

**Comments on Student Athlete Concussion Legislation, Bill 456**  
**Mother of 14 year old with concussion.**

**Julie Colglazier**  
**Simsbury, CT**  
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My 14 year old middle school daughter sustained a concussion July 4, 2009, by hitting her head in a pool while swimming. Her symptoms were not extreme immediately, but have been severe at times and have evolved over time. We went to many doctors before finding those that knew how to manage concussions. Until recently when she started to receive appropriate care, she could not be in public places, read, walk, or do much of anything without significant head pain and other symptoms. Today, eight months after the injury, after months of therapy, she is on pain killers (and is expected to be for many more months), still has physical and cognitive symptoms of that concussion, and has to rest off and on all day and manage her days very carefully with very little activity. We work to keep our hope up for things to get better. If education on concussions to the public and doctors had been better, she would almost for sure not have all these problems today.

The primary reason I am testifying is to let the legislature know that there is a vast lack of information in the medical and sports communities regarding concussions and concussion management, which has caused myself and many others I know whose children have had a sports-related concussion, a great deal of difficulty getting proper care. A key part of the bill presented today is the difficulty in obtaining health care professionals who are "trained in the evaluation and management of concussions". It is very important to address this problem especially with the increasing intensity of sports down to young ages. It is prudent to establish guidelines and educate coaches on concussion management for children from as early as when they start competitive sports. This bill is the first step. Knowledge of concussion management needs to spread down to the management of elementary school age athletes (around 4<sup>th</sup> grade), when the incidence of concussions begins to increase more rapidly with competitive levels of sports.

**The need for medical and sports care and education regarding concussions in Connecticut:**

Proper care and understanding of concussions is key to prevention of worsening of the condition. The various symptoms of concussion we found are not even understood by doctors who should be specializing in that area, and need to be better understood by the public, coaches and doctors. I am a parent who has always respected the opinion of doctors. However, very unfortunately, through the months following my daughter's concussion it has been extremely difficult to get proper care from doctors. I have had to go against the poor judgment and dismissal of my daughter's condition which well respected doctors provided. We received inaccurate and poor medical advice over and over again, and it was only through great diligence and a chain of advice beginning (with luck) with our local optometrist who recognized that my daughter's vision problems presented the same as his Iraqi Vet patients, that we have finally made it to a point now where my daughter is receiving help and rehabilitation.

Proper education needs to start with the public and coaches because they are on the front line of most concussions. Proper education and care needs to extend to doctors. **Incorrect diagnosis and dismissal of my daughter's symptoms was given by pediatric neurologists from Connecticut Children's Medical Center (CCMC) and Hartford Hospital, a neuro-ophthalmologist, an ophthalmologist, CCMC ER doctors, and our original pediatrician.** *These doctors attributed*

*multiple typical concussion symptoms such as significant head pain, dizziness, nausea, double vision, blurry vision, fatigue, light and noise sensitivity, and other standard symptoms of concussion/brain injury, to "stress" and "migraine", though we told them she was not under stress and that all symptoms came following a head injury.* Doctors believed that a hit on the head that did not cause my daughter to lose consciousness could not be significant. Obviously there is a great lack of knowledge in the medical field about brain injuries. Though in pain and with multiple concussion symptoms, my daughter could walk and talk and there was no physical picture to show anything was broken (as there is not with concussion), so her condition was misunderstood by the very specialists who should be able to advise her on her condition and help her in rehabilitation. For neurology, we finally turned to Boston Children's Hospital Brain Injury Dept., which was booking three months out. The neurologist there was the first neurologist of three to understand my daughter's symptoms. Now my daughter is finally receiving the medical care she needs with neurology and a more comprehensive understanding of concussion management at Children's Hospital Boston. If it is this hard to get care in the medical community, the sports community has a far greater risk of lack of knowledge. I have gotten to know several parents of children with concussions. Everyone we know with a child where a concussion lasted more than two weeks has had a similar experience to ours; poor medical care/lack of comprehensive understanding with regard to concussion management.

For my daughter's care, early on I did seek the help of the CCMC Concussion Clinic, but because of her multiple symptoms, the complexity of her condition, and the fact that she could not get to an asymptomatic condition which is the general recommendation of the Concussion Clinic, my daughter needed more significant help and the understanding of a neurologist. Our experience with the Concussion Clinic was mixed. They were not thorough, did not give very much advice, but supportive and seemed correct in their simple/basic diagnosis. Because of the complexity and severity of my daughter's condition I sought the help of all of the professionals listed above. It should be noted that every concussion is different with different symptoms, and requires the expertise of different specialists. It was very hard for me to find those specialists, and I was on my own to figure that out.

Many times different types of therapies are needed for concussion rehabilitation. These were unknown to us for some time, but should be known to those who sustain a concussion. My daughter would not have even started to get better without the extremely important and necessary help of a cranial sacral therapist who has a keen understanding of the cranial sacral mechanism involving fluid, structural and nervous system components; all affected by her concussion. Because of the complexity of a concussion, this type of care and understanding is necessary. It is important to note that there are many cranial sacral therapists who should not be handling concussions. I had never heard of this type of therapy before my daughter's concussion, but it is that one person who is solely responsible for starting the healing process for my daughter's brain. The need for greater education and information on the complexity of care needed must be extended to the public. Major insurance companies do not recognize the medical need for recovery of certain therapies which are exactly those that turned my daughter around and started the healing process. Many people would not be able to afford this private cost we have incurred. Likewise, an optometrist who specializes in vision therapy and understands head injuries is responsible for rehabilitation of my daughter's eye problems. Vision therapy also helps cognitive functioning. Other doctors we were seeing at the time, neurologists, ophthalmologists, and neuro-ophthalmologists strongly recommended against this very important part of my daughter's rehabilitation.

