

*by Mary Robinson*

The Massachusetts CFIDS/ME & FM Association Summer 2000 *UPDATE*

As I was reading Dr. David Bell's article on the blood volume studies, my mind went back to 3 years ago and the role my son played in this path that our research has taken. My then 13-year-old son was in the 7th grade and had been very ill with the Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFIDS/ME) for over 3 years. We had tried so many treatments but he just seemed to continue to go down-hill. Dr. Bell was concerned over the fact that my son's ADH level was very low or nonexistent. He called Dr. Peter Rowe to see what ideas he had at the time. Dr. Bell had been very interested in Dr. Rowe's findings involving neurally mediated hypotension (NMH) and florinef treatment. So I was thrilled to have him seeking out his advice concerning my son's treatment.

Dr. Rowe sent Dr. Bell to an endocrinologist who was closer to our area, Syracuse, NY; who had been doing some fascinating work with Orthostatic Intolerance. The doctor's name was Dr. David Streeten, and Dr. Bell had never heard of him. He phoned him on behalf of our son and was intrigued by the work that Dr. Streeten was undertaking, especially the ability to measure a person's blood volume. Well the rest is history. Dr. Bell was so intrigued by the findings of my son's tests that he immediately began choosing others to meet Dr. Streeten and soon Dr. Bell was collaborating on these studies. So what happened to our son, who was so ill that Feb. of 1997?

He is doing remarkably well!! Should I call it remission or recovery? I do not know, because with CFIDS/ME there is little that is known and a lot that is unknown. In Dr. Bell's mind it is recovery, and lately I too am leaning in that direction. Following our trip to Syracuse we decided to give florinef and salt another try. It took 6 months to really see an improvement, and we couldn't believe it when it happened. In the beginning of 8th grade he was able to attend 3/4 of the day at school (up from 1 hour at most in 7th grade.) As the fall progressed we waited as we did every fall for the crash. BUT it didn't come. He dropped back to attending school for only a half day due to a decline in his health, but not a real crash. He had his ups and downs and by spring was up to almost full-days. He was never as sick as he had been the previous year. We were elated!

By the spring of 8th grade he was contemplating trying out for the summer baseball team. I was scared. What if it sent him into a spiral downhill? With Dr. Bell's encouragement I relented and he tried out, and made the team. And he gave it 110% and did great. Not only did he play, he was a starter as a first baseman! The following fall he would enter 9th grade—High School! We were so worried that he wouldn't be able to handle the extra pressure, and the classwork. But he wanted to try. He wanted to just start out with a full day, something he had not attempted in years. I could-n't imagine that he could be up by 6 AM each day and attend for an entire day. But we had to let him try, it was his life. And we did.

That was 1 1/2 years ago, and, he was right. Aside from a few minor setbacks last year, never lasting more than 3-4 days, he has remained healthy and symptom free. Last year there were times I worried, times he would have a brief recurrence and be down and out. But on the evening of the 2nd to 3rd day he would pop up, get his homework done and be back to school. We noticed a cycle in 9th grade of this occurring every 3-4 weeks, but he ALWAYS bounced back stronger than ever. He made the JV baseball squad last year, and played ball all summer as a starter.

By the beginning of 10th grade he was ready to go off all his medicines. That meant no more florinef. I was scared to death. I knew that Dr. Bell supported this path, but had offered only respect of my fears of this decision. We again let him follow his heart, and since last August he has been off all medicines. He has had NO setbacks. He got the flu for 3 days in Dec. but it was really the flu—the normal one that you actually recover from and are back to normal after 3 days. He got a bad strep infection last month and I thought, "this is it!" Even Dr. Bell was expecting a bit of a setback, but it didn't happen. He recovered as fast or faster than any other healthy teen. And he is back to a heavy baseball practice schedule.

And academically? He is one of the tops in his class! This boy who had dropped to under grade level in math and reading in the 6th grade, is now back at his peak in 10th grade and scoring ahead of his classmates in these same areas. His teachers praise his efforts and his attitude. And he beams with the ease that he seems to manage these accomplishments. Socially he has many friends, and talents. He is still shy, and always will be, but he is trying new things and has a self-confidence that I don't see in most of his friends. *He has battled the dragon and won.*

I have been getting a lot of calls from parents of children with CFIDS/ME lately. While I share their feelings of parenting a child with CFIDS/ME, as I am still in the trenches with my 9-year-old's battle with this illness, I also offer them hope by sharing the story of my son's "recovery." I still get goosebumps when I say that word, *recovery*. And maybe it is the other "R" word, remission. Either way, our boy, our oldest child who was struck severely ill after a

tonsillectomy and chicken pox in 4th grade is healthy. Recovery—Remission—does it really matter what we call it? I will never stop worrying about him when he gets a sore throat or a stomachache. I will always pray when he seems more tired than usual, or a headache isn't abated with the usual Tylenol. And I will pray that he never has to tell me that he is crashing. But if I do get that call, I will thank God for every day he has had of blessed good health.

My hope, my prayer for all of our children is a recovery/remission like our son's. May they all have their day when the world is once again theirs to rule!

*Permission was granted to reprint this article from the newsletter by Dr. David Bell 'The Lyndonville News.'*

*This newsletter,*

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*joint effort of Dr. Bell, Jean Pollard, and Mary Robinson, is written for people with CFS/CFIDS/ME, or who have an interest in CFS/CFIDS/ME. Issues cover current research and theories, politics and ramblings, living with CFS/CFIDS/ME and dealing with parenting a child with CFS/CFIDS/ME.*