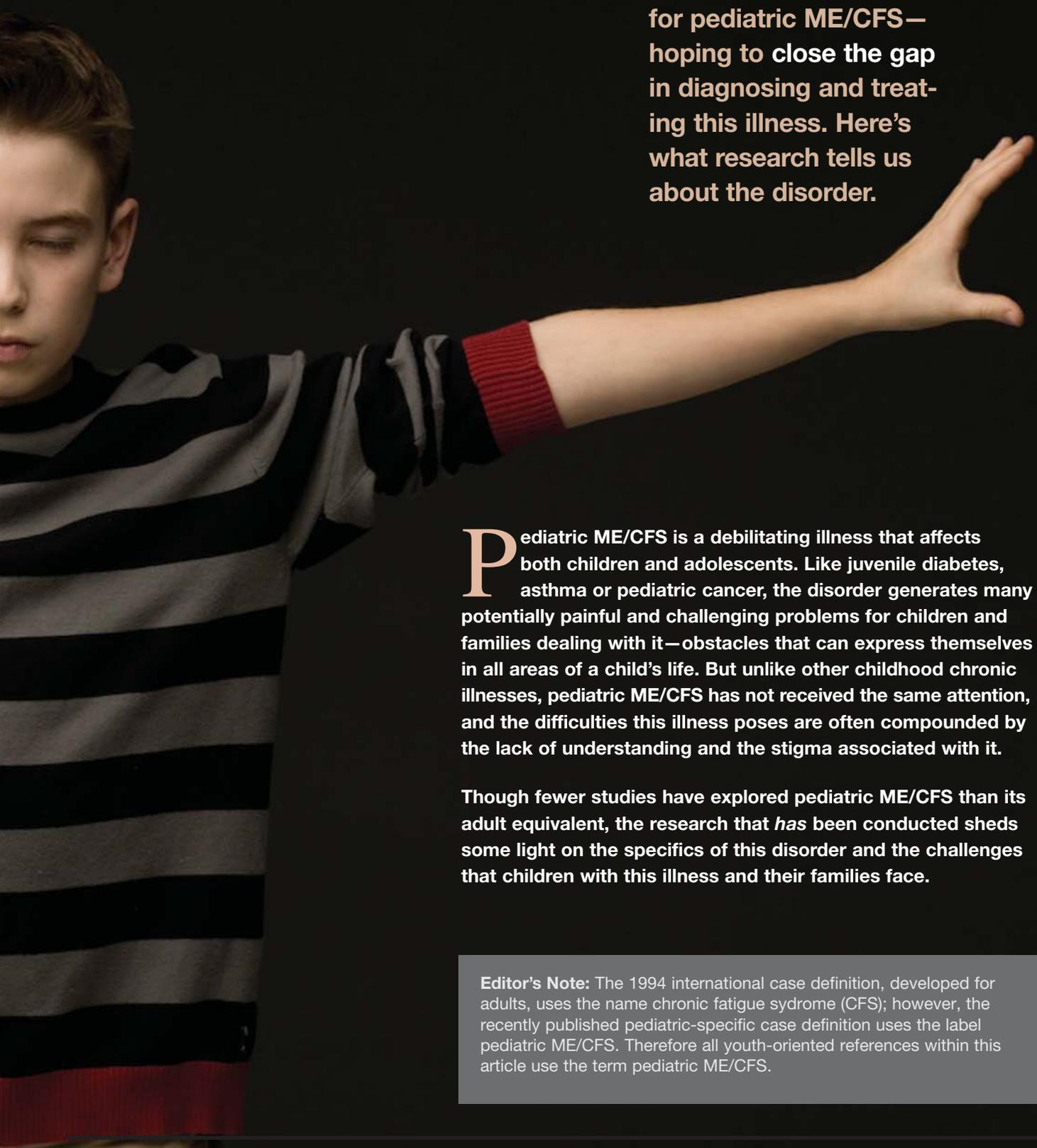


Childhood CFS

BY LEONARD JASON, PhD AND NICOLE PORTER, PhD

An international group of researchers and clinicians just published the first case definition for pediatric ME/CFS—hoping to close the gap in diagnosing and treating this illness. Here's what research tells us about the disorder.



Pediatric ME/CFS is a debilitating illness that affects both children and adolescents. Like juvenile diabetes, asthma or pediatric cancer, the disorder generates many potentially painful and challenging problems for children and families dealing with it—obstacles that can express themselves in all areas of a child's life. But unlike other childhood chronic illnesses, pediatric ME/CFS has not received the same attention, and the difficulties this illness poses are often compounded by the lack of understanding and the stigma associated with it.

Though fewer studies have explored pediatric ME/CFS than its adult equivalent, the research that *has* been conducted sheds some light on the specifics of this disorder and the challenges that children with this illness and their families face.

Editor's Note: The 1994 international case definition, developed for adults, uses the name chronic fatigue syndrome (CFS); however, the recently published pediatric-specific case definition uses the label pediatric ME/CFS. Therefore all youth-oriented references within this article use the term pediatric ME/CFS.