My daughter had significant cognitive executive functioning loss. Psychologists and neuro-psychologists generally do not specialize in concussion management, and almost all I contacted told me they were not qualified to manage my daughter's condition. Finally, we were fortunate to find a neuro-psychologist specializing in concussion management with the help of the Brain Injury Assn. of CT.

*What would have helped my daughter (and many we know with more significant concussions) the most would have been education on concussions and centralized medical help where doctors would provide thorough concussion management and rehabilitation and referrals for specialized help. General education of doctors on the complexity and individuality of concussion symptoms would have helped my daughter and many we now know who have suffered similarly, significantly.* Boston Children's Hospital doctors validated all of my daughter's symptoms as a concussion, as well as the rehabilitation I had sought for my daughter. They have an organizational structure such that they address concussions in one area, rehabilitation from brain injury in another, neurologists on staff who are an integral part of all. This would have been very helpful to have in Connecticut, an organized network of physicians who understand the various aspects and complexities of concussions.

I did not find out about the Brain Injury Assn. until early this past winter. They have supported me through my subsequent care for my daughter. This organization plays a very important role in concussion management, providing support, resources, education and guidelines for prevention and management of concussions.

**The need for guidelines/education of coaches and the public regarding concussions down to young ages.**

Because children start sports at an elementary school age and sports are intense at young ages, it is important to address head injuries far before a person gets to high school sports, and by middle school. Concussions have a cumulative effect. The bill presented today needs to go further to help students/children when they start getting blows to the head and concussions in sports at the elementary school age. At the very least, education of these coaches should be provided also. My daughter is believed by doctors now to have sustained multiple sub-concussive, or possibly concussive blows in soccer with soccer headers, and at swim team (when she was told to swim without goggles to practice for an instance when she may lose her goggles during a race). These blows started in second grade in these sports. With all of my children in sports, we see concussions at an elementary school age in every season in every sport they are in.

My experience with my children in sports is the same as other families. The intensity of sports (travel teams, etc.), starts in about fourth grade. That is when we started to see teammates and friends incur concussions at an increasing rate. Coaches generally do not know a lot about the signs and symptoms of concussion. Since we know that it is extremely dangerous for a person to sustain a second concussion while still symptomatic, it is prudent that guidelines be established for "return to play" for all sports starting at a young age. Children get embarrassed, in some cases tend to minimize their condition, and in some instances simply have a strong desire to go back to play. It should be noted that for many reasons an athlete may not communicate correctly their symptoms. Also, a student may not be experiencing severe symptoms right away as in the case of my child.

I believe this bill should go further in the area of education, extending to the students themselves and parents. At a middle school level, all children should be educated on the signs and symptoms of a concussion.

We have been fortunate in that my daughter's case in that our school district has been understanding of her condition despite lack of strong medical advice. I developed my daughter's 504 Plan with the help of basic ideas from my daughter's neuro-psychologist. However, doctors have told me schools are often not accommodating. Because it is known that forcing too much on the brain after a brain injury can be harmful, there should be guidelines for schools, guidelines for developing 504 Plans, and education for supervisors and students and coaches, keeping in mind that all concussions are unique.

My daughter is an example of one who did not get the IMPACT test until after her significant concussion. Many student athletes sustain sports-related concussions, sometimes multiple concussions, in middle school or before, well before high school sports when the IMPACT test is now administered as a baseline in our district. The IMPACT test should be required starting in middle school, and can be used for determining return to play and return to normal academic responsibilities. Some private schools administer the IMPACT test upon entry. Following a concussion, obtaining baseline on the IMPACT test can then be used to determine when the student should both be allowed to return to play and when they should be responsible for normal academic work. Some kind of guideline for returning to normal academic responsibilities would be extremely helpful for management of my daughter's care.

### **Recommendations and Conclusions:**

As the parent of athletes, one who had a significant concussion, I have known the vast lack of information, education and care available for those who suffer concussions in Connecticut. I have had to work very hard to find the right people to care for the very scary and serious aspects of my daughter's concussion/brain injury disabilities. I have found that a great deal of work and change is needed in Connecticut in concussion management, where there is a huge void of care and management. Legislation presented today in Bill 456 requiring education of coaches is the first step.

### **Needed Concussion Legislation:**

- Concussion education for coaches, the public, and middle school students. This should emphasize the individuality of each injury and safe management. It should include educating coaches on the dangers of such practices of "headers" in soccer, and any sport practice which may involve blows to the head.
- Centralized thorough concussion care/management with referral to doctors who understand conditions relating to concussions.
- Education of pediatricians, neurologists and other doctors such as ER doctors.
- Guidelines for "return to play" from elementary-aged children on up.
- School guidelines for students returning to school from a concussion, including 504 Plan guidelines as necessary.
- IMPACT testing starting in middle school sports.
- Further legislation focused on prevention of concussions in sports. For example, the requirement of helmets in girl's lacrosse.