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At Risk for Huntington's Disease

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It's playoff time – and a reminder that brain health comes first

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▼ 2013 (30)
 - ▼ December (3)
 - [It's playoff time – and a reminder that brain heal...](#)
 - [Creating a Christmas memory for a Huntington's family](#)
 - ['Alive and Well' captures struggle against untreat...](#)
 - ▶ November (3)
 - ▶ October (3)
 - ▶ September (3)
 - ▶ August (2)
 - ▶ July (1)
 - ▶ June (1)
 - ▶ May (3)
 - ▶ April (4)
 - ▶ March (2)
 - ▶ February (3)
 - ▶ January (2)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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TUESDAY, DECEMBER 31, 2013

It's playoff time – and a reminder that brain health comes first

During the winter holidays, many Americans celebrate our culture of competition by watching football – from state high school championships to college bowl games to the National Football League (NFL) series culminating in the Super Bowl.

However, recent news regarding head injuries has spurred the greatest concerns about player safety in the recent history of the game.

As I [wrote last January](#) on the eve of the 2013 Super Bowl, “the negative consequences of football on the brain have come under intense scrutiny.”

I noted that Junior Seau, the former San Diego Charger who had committed suicide in 2012, suffered from CTE (chronic traumatic encephalopathy), a brain disease produced by trauma to the head. According to Seau's relatives, his behavior included depression, wild mood swings, forgetfulness, irrationality, and insomnia – symptoms noted in other players who have sustained brain injuries.

These symptoms are very similar to those seen in neurological disorders such as Alzheimer's, Parkinson's, Lou Gehrig's, and Huntington's disease, which claimed my mother's life.

I carry the mutated gene that causes HD but have so far escaped its inevitable, terrible symptoms.

Today I turn 54, an age at which my mother had already begun a steep decline. Birthdays always make me introspective and retrospective, and as I draw to a close an especially intense year in HD advocacy, professional work, and family life, I feel a special need to reflect on my concerns about HD and CTE while waxing nostalgic and a bit autobiographical.

CTE, the NFL, and a 'public health crisis'

In August, one week before the start of the NFL season, the league settled a lawsuit brought by some 6,000 former players and families who accused the league of hiding the connection between football and concussions. The NFL agreed to pay the players \$765 million and was expected to pay an additional \$200 million in legal fees.

However, the settlement did not require the NFL to admit any wrongdoing, nor did it state any conclusions about football and brain injuries.

With a dispute emerging over legal fees, the federal judge overseeing the case has yet to approve the settlement. New lawsuits filed since the settlement have increased the likelihood that the concussion issue will enter a courtroom ([click here](#) to read more).

HD Links

[Huntington's Disease Society of America](#)

[International Huntington Association](#)

[Huntington's Disease Drug Works](#)

[Huntington's Disease Lighthouse](#)

[Hereditary Disease Foundation](#)

[Huntington's Disease Advocacy Center](#)

[Thomas Cellini Huntington's Foundation](#)

[HDSA Orange County \(CA\) Affiliate](#)

[HD Free with PGD! Stanford HOPES](#)

[Earth Source CoQ10, Inc.](#)

HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)

[Angela F.: Surviving Huntington's?](#)

[Heather's Huntington's Disease Page](#)

In August, ESPN (Entertainment and Sports Programming Network) abruptly ended its relationship with the PBS (Public Broadcasting System) documentary program *Frontline*, reportedly because of pressure from the NFL regarding an upcoming documentary.

Nevertheless, in collaboration with two ESPN-based investigative journalists, *Frontline* in October aired a two-hour report titled “League of Denial,” revealing the NFL’s attempts to hide the seriousness of brain injuries from the players and the public even as physicians studying concussions found CTE in the autopsied brains of dozens of deceased players.

In early November, it was reported that several former NFL players were diagnosed with CTE. They were the first living players to undergo a new kind of brain scan capable of detecting signs of CTE.

Days later, two former college football players filed a federal lawsuit against the National Collegiate Athletic Association (NCAA), claiming it failed to inform players about the risks of concussions and demanding medical monitoring for former players.

Meanwhile, news organizations reported that Pop Warner, the nation’s largest youth football program, registered a nearly ten percent drop in participation between 2010 and 2012. That suggests the general public had taken strong note of the dangers of football.

