

*by Claire McGrath*

My son was 12 and had just come back from Trick-or-Treating with a group of kids. It was Halloween 2004. The night was balmy. He was not his usual chipper self but seemed removed and a bit disappointed. He said Trick-or-Treating was not the same this year. Was he getting older? Or did the group dynamics take a turn?

Grady went to bed. He slept for 2 weeks straight. He slept 14-16 hrs per day. He woke up each morning to pull himself out of bed, walk to the couch and fall asleep for another 6 hours.

Doctor's visits became a blur. It was a virus they said. It will pass. The third week they sent him for tests. He had blood tests and x-rays. The results were negative and they still said it would pass. They sent him for more tests. His sore throat worsened, his chills became uncontrollable. He had throbbing headaches, barely ate and seemed despondent most of the time. His thirst became uncontrollable. He had been out of school for a month. He quit the middle-school basketball team.

Soon specialist visits were recommended (ENT, immunologists etc.) and the consensus was gastro-esophageal reflux (GERD). Next came the endoscopy confirming the diagnosis. Medications began and we were hopeful for recovery. Nothing improved. Lyme disease, parvovirus, mono? More blood tests. All negative. Off to Children's Hospital, Boston to have our first discussion about "repeated viral syndrome"...another name for CFS/CFIDS/ME.

The winter ensued, Grady barely attended school. He would attend a few days and relapse for a week or two. The unpredictability of this disease was intolerable. Our family life deteriorated.

It was Mother's Day, 2005. My son Mitchell made his 1<sup>st</sup> communion and Grady and I came home from the church, packed the car and left for a 9-hour drive to Lyndonville, N.Y. We had the pleasure of meeting Dr. David Bell, a most compassionate doctor who confirmed the obvious: Grady had Chronic Fatigue Syndrome. We talked a long time and it was clear that Dr. Bell had devoted most of his life to pediatric CFS/CFIDS/ME patients. It was refreshing to speak to someone who could understand and relate to the symptoms. He understood the

psychological aspects of the disease and made suggestions for coping. He was hopeful but realistic and outlined a wealth of information on the research front. Being a scientist myself, it validated the disease for me. Although hating the diagnosis, I found a sense of relief in his diagnosis. It was time to forge ahead and start coping with the illness rather than swimming to survive.

Grady was out 120 days for the 2004-2005 school year. He made it to school only 60 days that year and still graduated to 8<sup>th</sup> grade. Working as a scientist during the day, I reserved my evenings for tutoring. I learned American History again and am pretty darn good in 7<sup>th</sup> grade algebra.

8<sup>th</sup> grade was better. I set up a 504 plan immediately at the school. This allowed me the opportunity to secure a school-paid tutor for 5 hrs/week and also the opportunity to educate the teachers, nurse and guidance counselors. I printed out literature and made myself available for questions and concerns. The teachers were very receptive and liaised with Grady's tutor. We coordinated a mid-year plan to drop him to half days that allowed him to complete all his core courses through careful scheduling. By spring, he was back to full days completing the school year with 34 absences, graduation to high school and a class trip to Washington D.C. for three nights. It was the highlight of the past two years!

Each school start is difficult and 9<sup>th</sup> grade was no exception. We have come to expect a rocky start. Having gotten through the beginning of the year, I can say that November was the worse. The shortened days and lack of sun in the Northeast during the fall season have often been problematic for Grady. Purchasing a SAD (seasonal affective disorder) light has made a world of difference. An exposure of 20 minutes/day has increased his overall energy.

Puberty has been the main obstacle this year. With the ever changing hormones that affect the body, CFS/CFIDS/ME can rage. Over the last three months, he has experienced great benefits from kinesiology. Kinesiology is the holistic study of applying muscle testing diagnostically and therapeutically to different aspects of health care. His health is improving daily and we are hopeful that recovery is on the way.

Teenagers with CFS/CFIDS/ME have a very unique set of coping problems. The lack of socialization due to multiple absences from school plays a huge part in their lives. Imagine how hard it is for a healthy teenager during the middle-high school years and then imagine a

teenager with CFS/CFIDS/ME. They feel isolated from their friends and also bombarded with questions. "Where have you been, why are you always sick?" The constant feeling of demoralization becomes all too familiar.

Work your hardest to build a social network for your child. Make your lives accepting to friends and family. Keep your door open and revolving to limit the isolation that can be so enveloping.

Control is another issue we struggle with daily. Due to lack of any control in his life, Grady believes that he can make all decisions pertaining to his life. Arguments persist about sleep-overs, late nights out, etc. Compromise is the key. Teenagers can not judge their illness. They will let their desire to spend time with their friends govern over all else. We can only hope that maturity will change this behavior.

I have learned many things since my visit with Dr. Bell two years ago.

- Make sleep the highest priority.
- Be your child's #1 advocate. You are all they have!
- Get a therapist for yourself and your child.
- Don't ever question your child's symptoms. Play the rating game and have them rate their discomfort 1-10. This will guide you with both physical and emotional expectations.
- Relapses cause reactive depression not "real " depression.
- Try EVERYTHING—from massage to SAD lamps to vitamin supplements to kinesiology. Everyone is different and many have found relief in holistic measures.
- Replace activities they can't perform. If your child can't play sports, they can coach. If they can't have a part-time job, give them jobs at home.

Few understand CFS/CFIDS/ME and even fewer have experienced it. Educate the public. Allow them to understand the disease and accommodate the individual.

I tell Grady every day that this experience has made him into a special person. He has learned compassion, empathy and a power within that will fuel his life with success!