

By Mary Z. Robinson

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

As we crawl out from under our warm winter blankets and begin to dream of sunny spring days and flowers promising to bloom, why would we want to devote our energy to next year's school issues? When you may have just managed to get this year going the way you want it to, you may be asking yourself, "Why waste my energy now thinking about what might happen next fall? My child may be much healthier by then and not need any extra accommodations."

Many parents probably feel this way, especially if they have spent this past year striving to get their child the services they need to succeed in school. I admit that I am one of those parents. We have just recently been able to secure for our third grader, a young person with CFIDS (YPWC), services under the educational plan that will best meet her needs now and in the future. It was an uphill struggle to convince the school that her academic needs could be better met under an IEP plan than under her 504 plan. (I will not go into all of the details of these two educational options in this article. But if you have questions on what your child's options are, please refer to the references at the end of this article.

One thing my husband and I like to do each spring is to look ahead to the coming school year with a best-case/worst-case scenario in mind. This is the time of year when the school personnel are making up class lists and schedules for the coming year. It is far easier to honor a request for a specific teacher or teachers at this time of year, rather than to try to rearrange things in the fall. Let me give you an idea of how we did this when our son was in middle school.

First we looked at all of the subjects that he would be required to take and the possible electives for the coming year. We then looked at the master schedule that the school had planned for the coming year. We felt that the most important classes he would need would be science and math, followed by English and social studies. We then considered his "best" time—for consistent attendance—which was after 10 AM. With all this in mind we built the following tentative schedule:

We began with his minimum of one class at school to a maximum full schedule. Because his most important classes (math, science) were scheduled for his optimum time, he was able to get in for at least one of them all year. During his good months he was able to make it from English through social studies. Sometimes I would bring him home for lunch, other times he stayed at school.

The second year we did this we were able to arrange a full schedule for him, and he tolerated it for the first 10 weeks before we had to go to a shortened day. This plan of outlining options in the spring, along with teachers who are the most accommodating, really has helped both of our children to be successful. When we first asked to talk to the counselor about this, we explained that we knew all our requests could not be guaranteed, but we just wanted to have an opportunity to voice our ideas. If the school personnel feel that you have faith in them to do the best that they can for your child, and that you are coming in only to share ideas, they may be more willing to listen and to brainstorm solutions with you.

When you take the time at this point in the year, to start thinking ahead, you can share your ideas with the school about possible scheduling arrangements for the fall. Ideally, you can get an accommodation Plan in place and relax a bit in the months to come. (This may help to ease your mind that things are as set as they can be for the next school year, and you can enjoy your summer vacation!) Near the end of the summer we contact the school again to let them know how our children are doing, and what to expect from them when the year begins. Sometimes they plan to start out with full days, and other times an amended day is needed right off. This is a good time to share any notes from your child's doctor on any needed accommodations, such as a shortened day, home tutoring, or dealing with physical-education requirements.

I realize that the ideas outlined here may not work for all of you. I would love to hear new ideas and solutions that you have found to be successful. It is our hope to discuss the options surrounding home schooling in a future issue of *The Lyndonville News*.

For more information on these educational programs and your child's right to a free and appropriate public education, start with the references below.

Book: *A Parents Guide to CFIDS: Being an Advocate for Your Child with Chronic Fatigue Syndrome*, by Bell, Robinson, Pollard, Robinson, Floyd. Haworth Press, 1999.

The Web:

1. *NICHCY*—National Information Center for Children and Youth with Disabilities:
www.nichcy.org
2. *Education—National Clearinghouse for People with Disabilities Pursuing Education or Training After High School* : www.acenet.edu
3. *Wrights Law*—A great informational website that also publishes a free online newsletter on special-ed laws: www.wrightslaw.com

There are numerous other websites and resources you will find useful, but the above will provide a good start.

Mary Z. Robinson, parent of two YPWCs, works with Dr. David Bell. This article was reprinted by permission of The Lyndonville News, where it first appeared. The newsletter, which is a joint effort of Dr. Bell, Jean Pollard, and Robinson, is written for people with CFIDS or an interest in CFIDS. Topics include current research and theories, and issues dealing with parenting PWCs. Subscriptions are available both by email and snailmail.