“There has never been anything like it in the history of modern sports: a public health crisis that emerged from the playing fields of our 21st-century pastime,” wrote the ESPN journalists, Mark Fainauru-Wada and Steve Fainuru, in an excerpt from their book *League of Denial: The NFL, Concussions, and the Battle for Truth*. “A small group of research scientists put football under a microscope – literally.... What the researchers were saying was that the essence of football – the unavoidable head banging that occurs on every play, like a woodpecker jackhammering at a tree – can unleash a cascading series of neurological events that in the end strangles your brain, leaving you unrecognizable.”

Common problems and goals

I am struck by the similarities between HD and what scientists, physicians, and former players have described as the symptoms of CTE. HD effaced my mother’s ability to speak and interact with others, leaving her a mere shadow of herself.

I fear the same fate.

As an HD advocate, I believe the neurological disease communities, as well as victims of stroke and traumatic brain injuries from military combat or other situations, should support the efforts to research the causes and symptoms of CTE and support those afflicted by it. Research on these various conditions is mutually beneficial. We’re all part of a larger quest for improved brain health.

Like HD, CTE involves our most important natural resource: our brains. The brain controls all that we do. It makes us individuals and provides us with enormous capacities.

Conditions such as HD and CTE can put a huge emotional, medical, and financial burden on families and caregivers. We need to find ways to prevent, treat, or cure these conditions as quickly as possible.

Advocacy in the workplace

In November, I brought my advocacy into the workplace.

When the University of San Diego (USD), where I chair the history department, announced its voluntary withdrawal from postseason football competition while it investigates a potential violation of rules regarding financial aid and athletic recruitment, I urged the administration to also conduct a review of player safety in light of the revelations about CTE.

My e-mail message led to a constructive dialogue with the athletic director, the NCAA faculty representative, and others to seek ways in which USD, fulfilling its mission of education and social justice, can inform the campus and the local community on the issue of CTE and brain health.

I hope to report progress on these efforts in the coming months.

The larger implications of sports

I have long cultivated an interest in the social, historical, and health-related implications of sports.

During my freshman year at Yale University, I helped support myself by working ten hours per week as an assistant public relations person in the university's sports information office. I also reported and wrote columns for the *Yale Daily News*. One of my articles described my experience as one of the first – if not *the* first – male reporters to enter a female locker room.

In another article, a quotation from Yale's athletic trainer, Al Battipaglia, summed up my own current philosophy about student athletics: "Vince Lombardi said winning is the only thing. Al Battipaglia recites the athletic trainer's prayer: 'It's not if we win or lose, but if nobody gets hurt.'"

At the time, Yale had an extremely cautious, automatic ten-day suspension for any athlete with a head injury.

At Yale I also had the privilege of studying in a seminar on the "American sports syndrome" directed by ABC Sports broadcaster Howard Cosell, one of the most trenchant sports commentators of the 20th century. Cosell taught us about the contradictions and hypocrisy involved in the world of sports.

Brazil, soccer, and the 'opiate of the people'

Later, I had far less time to follow American sports as I pursued a career as historian of Brazil, with a specialization in the history of the Brazilian Catholic Church, dictatorship, human rights, and reproductive issues. Throughout much of the 1980s and 1990s, I paid more attention to soccer.

Serious injuries occur in soccer, and fan devotion and violence make our Super Bowl craze seem mild in comparison.

In the past, some political leaders have used soccer as an "opiate of the people" to manipulate the masses. This year millions of Brazilians protested in the streets against their leaders, in part because they were angry over the billions of dollars in government spending on stadia for the 2014 World Cup while public transportation and the health and educational systems remain substandard for much of the populace.

Nevertheless, in terms of the sport itself, I consider soccer as a more graceful and civilized activity when compared to the brutality of football.

Uneasy about football

Starting in the early 2000s, HD rekindled my interest in pro football, thanks to the Chargers' commitment to the Huntington's cause.

However, as I've reflected on the devastation that disease and trauma can cause in the brain, I've become increasingly uneasy about watching football games.

The *Frontline* documentary “changed forever how I will watch a professional football game – if, indeed, I can bring myself to do so again,” I wrote in my USD e-mail message.

Tracking CTE

My HD advocacy has led me to expand into the history of science, technology, and medicine. Now, with my added concern about athletes and CTE, I will add yet another layer to my advocacy, using my skills as a historian and former journalist.

I aim to track significant news reports about CTE. (*Frontline* has set up a “concussion watch” of officially reported NFL head injuries. So far this year it has registered 146 incidents.)

