

Dear Members of the CFSAC:

My name is Barbara Soliday and I live in Miami, Florida. My daughter has been seriously ill with CFS since 1998 and I have been active in support and advocacy groups since that time.

First, let me thank you for your service on this committee. Everyone in the CFS advocacy community benefits from the work you do. My comments and recommendations below are similar to ones that I sent to the CDC in May. I am sending this on to you so that your committee will know my view on one of the most important issues in CFS.

One of my major concerns is provider education. Even if no new research is done, general practitioners can learn to diagnose and treat many of the symptoms of CFS. Although the medical providers will not be able to cure the condition, they will be able to relieve a lot of the suffering and help their patients function better in their daily lives. Here are a few examples of currently available treatments, based on my daughter's experience:

1. Dizziness: Doctors can send the patient to a cardiologist for a tilt table test. If the patient has neurally mediated hypotension (which is common in CFS), some common medications can make a huge difference, along with advice about managing activities of daily living.

2. Digestive problems: These can often be improved with an antibiotic followed by regular use of probiotics (available in grocery stores), and with dietary adjustments.

3. Fatigue: A sleep study may indicate the need for a CPAP machine, along with sleep behavior modifications. An important consideration would be to avoid use of certain sleep medications which can make the CFS condition worse.

4. Pain: This can be reduced with various medications along with certain stretching techniques. General practitioners already provide many of these treatments routinely; they just are not used to seeing so many problems in one patient, so CFS patients look very complicated. Complicated, however, is not the same as untreatable. Physicians can learn to help these patients by using familiar treatments, if the physicians can obtain protocols along with background information about CFS. Physicians look to the CDC for information and guidance about unusual conditions. The CDC is in a position to provide this guidance about diagnosis and currently available treatments, right now, without waiting for further research. The CDC should aid physicians and their patients by making this information available immediately. Thank you for your interest in CFS, and for listening to my thoughts about the problems patients have with finding treatment this devastating condition.

Yours truly,
Barbara Soliday