Reprinted form NJCFSA Newsletter, The Journal, Spring/Summer 2006

Educating the Child with CFS

***Shanon McQuown** is a Special Education Coach and the author of "Harnessing the Wind: Chronic Fatigue Syndrome and My Son."*

Shanon McQuown is a person who doesn't let any obstacles stand in her way. A special education coach and paraprofessional, Shanon is the mother of a young man with CFIDS and has herself battled rheumatoid arthritis and lupus. Although a person with vast experience and expertise in dealing with children with CFIDS, Shanon says her most important qualification is her "MOM" degree – she is an "expert in Anthonyology" (Anthony is her son).

Shanon has been a member of the Special Education Advisory Committee in her county in Virginia for three years and is a paid School Consultant appointed by the Superintendent. She is also the author of "Harnessing The Wind," a book she describes as "the easiest way to reach the most people with what I have learned and to provide strategies to help parents." The title comes from her frequent use of nautical terms (e.g. we never know what the wind is going to do, which way it is going to blow).

In her role as a Special Education Coach, Shannon empowers parents to advocate for their children. As a member of the organization "Partners in Policy-Making," she has learned all aspects of special education law and has worked with children with mild mental retardation, autism, and learning disabilities. Ironically, she received this education and experience before she knew that she would have to advocate for her own child.

Prior to her education, Shanon had heard that CFIDS affects only "affluent Caucasian women" and wondered how something that "sounded so benign ('yuppie flu') could be doing all these things to her son". When Anthony was diagnosed, Shanon was prepared. Because of her background, no one was going to convince her that he was just having "growing pains." (She had also been told that about herself until her lupus diagnosis at age 24.)

Since children are legally required to go to school no matter how bad they feel, parents who allow their kids not to attend may be subject to intervention by organizations such as Child Protective Services. Shanon's presentation focused on how parents and physicians can prevail upon school systems to provide children with CFIDS the tools to enable them to receive the education to which they are entitled by law.

What Can Parents/Physicians Do To Help

- understand how CFIDS impacts a child's education
- become familiar with available accommodations, modifications, adaptations, resources
- when writing to school officials, learn how to write letters that are specific to the child's needs

Ways In Which Children Are Affected

- fatigue
- muscular/joint pain
- cognitive disturbances
- visual, auditory and digestive disturbances
- sensory sensitivities
- immune dysfunction

(When explaining CFIDS, symptoms may be better understood if they are related to more well-known diseases such as heart problems, autism, HIV.)

How Symptoms Are Manifested in Educational Settings

Fatigue: lays head on desk - falls asleep in class - often late and absent

Accommodations for Fatigue

- scheduled rest breaks
- modified physical education
- part-time school-based education
- half-day school-based education
- homebound education

(Affected students have the same right to elective courses such as: music and art, as well as social events in which they are able to participate.)

Muscle/Joint Pain: difficulty sitting still - often absent - difficulty participating in P.E. - difficulty writing

Accommodations for Muscle/Joint Pain

- medications available in nurse's office

- allow student to adjust positioning as needed (Shanon explained how her son often gets into a sitting/crouching position; she likens it to a “little Buddha” position.)
- provide access to a keyboarding device (an “alpha smart” and a computer)
- observation by an occupational therapist, who can advise how to make a child’s environment more productive
- provide elevator pass
- provide an extra set of books for home use so that heavy backpacks aren’t needed
- provide voice-recognition visual technology
- provide large diameter pencils, pens and art instruments

Cognitive Disturbances: faulty memory – dysgraphia (difficulty with verbal/auditory processing) - difficulty writing (getting the thought from the brain to the page) - dyscalcula (inability to handle simple math) - poor reading comprehension - disorganization and disorientation (Shanon described how her son got lost in their neighborhood, where they had lived for 5 years.) - inability to multi-task

It is difficult getting school officials to understand how these symptoms manifest themselves. Schools must realize that a child’s intellect hasn’t changed, only his/her ability to handle the workload. It is most important that the child knows that he/she has a safety net of people around him/her who will be there for support if they get mixed up or confused.

Accommodations for Cognitive Disturbances

- shortened assignments (focus on <u>mastery</u> of the most important material rather than the number of questions)
- extended time (give them a safety net of time to complete tasks)
- provide verbal responses rather than written if the child has dysgraphia
- provide demonstrations of mastery in a variety of modalities (video, posters, timelines – get teachers to think “outside the box”)
- highlighted keywords on handouts and notes
- audio-record lessons (provide a voice-activated recorder in the classroom)
- repetition of instructions
- provide calculators, math charts, tables and formulas to save energy and time
- provide a spell checker to conserve energy and stress
- test by sections rather than chapters (get the information while it’s fresh)
- provide “word banks” (e.g. 5 words to choose from)
- multiple choice questions
- reduced number of concepts or problems per page
- provide graph paper for math problems (helps keep the child organized)
- allow for delayed processing time
- provide pre-printed materials (doesn’t need to copy and listen at the same time)
- provide study guides (teacher’s notes for parents’ use)

(Shanon likened a child with CFIDS to a computer – you can load him/her with information but he/she may crash from the overload)

Visual Disturbances: words “jumping” off the page - dyslexia - accommodative insufficiency (20/20 vision, but the eyes go too far while reading and comprehension is impaired) - blurred vision - light sensitivity – headaches - eye pain

Accommodation for Visual Disturbances

- natural lighting (sit the child near windows)
- books on tape (free through the Blind Association - may need special player)
- scotopic screening (CFIDS patients may have trouble with black print on white surface. Different color paper or overlays can be used. Shanon’s son uses cellophane binder dividers. One teacher provided a piece of cardboard with yellow cellophane to use as a guide while reading.)
- enlarged print
- limit use of overheads, which can be glaringly bright
- texts on CD
- large screen calculators
- screen magnifiers (filters out bright light, magnifies screen)
- magnification software
- board work notes
- color coding

