

Changing the Culture of Concussion: Education Meets Legislation

Richard H. Adler, Esq, Stanley A. Herring, MD

In October 2006, Zackery Lystedt, an outstanding 13-year-old athlete, was playing in his middle school football game. With 3 plays remaining at the end of the second quarter, Zack struck his head on the ground and lay writhing on the field holding his hands to his helmet in obvious distress. An injury time out was called, and Zack was helped to the sideline. After resting for a few minutes during half-time, Zack was returned to the game by his coaches. No medical personnel were available to assist in that decision-making process (as is typical in middle school sporting events).

Zack played in the third and fourth quarters but was confused, had difficulty remembering the plays, and had a mounting headache. At the end of the game, he collapsed in his father's arms and was airlifted to a level-1 trauma center. He underwent emergency brain surgery for his life-threatening injuries and survived but with significant neurologic injury and residual disabilities that affect almost every activity of daily living, including basic self-care, speech, school work, and mobility.

Certainly, no coach, school administrator, or parent would intentionally place a youth athlete at risk for catastrophic injury. Although it is not unheard of that permanent disability and even death can be associated with youth sports, such tragedies are compounded when they are preventable. This was the case with Zackery Lystedt. Simply removing him from play at the time of his first injury would have saved Zack and his family from facing a lifetime of incredible struggles. However, changing the culture around sports concussions has not been easy or necessarily successful. The challenge is how to change the culture and practice of minimizing an injury that has previously been referred to as a "ding" or "getting your bell rung" to a culture of appreciating that concussions are brain injuries and that all brain injuries can potentially result in life-altering consequences. This challenge is even more difficult because most athletes who experience sports concussions appear to recover without readily apparent consequence; however, this is not always the case.

The idea that all sports concussions should be taken seriously is not new. The Centers for Disease Control (CDC) created a now long-standing educational program, known as "Heads Up: Concussion in Youth Sports," that provides free concussion tool kits, posters, clip boards, fact sheets, videos, and DVDs to athletes, parents, and coaches. More recently, many of these materials have become available through free downloads, and the CDC has even developed a free online concussion education course for coaches (and soon will be launching one for health care providers). These well-established and updated educational efforts demonstrate that CDC leadership continues to view sports concussions as a major public health issue. In the general health care community as well, the idea that proper management of sports concussions is an important matter is certainly not new. For well over a decade, the opinion that the diagnosis and treatment of sports concussions (including providing clearance for return to play) is a medical issue has been articulated in numerous national and international concussion consensus statements [1-4].

The tragedy that befell Zack Lystedt and his family painfully identified that the public health and medical management messages about youth sports concussions were not always reaching their intended audiences. A confluence of circumstances provided the opportunity to rethink the message and implementation of youth sports concussion management. Zackery's story touched each of us in separate and overlapping ways as a legal counsel and community champion for survivors of traumatic brain injury and as a physiatrist and advocate for proper youth sports concussion medical management. The Brain Injury Association of Washington teamed up with the CDC and launched a "Heads Up" concussion awareness program for youth athletes in the

R.H.A. Adler Giersch, P.S.; Executive Board, Brain Injury Association of Washington, Seattle, WA

Disclosure: nothing to disclose

S.A.H. Departments of Rehabilitation Medicine, Orthopaedics and Sports Medicine, and Neurological Surgery, University of Washington, 325 Ninth Ave, Box 359721, Seattle, WA 98104; Seattle Sports Concussion Program, Seattle, WA; Team Physician Seattle Seahawks and Seattle Mariners, Seattle, WA. Address correspondence to: S.A.H.; e-mail: sherring@u.washington.edu

Disclosure: nothing to disclose

Disclosure Key can be found on the Table of Contents and at www.pmrjournal.org

state of Washington. Across the state, CDC materials were widely distributed, newspaper articles about sports concussions were written, public service announcements were aired, and lectures were presented to well over a thousand athletes, parents, coaches, and health care providers. We hoped that a more intense and directed educational effort would make a difference. We were encouraged by the interest and perceived understanding that this program brought, only to have a sober reminder of the challenges that remained. During the very time that the "Heads Up" program was being rolled out in the state of Washington, there were 5 youth sports concussion-related deaths across the United States.

