of vitamins made by a respected doctor, in addition to shots of vitamins, and Darkfield testing.

Janine has been seen at many of the top hospitals in New York and Kennedy Krieger Institute in Baltimore. It is hard to believe that so many highly rated children's hospitals could not help my daughter, these include, Morgan Stanley Children's Hospital, Montefiore, NY Presbyterian-Cornell, Westchester Medical Center, to name a few.
We have searched out specialist after specialist to help her, and have been to the following medical professionals:
3 Pediatricians, 4 Infectious Disease Specialists, 2 Rheumatologists, 2 Cardiologists, 2 Endocrinologists, 2 Geneticists, a Gastroenterologist, a Hematologists, 2 ENT's, 2 Doctors of Osteopathic medicine, 1 Pain management specialist, a Neurologist, 4 Psychologists, and 2 Psychiatrists.

Of all these medical experts, only 3 had any knowledge of ME/CFS. The others wanted to "fix" Janine, but in their way, some with medicine, some with tough love, and others giving her a new diagnosis.

Dr. Levine was the first doctor we met who understood. I cannot begin to tell you the relief to finally have validation that Janine and our family were not crazy.

We have gone full circle with Dr. Levine, as I continued my search for a cure, there had to be one. We finally returned to Dr. Levine who went through all the reports, which I carefully documented and put her on Clonidine and Compazine, which for the first time we saw an improvement. She was able to get up from bed without experiencing being nauseous and vomiting, which generally wiped her out for most of the day.

After three years of homebound instruction, Janine was able to return to school in September for 2 classes a day, Chemistry and Algebra II/Trigonometry with home tutoring for English and Social Studies. The return was difficult as most of her friends had moved on and she really didn't fit in with any group, but she was determined to go to school.

Janine will graduate on June 23, with an Advanced Regents Diploma; she was awarded the Presidential Award for Academic Excellence, and is a member of the National Honor Society. She plans to attend SUNY Oneonta. While we encourage her independence, we cannot help but worry if her health will hold out. She has a maturity beyond her years, and has learned to pace herself and save her energy for the things that are important to her. And she knows that there will be good and bad days, sometimes lasting longer. She has made friends and already has a roommate. There were many times, when we thought this would not happen.

Janine still has many unresolved medical issues, including gastric issues, short-term memory loss, TMJ that is not only causing terrible pain, but her teeth to shift. The doctors at Kennedy Krieger believe she has Ehlers Danlos, but our insurance has declined payment to them, so we can't go for a follow-up. We have stopped looking for a cure, Janine is tired of doctors. We are

just so happy that her quality of life has improved to the point she is able to enjoy some of the typical things her peers take for granted.

This is our story, but we are not alone. There are so many young people who are experiencing the same, challenging experiences as us. Thanks to Denise Lopez, and Sue Jackson, for their internet presence that has brought many young people and their families together with others that understand what they are going through.
Now imagine how different our experiences would have been if we had access to medical and educational professionals who understood and were knowledgeable about ME/CFS and how devastating this illness can be on a young person and their family.

I implore you to educate the medical and education professionals about the signs and symptoms of ME/CFS. Please support research to find a cure and/or treatment to improve the quality of life of these young people.

Thank you for your time and support.

Joan Militello