Auditory Disturbances: ears ringing - sensitivity to external stimuli (When Shanon's son has trouble with noise he puts his head on his knees and wraps his arms around his body)

Accommodations for Auditory Disturbances

- repetition
- clarification
- written instructions
- iconic directions (i.e. pictures rather than words)
- frequent immediate feedback to reinforce information
- reduce distracting stimuli (even projector/air conditioning noise can be a problem)
- headphones or ear plugs to filter out noise

Digestive Disturbances: diarrhea – constipation – nausea - weight loss or gain

Accommodations for Digestive Disturbances

- crackers, ginger ale, etc. to settle the stomach
- medications available in nurse's office
- laminated restroom pass (to go without asking)
- consultation with the school dietician
- provide breaks as needed

Sensory Sensitivities: to noise, movement, light, touch, smells and/or hot and cold

Accommodations for Sensory Sensitivities

- provide for small group settings
- mask for science classes (Shanon's son had a special respirator-like mask)
- natural or dimmed light
- sunglasses
- lunch with friends in a location other than the cafeteria, where there are too many smells, too much noise – too much of everything
- permission to dress in layers
- early dismissal from classes
- exemptions from pep rallies and loud assemblies
- limit exposure to perfume/cologne (Since Anthony can smell perfume a "mile away", Shanon wears natural scents such as myrrh or lavender.)

Immune Dysfunction: frequent colds, sinus and respiratory infections - prone to viruses and flu

Accommodations for Immune Dysfunction

- advance notification of widespread viral illness in the school
- have a plan in place for an extended absence (i.e. homebound services)
- meds available in the nurse's office

Most children with CFIDS fall under the general category "Other Health Impairments," which schools may use to categorize such kids. "Other Health Impairments" is defined as: limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as a heart condition, TB, rheumatic fever, arthritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, ADD, ADHD, and diabetes and adversely affects a child's educational performance. As part of this definition "Other Health Impairment Criteria" are listed, where a student's disability affects his/her performance in the following areas: written work, math skills, listening comprehension, oral expressive skills, gross and /or fine motor skills, reading skills, concentration for an extended time, organizational skills, emotional and/or behavioral issues. Shanon stressed that a good letter from a physician is critical to securing cooperation from a school to deal properly with a child with CFIDS. Some letters are too vague and general, not specific enough to a particular child's situation. A good letter should include specific details of CFIDS, the child's symptoms, things the child cannot do, what he/she is sensitive to and instructions for dealing with the patient. The doctor's credentials should also be included. Listed below is an example of such a "good "letter:

Dear Special Education Administrator:

My patient, John Doe, has been diagnosed with CFIDS. He experiences extreme fatigue, joint and muscle pain, some visual disturbances, sensitivities to light, noise and too much movement. John has difficulty concentrating and processing complex concepts. He also experiences some delayed auditory processing.

John has difficulty following multi-step directions. There is difficulty with reading comprehension. John also experiences sensitivity to temperature.

I ask the school system to conduct a full evaluation to determine if John is eligible to receive special education services under the IDEA.

A list of my recommendations for accommodations and modifications is attached. Please don't hesitate to contact me if I can be of any further assistance.

Respectfully,

Arthur Smith, M. D.

In dealing with her son Anthony's situation, Shanon explained that she faced many of the same obstacles she had discussed in her presentation. Anthony had scar tissue on his heart and serious digestive disorders (for which he was hospitalized). His primary physician had referred him to fifteen specialists. But in his letter to the school, the primary physician didn't adequately list all the various problems being addressed by the specialists. Thus the school assumed Anthony had just become lazy and wanted to avoid going to school. Officials said they first had to rule out that this wasn't a psychological issue. Shanon was surprised with the school's reaction when they knew what her background and training had encompassed and what she knew about the various options available to assist a child with these physical problems.

Ultimately, the school made Anthony sick by leaving him waiting one day for a school bus that never arrived. By the time he was picked up he was disoriented, couldn't remember anything such as where he lived or his mother's phone numbers. Anthony was unable to return to school that year. During her meetings with school officials over the matter, the case manager fluffed off her son's illness and refused to sign an education plan. This prompted Shanon to file a formal complaint with the state Department Of Education.

Shannon ended her talk with discussions of several children she has helped, including kids in Wyoming, Illinois and Georgia. One of the little girls told her friends that Mrs. McQuown "was coming to teach her teachers how to teach her because they didn't know what they were doing." Shannon was able to not only spend time with her teachers but the other kids as well, explaining to them that there was a little girl in their class who was disabled but looks OK. Shanon related it to her own need to use a wheelchair periodically because of her lupus, but she looks OK, too. The child's teacher thought the girl needed to be "pushed." As a result, the child began to suck her thumb (at 9 years old) and wondered how old she needed to be to quit school. Today, after working with Shanon, the girl has gained self-confidence and, in fact, wants to become an FBI agent.

Anthony told Shanon that he knows why God gave him to her. He said, "You have lupus and know what it is like to have a son who was told he had 'growing pains.' You wouldn't stop fighting for me, and won't fight only for me."

Shanon concluded by saying that CFIDS is what kids **have**, not who they **are.** Adults must help them "dare to dream," give them hope and give them a voice. An associate of Shanon's once said that she has an alter ego named Shanique who comes to the surface when she realizes kids aren't being treated fairly. Shanon is willing to help – anyone can call on her. She is a "pit bull" when it comes to helping out. Shanon McQuown has enabled herself, has written a book about her experiences and has become an expert in her field. She obviously isn't a person who will take "it's only growing pains" for an answer.