

# **Massachusetts CFIDS/ME & FM Association**

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## Janet's CFIDS Story – A Parent's Perspective

My husband and I have three wonderful children. In the winter of 2000, our girls Frances and Katie were nine and eight; our son Tim was five. As a family, we loved to hike, bike, and cross-country ski. All three children played soccer. Frances had recently taken up the violin and loved it. They were intelligent, motivated students. Frances, in particular, loved school.

My sister, who had struggled with CFIDS for many years, lived with us because she worked part-time and could not afford a place of her own.

That February, Frances and Tim were sledding when they hit a tree. Frances took the brunt of the crash and had extensive facial bruising, cuts and dental injuries that eventually led to three root canals. Regardless, she seemed to recover quickly and was back to school within several days.

However, in March and again in April, she caught viruses and was home sick for a week each time. In early May, she struggled for three weeks with exhaustion, headaches and swollen glands. She tested negative for mono but her blood work indicated that she was fighting a virus. She finished fourth grade that spring. We were glad for the summer and a chance for her to recuperate.

The following year in early January, our family spent a lovely weekend downhill skiing in New Hampshire. A few days later, Frances fell ill again with headaches, swollen glands, sore throat and fatigue. This time, the

symptoms did not abate. They worsened and she stayed home from school resting in bed. She would feel a bit better in the evenings, but each day she experienced the same symptoms. She looked pale with dark circles under her eyes. Her illness did not seem like depression, anxiety or school phobia. It seemed like a bad flu, but with no fever, and with evening times of respite from some symptoms. Frances did cry from sheer exhaustion, and from feeling sick and in pain, but she did not lack motivation or lose interest in life. She just did not have any stamina.

After several weeks, the pediatrician told us that Frances should go back to school. On Valentine's Day, we got her up and sent her in for the whole day with homemade Valentine cards to give to her friends. I was worried about her going because I knew she was very ill, but the school nurse told us she looked fine at lunchtime. She got home and collapsed. Her symptoms flared up and she could hardly get out of bed. "Don't ever do that to me again, Mom," she said.

Even though one of the case definitions says that doctors should not diagnose CFIDS until it has lasted six months or more, I asked the pediatrician if she could be developing CFIDS. The pediatrician told me she had never seen a child with CFIDS and I thought, "You may be seeing one now."

In May, we drove to upstate New York to visit a pediatrician, Dr. David Bell, who had worked with many children during an outbreak of CFIDS in his practice area. He diagnosed Frances. She followed up with Dr. Alan Gurwitt and he confirmed the diagnosis. We also went to a pain clinic where the doctors did not believe in CFIDS. Eventually and reluctantly, they confirmed that she had it, but it was emotionally wrenching for Frances to deal with the doctors' skepticism when she was so ill.

Frances worsened and spent the next three years largely homebound, unable to attend school and often unable even to meet with a tutor. Some

of the most worrisome symptoms were severe cognitive changes. When the school psychologist did WISC –III testing at home, her Verbal and Performance scores were low and 39 points apart. The School Occupational Therapist tested Frances and found she was having difficulties with Visual and Sequential Memory. She had difficulty producing legible handwriting, and doing basic counting and spelling.

After about a year of terrible health, Frances began to get better. Day to day, it was difficult to see the improvement, but after three years at home, she was able to return to school for two classes each day. It took all her stamina, but she went.

One of the most emotionally painful aspects when she returned to school was her social life. She had missed all of middle school and her close elementary school friends had moved on. She had gained weight with the illness. Some of her friends ignored her in the hallways. She felt awkward and shy and was often in pain, just struggling to get through the day. She had had to give up playing the violin and sports. At times, she said she felt invisible. Eventually she connected with her teachers and with other students in poetry club. That made a huge difference.

Frances considers herself to be lucky in her recovery, although she still has many symptoms. She now has about 75% of the energy of a healthy young person. She graduated from high school in five years and completed her junior year of college. With support and accommodations, she has stayed on track to graduate from college in four years. She recently completed a junior semester in Washington, D.C. doing an internship with a nonprofit disability organization.

For our family, unfortunately, that is not the end of the story. Both Frances' sister Katie and her brother Tim also developed CFIDS gradually over the last seven years.