A critical look at the education-only effort demonstrated an "inconsistency gap." In other words, coaches from different school districts, or even coaches within the same school district, had a varied level of understanding of concussions. Also, the school districts' administrators had a different level of interest in concussion policy. We realized that, even when school district policy had a concussion plan in place, its implementation and effectiveness often was entirely based on an individual administrator's or coach's desires and input. Should either one leave his or her post, the robust concussion management plan would similarly disappear, and, if one of them left the school, then the protocol left as well, and no "institutional memory" remained. Our "Heads Up" Washington educational campaign seemed most valuable as a means to create an opportunity for more substantial change. It appeared that the best chance to implement a consistent concussion policy that would help keep sports safer for athletes such as Zack was to work toward a standard that was uniform across all school districts as well as in all nonschool youth sports leagues. A critical cornerstone of that uniform standard would be mandating that all youth sports concussions be managed by medical personnel. To realize this goal of a uniform concussion policy, it was clear that legislation would be necessary. If education was a "bottom-up approach," then legislation would be a "top-down approach." One without the other could achieve much, but the synergistic combination created an impact that would prove to be much more effective.

As transparent as the need was to pass the sports concussion law, the legislative process itself was equally opaque. Organizational partnerships were essential for any chance of legislative success, and every such partnership must have one champion lead the way. For our concussion law effort, the Brain Injury Association of Washington was that organization. Reaching out to other community organizations that were identified as stakeholders in the effort to promote sports concussion safety was necessary to build a broad-based coalition: Harborview Medical Center (the premier level-1 trauma center in the Pacific Northwest), the University of Washington Medical Center, Seattle Children's Hospital, Washington Youth Soccer, the Washington State Athletic Trainers Association, the Washington Interscholastic Activities Association, insurance risk pool managers, and many others joined the coalition. This robust group, which represents brain injury advocacy, health care, youth sports or-

ganizations, school administration, insurers, and others interested in brain safety for young athletes advanced the legislative effort with the depth and breath necessary to gain the sincere attention of state government officials.

Along with this organizational partnership, a skilled and experienced lobbyist was employed to provide critical insight and access to law makers and their aides, and equally important was identifying a key state legislator who would introduce and support the bill throughout the process. Representative Jay Rodne, the House of Representative member from Zackery's district, agreed to meet Zack and his family. Like many before him, Mr. Rodne was profoundly touched by the courage and determination of Zack and his family, and, after he spent an evening with the Lystedts at their family home, he announced that his number one priority in the upcoming legislative session would be to see a youth sports concussion law passed. Developing the coalition of organizations and the addition of our lobbyist and state legislator offered the framework for committed, consistent, and generous work by many individuals from all of the involved groups that were needed to achieve success. Our message was carefully crafted: a youth sports concussion law would help prevent preventable brain injuries for boys and girls in all sports. The wording of the law was carefully chosen, testimonies were rehearsed and given, and frequent problem solving was used as unforeseeable problems arose. The end result was extremely gratifying: a unanimous vote for approval by both the Washington State House of Representatives and Senate of Engrossed House Bill 1824, named the Zackery Lystedt Law, which was signed in front of the Lystedts by Governor Christine Gregoire on May 14, 2009 [5]. Although there was tremendous jubilation when this groundbreaking law, the first of its nature in the country, was signed by the governor, that joy was tempered by the melancholy that came from understanding that this public health and safety triumph had come at such great personal expense to Zack and his family.

Similar organizational partnerships have developed in other states, and national organizational partnerships also have evolved and created a combination of strong coalitions effective in spreading the legislative effort. Soon after the Lystedt Law was signed in May 2009, the American College of Sports Medicine, at its 56th annual meeting, issued a national call to action for similar Zackery Lystedt laws to be passed in all 50 states and in the District of Columbia. The interest and support of American College of Sports Medicine, the world's largest sports science and sports medicine professional organization, was very helpful in raising awareness regarding the role for education and legislation in managing sports concussions. In October 2009, Roger Goodell, commissioner of the National Football League (NFL), announced the support of the NFL for the goal of seeing Lystedt laws in every state and in the District of Columbia. He delivered the NFL's significant manpower and economic support, and noted that the involvement of the league would not waver until this goal occurred. The endorsement and participation of the NFL significantly expanded and accelerated the nationwide

legislative effort. Also, there was another important addition to the cause. In January 2010, all the state-based chapters of the Brain Injury Association of America signed on to advance the core principles embedded in Washington's Lystedt Law in every state.

