

Massachusetts CFIDS/ME and FM Association presentation to the Institute of Medicine Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

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by Charmian Proskauer, President

Good afternoon, and thank you for inviting me to speak, and thank you for taking on this awesome responsibility. My name is Charmian Proskauer and I am president of the Massachusetts CFIDS/ME & FM Association. I am also a member of the Let's Get It Right group. My written comments are more complete than these brief remarks and also include references to back up my statements.

I am here to speak on behalf of children and adolescents with this illness.

Children and Adolescents are an important group to consider separately (not merely as a “sub-group” of the adult illness).

For the last two years our Association been working to educate school nurses about ME/CFS in children and adolescents. School nurses can serve as gatekeepers to help identify ill children who may have ME/CFS and give information and support to their families and to the school.

There are several conditions that would alert a school nurse (or an informed pediatrician) to the possibility of an ME/CFS diagnosis.

- The clinical presentation, while variable, fits into patterns that are described by the existing case definition for pediatric ME/CFS.
- The illness often follows mononucleosis — 13% of mono cases develop into ME/CFS.
- As in adult ME/CFS, symptoms can wax and wane. A child who arrives at school and seems OK may need to go home by lunchtime. A pattern of variable symptoms over time may be an indication of ME/CFS.
- ME/CFS is the most frequent cause of prolonged absence from school, and it is this prolonged absence that often leads school officials down the wrong path of falsely labeling ill

children with “school phobia” or taking the parents to court for Medical Child Abuse. *Children with ME/CFS want to go to school — and will tell you that if you ask them!*

A separate clinical definition for pediatric ME/CFS has been developed and should be added to the list of clinical definitions that you consider in your study.

- The adult definition is not appropriate for children and youth, as the initial presentation of symptoms may be quite different from that of adults. Also it may not be appropriate to ask an ill child to wait until the symptoms have persisted for 6 months (most of a school year) before receiving a diagnosis which will allow helpful management and treatments to be put in place.

- While the onset, symptoms and course of the illness in youth can be quite different from that in adults, as in adults the symptoms vary in nature and intensity on any given day. This variability can cause providers and others uninformed about the illness to believe the symptoms are psychological.

- Also as in adults, the illness is usually prolonged, lasting from several years to 10 or more. When a child changes schools, often the process of educating school officials has to start all over again.

- The range of issues needing to be dealt with is also different — important aspects for a child include educational needs and social development as well as physical health. Addressing these issues involves the school, the family, and the community as well as providers of health care.

Families with a chronically ill child already face many challenges. Caring for an ill child who does not have a recognized diagnosis, or with a diagnosis that family, friends, and school officials do not understand, is especially difficult. Without a diagnosis, the more severely ill a child is, the more likely the family will be under pressure from the school and the threat of legal action against them.

Pediatricians, at least in our state, have little knowledge of ME/CFS. When a school nurse recognizes a child with symptoms suggestive of ME/CFS, it is usually very difficult or impossible to find a pediatrician who can make the diagnosis which would allow the child to receive needed educational accommodations and begin appropriate treatment. Lacking a correct diagnosis, there is a significant risk, especially in the case of a severely ill child, that an incorrect diagnosis of Medical Child Abuse or Munchausen syndrome by proxy may be given, and the situation may escalate to the point where the child could be removed from the home or legally required to undergo an inappropriate treatment.

On the positive side, outcomes for youth, if good information, treatments, and social and educational support are provided promptly, seem to be better than outcomes for adults. However it should be noted that these studies do not include the most severely ill children, so we do not know the outcomes for them.

In summary:

- **We urge this committee to give pediatric ME/CFS sufficient attention during your review.**
- **You should add the existing clinical definition for Pediatric ME/CFS to your scope of study.**
- **Your plan to educate physicians should explicitly address pediatricians and school nurses, as well as the providers of adult care. Pediatricians need to be confident in diagnosing this illness as a physical, not psychological, one.**

Please do not defer this; great harm is done every day to children and families due to this lack of knowledge.

I would like to thank the NJ Chronic Fatigue Syndrome Association for their pioneering work with children and youth, and to the patient associations in NJ and CT for setting the model for providing support to children with ME/CFS and their families.

I now share **three brief but very important points concerning your review of the research literature**

1) Reviewers need to **focus carefully on the case definition used to select patients for the study**, since this greatly influences the results of the study. A study group that is overly broad or heterogeneous will lead researchers to incorrect conclusions.

2) In any research which discusses psychiatric symptoms (such as depression) in the study group, a careful **distinction must be made between pre-existing and post-illness manifestations** of the condition. Depression **following the onset of ME/CFS**

often occurs, as it does in many chronic illnesses. Any paper which does not clearly make this distinction is suspect and should be disregarded. Such flawed “research” is responsible for much of the misinformation about ME/CFS being a psychiatric illness not a medical illness, leading to recommendations of psychiatric care as the primary treatment instead of attempts to treat the underlying medical condition.

3) In closing I want to point out that over the years at least some mainstream journals have refused to even consider publishing papers on ME/CFS, regardless of their merit. This has forced ME/CFS researchers to sometimes seek less traditional avenues to publish their work, especially in years past. **Please do not overlook these contributions just because they do not appear in the journals you may usually read.**

Thank you.