“This illness is so frustrating because it’s so unpredictable. I can have an up day where I can do almost as much as anyone else, but the next day I may not get to do something I was really looking forward to because I can barely move. It’s stressful.”

- Brian Bernard, 13-year-old CFS patient and spokesperson



Challenges stretch beyond the physical

Pediatric ME/CFS is a serious and debilitating physical illness for many youth. Studies have shown it to be the most common cause of prolonged medical leave from school among adolescents, often profoundly impacting a child’s academic performance. Research indicates that only 14% of adolescents with pediatric ME/CFS continue to attend school regularly after the onset of the illness, and a third of adolescents with the illness experience severe activity restrictions and marked drops in school achievement. Researchers have reported that in some samples, students miss an average of 80 days in a six-month period. Other studies estimate an even greater effect on activity and achievement, with 55% of youngsters suffering a decline in academic performance and 80% experiencing a major reduction in extracurricular activities. This, at a time when learning and social interaction are a core element of social development and self esteem.

These issues touch on one primary way that pediatric ME/CFS *does* differ dramatically from other chronic juvenile illnesses. Due to the lack of understanding and the long absence of a clear, pediatric-specific case definition for the illness, under-diagnosis or medical misunderstanding can lead to long-term developmental impediments not directly related to the physiological disorder.

For example, without a clearly defined medical explanation for frequent absences and academic challenges, the skepticism, marginalization and punitive measures taken by many school districts and local judicial systems have caused

additional problems for many families already dealing with the immediate difficulties associated with this illness. Disturbingly, these diagnostic problems sometimes lead to juvenile truancy charges and even allegations of parental abuse and neglect. This makes the misdiagnosis and under-diagnosing of pediatric ME/CFS a critical issue—forcing a family to negotiate the continuous compromises to the child’s physical health, while also struggling against a system that doesn’t understand and validate the illness and special issues the child faces.

“Right now, adequate medical care for pediatric ME/CFS is about identifying and treating the symptoms—but they are very important symptoms to treat.”

- Dr. David Bell, renowned CFS clinician (quoted from a pediatric ME/CFS discussion at the IACFS/ME patient conference, January 2007)

MISUNDERSTOOD

Historically, misinformed physicians have sometimes incorrectly concluded that pediatric ME/CFS is a physical manifestation of family dysfunction. Some physicians have even gone so far as to suggest that a child’s symptoms are merely a technique utilized for personal gain, to cope with normal developmental issues or to deal with family problems. Research tells a different story.

Group comparison studies indicate that family functioning and marital problems are no more prevalent in families dealing with this illness than other chronic illnesses, or even physically well populations. Indeed, research has found no differences between families of adolescents with pediatric ME/CFS and those with cancer or families not dealing with any chronic illness.

Considering the potential stress of negotiating the many physical, economic and relational challenges associated with pediatric ME/CFS, these findings are especially telling.

This is just one of many reasons the health care community needs more and better information about the specifics of pediatric ME/CFS.

A pressing health issue

Pediatric ME/CFS is prevalent enough to cause serious concern. A 2004 study found that “CFS-like illness”—characterized by prolonged fatigue accompanied by fever, decreased endurance with exertion and pain—occurs at a rate of 4.4% among adolescents seen in primary care settings. Our own study in 2006 found the prevalence of pediatric ME/CFS among the general adolescent population to be about .18%. If accurate, that makes pediatric ME/CFS a pressing matter expressing itself in 1.8 out of each 1,000

American children. In fact, according to these rates, it’s among the most prevalent debilitating chronic childhood illnesses in the Western world—more widespread than sickle cell anemia (1:3573), pediatric heart disease (1:1000) and Down’s syndrome (1:1000).

Significant symptoms, disrupted lives

Research shows that children with this illness experience some unique symptoms as compared with adults. For example, symptoms like rashes and abdominal pain are more frequent in pediatric ME/CFS. It’s also possible that the illness expresses itself differently in different children. Some children may primarily express debilitating fatigue and serious cognitive problems, while others will experience severe joint and muscle pain and weakness but limited cognitive impairment.

Nonetheless, some symptoms are common to most children with the illness and consistent with their adult counterparts. In addition to debilitating fatigue, the three most common complaints in children with pediatric ME/CFS are headaches, sleep disturbance and cognitive difficulties.

Far from being depressed or lazy, researchers describe the usual pediatric ME/CFS patient as being previously athletic and ambitious, high-achieving teenagers. In fact, one of the clear distinctions between school phobia—a common misdiagnosis—and pediatric ME/CFS is that once a child with school phobia is allowed to remain home, symptoms usually disappear, and there are generally no complaints during school breaks. Children with pediatric ME/CFS experience symptoms regardless of their surroundings and are often unable to maintain their normal

extracurricular activity levels. They *want* to participate in school and other activities, but often they physically cannot.

While some clinic and community samples have found that more females than males have the illness, other adolescent studies have indicated similar rates for both males and females, suggesting it's an "equal opportunity" childhood illness.