I will also monitor the continuing debate about whether football head injuries cause the condition. One worthwhile, in-depth debate about “League of Denial” took place in a published e-mail exchange between journalist Daniel Engber of *Slate* and author Stefan Fatsis ([click here](#) to read more).

Science and risks of CTE

As I've learned so well from the Huntington's movement, effective advocacy requires understanding scientific research. Therefore, I also aim to track the science of CTE.

A number of reports and academic articles on CTE have appeared in the last few years.

The National Institute for Neurological Disorders and Stroke, a division of the National Institutes of Health (NIH), issued a brief report on its December 2012 workshop on the neuropathology of CTE. The report raised more questions than it answered, demonstrating the infancy of research on CTE and outlining a plan for sustained, coordinated research on the condition.

(In August 2013 the NFL donated \$30 million to the NIH for research on CTE and other medical conditions affecting athletes.)

Other articles have warned of the potential risks of sustaining brain injuries in contact sports.

“Symptoms of CTE may begin years or decades (after one or multiple concussions) and include a progressive decline of memory, as well as depression, poor impulse control, suicidal behavior, and, eventually, dementia similar to Alzheimer's disease,” one article states. “Given the millions of athletes participating in contact sports that involve repetitive brain trauma, CTE represents an important public health issue.... It is now known that those instances of mild concussion or ‘dings’ that we may have previously not noticed could very well be causing progressive neurodegenerative damage to a player's brain.”

Another article outlined the history of traumatic brain injury (TBI) and its relationship to neurological decline, including cases of CTE. “The best data indicate that moderate and severe TBIs increase risk of dementia between 2-and 4-fold,” the authors concluded. “It is less clear whether mild TBIs such as brief concussions result in increased dementia risk, in part because mild head injuries are often not well documented and retrospective studies have recall bias.”

Autopsies of six Canadian Football League players with histories of concussions and neurological problems showed that three had CTE, while the others had Alzheimer's, Parkinson's, and Lou Gehrig's.

Skeptics, the media, and future goals

Some scientists have expressed skepticism about the research on CTE so far.

The latest and most prominent example appeared in a special issue of *Neuropsychology Review*, published in November and consisting of six articles by a “distinguished panel” of scientists and also an editorial, all on the topic of sports-related concussions.

“One cannot deny that boxing and other contact sports can potentially result in some type of injury to the brain,” the two authors of one article conclude. “There currently are no carefully controlled data, however, to indicate a definitive association between sport-related concussion and increased risk for late-life cognitive and neuropsychiatric impairment of any form.”

While agreeing that CTE is an “important public health concern,” the journal's editorial highlights the problem of the divide “between media and evidence-based accounts of sports concussion.”

While the *Frontline* documentary took a positive step in informing the public, it also illustrated a stark societal imbalance.

As the documentary contrasted a scene showing thousands of journalists attending an official 2013 Super Bowl pre-game media event with the handful of reporters who covered a press conference where scientists presented evidence on CTE, it's painfully evident that sports coverage remains largely an act of cheerleading rather than skeptical journalism.

Further, sports sections of daily newspapers routinely give footnote status to most news about athletes' injuries. Such coverage focuses on the injury as a factor in a team's success and rarely in terms of the athlete's long-term health.

Although the scientific articles referenced here (as well as others) differ in perspective and conclusions, one fact is clear: more research is needed, because the number of case studies of CTE still remains quite small.

A playoff party and nagging concerns

I must admit that, even after keeping the TV and radio off most of this NFL season, I listened with excitement to last Sunday's radio broadcast of the Chargers' overtime victory, which, against enormous odds, secured the team a spot in the postseason quest for the Super Bowl.

My family and I are planning a Chargers playoff brunch and mini-party for next Sunday morning, when the team plays in the first round against the Bengals in Cincinnati. We're inviting friends who, like us, know the devastation of Huntington's disease – and the Chargers' many contributions to the HD cause.

I'm sure we'll all root for the Chargers.

However, we'll also be crossing our fingers that nobody suffers a concussion or any other serious injury.

Personally, I'm torn between participating in a cultural ritual and standing up for my position as an advocate for brain health.

It's playoff time – but also time to think of how we can all make the world a better and healthier place in the New Year.

For me, that includes resuming my role as an advocate for brain health and, with the rest of the neurological and genetic disease communities, imagining a world in which CTE, HD, and other similar disorders can be fully treated and, even better, prevented.

Posted by [Gene Veritas](#) at [11:10 AM](#)      

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