The American College of Sports Medicine, NFL, and the Brain Injury Association of Washington together developed a strong organizational coalition, which has been joined by a variety of other sports and health organizations, including the National Collegiate Athletic Association, the National Federation of State High School Associations, USA Football, USA Lacrosse, and numerous other national governing bodies for sports, and many other groups all advocating for youth sports concussion legislation to be enacted in every state. Both the original Washington State organizational partnership and this national organizational partnership continue to promote education as well as legislation, and the CDC has remained a stalwart partner, providing ongoing educational resources for the effort. At present, there are 27 states with Lystedt-like laws passed and signed by their governors, and a law also is in the place in the District of Columbia. Several other states are in the process of drafting legislation, and almost every remaining state has a working group that is considering youth sports concussion legislative options.

The progress has been very exciting, and all local, state, and national advocates remain committed to the cause of each state having a Lystedt-like law in place. Although educational efforts alone did not prove to be consistently effective in altering the behavior regarding the medical management of sports concussions, they remain a valuable component of the effort to change understanding of this injury. Indeed, we recommend education of athletes, parents, and coaches as one of the principle components of any concussion law that is to be developed. Also, the passage of similar laws in all 50 states and the District of Columbia is only the first step in developing a comprehensive concussion management program to help keep youth sports safe and forge a greater understanding of brain health. In the near term, preliminary survey data [6] in the state of Washington has demonstrated a high level of awareness and knowledge about sports concussions in parents and coaches, and adoption of the Lystedt law does not appear to have inadvertently driven athletes to hide potential concussions. Conversely, increased awareness of the signs and symptoms of concussion and the potential danger of concussions appears to have led to an increased rate of reporting of possible injury. While awaiting further research regarding cause and effect of Lystedt Law, during the last high school football season in Washington State, for the first time in 5 years, there were no deaths or operable subdural hematomas (Richard Langum, personal/oral communication, August 2011). In the long term, the best educational policies and practices for athletes, parents, coaches, administrators, and health care providers will need to be developed and validated, and ongoing studies to deter-

mine the best strategies for implementing the law and measuring its compliance should be developed. Lystedt-like laws in each state are living documents and should be subject to changes to make them stronger as new information is gathered about their usefulness and as knowledge about sports concussions evolves. Initial studies of these laws are underway, and which metrics are eventually chosen to measure the effectiveness of these legislative efforts (posteducation knowledge retention testing, surveys of school administrators and officials regarding policy implementation, change in concussion injury reporting rates, decrease in disabling and/or catastrophic consequences of concussion, or others) remain to be determined. However, without initially putting sports concussion laws in place that mandate a consistent, medically based approach to the diagnosis and immediate management of youth sports concussion, the foundation for enacting change was unattainable.

Because Zackery Lystedt was returned to play in the same game, a mild brain injury turned into a much more severe and devastating problem, and left him and his family facing a lifetime of incredible hardships. Zack has had choices along the way: anger or kindness, despair or hope, and surrender or determination to improve. He has met each hurdle with remarkable grace and courage, and his parents have shown devotion and strength of character of magnificent proportion. This quietly heroic family inspired us and many others to attempt to honor their sincere wish that this tragedy not happen to any other young athlete. In that process, we have discovered that trying to improve youth sports concussion care through educational outreach alone was not the answer. Combining those educational efforts with legislative ones is already preventing preventable brain injury. Much more remains to be done, and our enthusiasm for the tasks ahead has not faltered.

REFERENCES

1. Aubry M, Cantu R, Dvorak J, et al. Summary and agreement statement of the First International Conference on Concussion in Sport, Vienna 2001. Recommendations for the improvement of safety and health of athletes who may suffer concussive injuries. *Br J Sports Med* 2002;36:6-10.
2. McCrory P, Johnston K, Meeuwisse W, et al. Summary and agreement statement of the 2nd International Conference on Concussion in Sport, Prague 2004. *Br J Sports Med* 2005;39:196-204.
3. McCrory P, Meeuwisse W, Johnston K, et al. Summary and agreement statement of the 3rd International Conference on Concussion in Sport Held in Zurich, November 2008. *PM R* 2009;1:406-420.
4. Concussion (mild traumatic brain injury) and the team physician: A consensus statement. *Med Sci Sports Exerc* [In press.]
5. Certification of Enrollment, Engrossed House Bill 1824, Chapter 475, Laws of 2009, 61st Legislature, 2009 Regular Session, Youth Sports—Head Injury Policies, effective date: 07/26/09, State of Washington. Available at: <http://www.sportsconcussions.org/Documents/1824-SL-Legislation.pdf>. Accessed August 6, 2011.
6. Shenouda, CN, Hendrickson P, Davenport M, Barber J, Bell KR. Concussion and Lystedt Law Awareness Among Youth Soccer Players Associates: A Survey. 3rd Federal TBI Interagency Conference, Washington, DC, 2011. Poster Presentation.