Katie loved to sing and act. She had the lead role in several musicals until upper respiratory infections, laryngitis and daily headaches forced her to stop. During middle school when she first got sick, she went to the school nurse with headaches and viral symptoms. At first we thought she had a sinus infection and allergies. She would have appreciated the teachers being supportive while we figured out how to help her. Some teachers were punitive about her missing school. Katie rarely cried but she had tears in her eyes talking about one teacher who berated her in front of her classmates and told her if she went home early with a headache, she still needed to complete all her homework. Children with CFIDS are not faking illness to get out of school work. Katie was not only feeling ill, but was frightened because she knew how sick her sister was.

After two years at a parochial high school, she had to leave the school she loved and transfer to a public school that could provide accommodations. She, like Frances, graduated from high school in five years. In both cases, my husband and I educated nurses, teachers and administrators and advocated for our daughters. The guidance department at the public high school fully supported our family.

After completing a few college courses from home, Katie has had to take a medical leave of absence. Katie loves young children and has hopes of teaching kindergarten some day, but even occasional babysitting jobs exhaust her. Her muscles ache and her immune system is weak. She has developed multiple chemical sensitivities, gastritis and iron-deficiency anemia. She learned to drive but had to give it up because her dizziness made her feel unsafe on the roads. She is mostly homebound. She goes on brief outings and walks around the block. On the rare occasions now when we hear her singing, we are thrilled.

Tim just completed his junior year in high school and we are hopeful that he will graduate in four years. He has reduced his schedule to five classes from seven, been excused from physical education classes, and misses 2 and sometimes 3 days of school each week. He is largely teaching himself

advanced placement and honors classes. Except for his activities, scouting and band, Tim has little in the way of a social life. Most students do not understand why he misses so much school and do not include him when they make plans.

Often teachers and school administrators fail to understand what an effort a student with CFIDS is making because the student misses so often and when they see the student, he or she looks fine. When Tim misses classes regularly, he is often too ill to do work at home. He goes back feeling behind and then gets even more assignments. It makes it much more difficult for him to return to school after he has missed a few days. When Tim does go to school, he stays after school to make up quizzes, labs and tests.

At times, Tim chooses to go on a weekend scout trip that we know will leave him exhausted. We try to honor his choices and support his interests outside of school whenever we can. There are days when he is home from school but feels well enough to attend an evening band concert. Generally, schools prohibit students from doing evening activities if they have missed school. It is helpful if the 504 Plan or IEP states that students who are ill with CFIDS be allowed that privilege.

School nurses can make a huge difference to kids diagnosed with CFIDS by believing in them, allowing them a safe place to rest, and letting them go home as soon as they say they need to go home. The symptoms of CFIDS do overlap with the symptoms of other viral and psychiatric conditions but they form a pattern. Kids with CFIDS often complain of sore throat, headache, dizziness, muscle aches or exhaustion. They may take a long time to recover from ordinary viruses because their immune systems are weak. They may have one symptom really bothering them and then when that eases, another symptom crops up. They may end up seeing many different specialists – neurologists for headaches, cardiologists for hypotension, rheumatologists for aching joints. Each of my children presented differently but each had certain key defining symptoms of CFIDS.

They each developed hypotension, had post-activity exhaustion that could last several hours to several days, had headaches of a new type and had trouble falling and staying asleep. My kids never ran a fever. On two occasions, Tim had syncope from low blood pressure in school. One nurse checked his pulse, gave him orange juice and crackers, called me quickly and suggested he follow up with his doctor. One thought he had had a seizure and called an ambulance. Both times, the nurses were terrific.

Kids with CFIDS tend to have far more absences than kids with most other illnesses. If you see children or teens that fit this profile, please alert their parents, so they can have them evaluated for CFIDS.

After the doctors diagnosed my first daughter with CFIDS and I had shared that diagnosis with friends, some of them asked me repeatedly whether she had gotten a diagnosis. I think they did not understand or believe that CFIDS could be so severe. Unfortunately, many people use CFIDS and "chronic fatigue" interchangeably, when they are not the same. The name Chronic Fatigue Syndrome or even Chronic Fatigue and Immune Dysfunction Syndrome does not in any way reflect the severity of the illness.

I appreciate your interest in learning about pediatric CFIDS and am happy to answer any questions you may have. Thank you.