

Testimony
Denise, Alexander and Matthew

15 Sept. 2010/CFSAC Testimony

Thank you for this opportunity.

We are very glad that the CFSAC charter has been renewed and that this second meeting of 2010 is more than a single day in length. Thank you for listening to everyone's input about this.

Please publish the agenda at the time of meeting announcements in order for people to be better able to plan to attend.

It would be very helpful to have more than one-month's notice about the date of meetings so that patients can allocate energy to make the trip and be able to make travel arrangements at reasonable prices.

Please give at least a month to prepare testimony. It takes a lot of time to filter things through brain fog, energy to put things in writing, etc.

Today, I would like to garner more attention for quality of life.

The following is from my 17-year-old son Matthew:

"The horrible thing is, I'm not sure how devastating this illness really is. I've been sick for so long (over 5 and one half years), that I don't know what normality feels like. But I'll try.

I used to swim 4 times a week, 5 miles each time.

Now I can get my heart rate over 160 beats per minute by running in place for 30 seconds. I am NOT deconditioned, I do aerobic and strength conditioning three times a week and stretching every day.

I used to be a straight A student.

Now I can barely concentrate for 20 minutes in a day (no more than 3 times a week). After that, it gets exponentially more difficult and exhausting.

I used to have a typical, active life.

Now my daily life is impossible to plan in advance, because there are days when getting out of bed seems beyond absurd.

Lesser illnesses are as common dirt to me. Every other week, sometimes more often, I come down with some petty cold or other infection that, on its own, would barely be noticeable, but now it wipes me out - even more than I am already wiped out."

This is from my 19-year-old son, Alexander: "I taught myself to read at the age of 4.

At the age of six, I was reading computer-troubleshooting magazines.

Now, I read and reread things to try to ensure that I understand them.

I used to be able to remember where I had last seen a book, a game, a drink...

Now, if I set my water bottle down close to the sink to wash my hands, I often walk away, having totally forgotten that I wanted to take a drink back upstairs with me.

I used to empty and fill the dishwasher, change the sheets on my bed, put away my clothes, as some of my responsibilities.

Now, each of these activities triggers tachycardia (POTS episodes). For a long time I thought it was normal to have to crouch down in the shower, and then lay on the floor after a shower, because of a pounding, rapid heartbeat that exhausts me and leaves my brain even more fogged. I used to attend school fulltime, participate in theatre and swim competitively. Now, I am housebound. I can leave the house no more than twice a week for physical therapy (Yes. That's right, I cannot go as often as my brother can) without overwhelming payback afterwards.

I **want** to be more active.

I **want** to be able to hang out with people.

I **want** to be able to go to school.

I **want** to be MYSELF again.”

From me:

Flexibility and patience are 2 things I have long needed to improve in myself. I am learning these skills, but working on these skills because of my childrens' illnesses is NOT a way I want ANYONE to have to do it.

These are a few of the accommodations we make because of Matthew's illness:

In order not to be in extreme pain when he rides in the car (all of his joints and muscles hurt) Matthew has 3 pillows in the car. One under him, one next to him (buffering him from the side of the car) and one behind him. We try to let him have the back seat all to himself so that he can lay down as much as possible, especially on long rides.

We are careful to keep sound levels low especially while he is trying to sleep. Remember, my sons are teenagers --- and we have to keep things QUIET????

As unrefreshing as his sleep is, his own bed is preferable to any other. Vacations exact a huge toll, because when he is away, his sleep is even worse than at home.

Matthew takes his conditioning very seriously. Conditioning is one of the few things he CAN do to help himself. Because of the toll it exacts upon him, he doesn't go anywhere other than physical therapy. If we have to go somewhere else, he has a huge payback lasting weeks. Following conversations when multiple people are talking is almost impossible and increases his headache and fatigue.

Standing upright and talking leads to increased fatigue and makes following conversations very difficult. I let him pace or fidget as much as he needs to. This also leads to increased fatigue but enables him to have a slightly longer conversation.

I am on alert 24/7: to stand up for my children when people – family, friends and others - don't believe they are ill;

to explain, repeatedly,

how impaired my children are;

that cognitive efforts fatigue them as much as physical efforts;

that they cannot carry on extended conversations because they lose track of the conversation;

that talking hurts all day, every day and on and on.

Don't get me started on what I think of people who don't know me, deciding, based on what others tell them, that I am working to keep my children sick. Though, if I am that good at

manipulating other people into doing what I want, why have I not extended this to the rest of my life and become super-rich?

The first time I met a group of parents of kids with ME/CFIDS I was stunned at the difference in my energy level. In talking with people who understand, I could relax and enjoy at a different level than in my typical life. Not having to be on alert meant that each of us could more fully enjoy ourselves.

Most of us know the phrase: “What if they gave a war and nobody came?”

I propose the following phrase: “What if we gave a CFIDS support meeting and nobody came?” – because there was no longer a need to do so.

Help us (patients, caregivers, family, friends) **get back the lives we deserve.**

With appropriate research and appropriate treatments we **can make** this a reality.

Let's do so!

Thank you!

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