A new case definition offers hope

Fortunately an opportunity has emerged to improve some of the problems in diagnosing and validating pediatric ME/CFS. This past winter, the *Journal of Chronic Fatigue Syndrome* published an article that for the first time pro-

vides a case definition for pediatric ME/CFS—developed by an international group of researchers and clinicians under the auspices of the International Association of CFS/ME (IACFS/ME). This international group also developed an instrument to assess symptoms, and this instrument is currently being used in an international study of the illness.

According to the pediatric case definition, a child must have experienced three months of clinically evaluated, unexplained fatigue, and exhibit the following five classic symptom categories. Each must be present for a diagnosis of pediatric ME/CFS:

- postexertional malaise
- unrefreshing sleep or sleep disturbance

"DOWN" BUT NOT OUT

Brian Bernard went from being a healthy, active kid on April 6, 2005, to a sick one with severe flu-like symptoms the next day. In fact, for the first time ever the school nurse had to call his mom to come pick him up because he was too ill to make it through the day. Two weeks later he was still sick, with a profound exhaustion that left him worried.

"My body felt like it was glued to the bed," Brian explains. "It was like something sucked the energy right out of me." He also had difficulty sleeping, a sore throat, severe headaches, cognitive impairment, postexertional malaise and orthostatic intolerance.

Three visits to his pediatrician didn't help. She suggested Brian might have allergies or was exhibiting school avoidance. Next, she discussed depression with Brian and his parents.

Brian knew better. "It made me frustrated. I *like* school. I had a 4.0 GPA. I played on the regional soccer team. . . I knew I wasn't avoiding school, and I wasn't depressed."

Fortunately for Brian, his parents are both physicians, and they soon decided to seek help elsewhere. The family visited three top CFS experts who've helped treat Brian's symptoms. He also learned how to deal with the social challenges of the illness by being frank with friends and teammates about his limitations. Now his symptoms are more manageable, and his friends are learning that on what Brian calls his "down" days, going outside to play is not a possibility. Instead they might watch TV.

Brian says he's not scared he won't recover. But he knows that a lot more progress and understanding is needed to make life better for the many kids with pediatric ME/CFS. That's why he decided to share his story as a national spokesperson for the illness. In a recent *New Jersey Star-Ledger* story that was picked up by papers in at least six states, Brian explains it this way, "It's like the ancient Greeks. They didn't understand lightning, but that doesn't mean it didn't exist."

In "Living with CFS" (page 32) read excerpts from a mother's account of her family's journey with her son's illness. Her full memoir is available online at www.cfids.org/bonus/motherstory.pdf



- widespread or migratory myofacial, joint, abdominal or head pain
- two or more neurocognitive manifestations such as impaired memory, difficulty focusing or slowness of thought
- at least one symptom from two of three subcategories: autonomic problems, neuroendocrine problems and immune problems.

The case definition also designates a classification of “atypical ME/CFS” for children who meet certain, but not all, of the diagnostic criteria.

This new case definition and assessment instrument will facilitate future research on pediatric ME/CFS and will assist in the identification of subtypes. They’ll also facilitate long-term investigations into outcomes of the illness, helping to identify risk factors which may predict prognosis—perhaps even leading to higher risk children receiving earlier intervention.

What’s more, this new case definition can be referenced by pediatricians, legislators, researchers, school nurses and even teachers and staff responsible for developing and implementing education plans. In addition to the diagnostic and educational benefits, the criteria can also be useful to the families dealing with the illness, providing a mechanism to lend legitimacy to the child’s symptoms.

No child, family or community is immune to the problems associated with pediatric ME/CFS. But accurate and early identification of the illness, followed by comprehensive support and treatment, may very well increase recovery rates for all children and adolescents with this debilitating disorder. ■

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MISDIAGNOSED

The long absence of a consistent pediatric case definition and a reliable instrument to assess symptoms has led many children with pediatric CFS to be misdiagnosed with other illnesses. Inaccurately diagnosed with school phobia, allergies or any number of physical and psychological disorders, the child and family are often left without proper validation and treatment.

The lack of such instruments has also led physicians to overdiagnose the disorder as “an unexplained illness.” Aside from providing weak support for families’ efforts to gain special school accommodations for their child, this diagnostic “dumping” can cause researchers to inaccurately label children with a wide variety of symptoms as having pediatric ME/CFS, as well as possibly missing children who *do* have it. This can only lead to confusion in the research field.

With the recent release of a pediatric-specific case definition and assessment instrument, physicians, researchers and families now have a more definitive, reliable tool to employ.

“Perhaps the greatest impact of this illness is the inability of the child to engage in normal activities of adolescence that help with the healthy transition to adult life.”

- Dr. Peter Rowe, Johns Hopkins Children’s Center (quoted in an interview on the importance of pediatric CFS research and care, September 2005)

Online Bonus: Download a FREE copy of the pediatric ME/CFS assessment instrument, the DePaul Pediatric Health Questionnaire, for your physician. Visit www.cfids.org/bonus/pediatrictool.asp.