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'Concussion': advocating for the truth about brain diseases

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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.

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WEDNESDAY, DECEMBER 30, 2015

‘Concussion’: advocating for the truth about brain diseases

In this era of growing concern over sports injuries, increased prevalence of neurological diseases, and pioneering brain research, the just-released movie *Concussion* hits home.

With Will Smith starring as the Nigerian-born Dr. Bennet Omalu, a forensic pathologist in the Allegheny County, PA, coroner’s office who was the first to identify a debilitating brain disease in deceased former National Football League (NFL) players, *Concussion* reveals how powerful political and financial interests prioritize profit over health, trying to bend or even snuff out inconvenient scientific knowledge.

Concussion also shows how scientists and physicians must sometimes go beyond the lab – even risking their jobs – to advocate for the truth.

As a [Huntington’s disease advocate](#) also keenly interested in the condition studied by Dr. Omalu, chronic traumatic encephalopathy (CTE), I applaud how *Concussion* helps raise awareness about brain health.

Like HD-affected individuals, people with CTE can suffer from symptoms such as depression, wild mood swings, forgetfulness, irrationality, insomnia, dementia, and suicidal behavior.

Dr. Omalu’s fight to get out the word reminds me of the long struggle against ignorance, stigma, and denial faced by families confronting HD and other rare and neurological conditions.

‘Trauma chokes the brain’

I watched *Concussion* on December 27. It dramatically portrays Dr. Omalu’s discovery of CTE in the brain of Mike Webster after the former Pittsburgh Steeler star lineman died in 2002 at the 50, having struggled with behavioral issues, depression, and other cognitive difficulties.

At the end of his life, estranged from his family, Webster lived in a pickup truck. Suffering from severe insomnia, he would shock himself with a Taser gun in order to fall asleep.

Using data from the Webster autopsy, Dr. Omalu and other researchers published an article in the scientific journal *Neurosurgery* suggesting that the impact of Webster’s football career caused CTE.

Dr. Omalu then found CTE in two other dead players.

“Repetitive head trauma chokes the brain,” Dr. Omalu declares in *Concussion*.

Ignoring the evidence

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](#)
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[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](#)

"You're going to war with a corporation that owns a day of the week," warns Dr. Omalu's boss, coroner Dr. Cyril Wecht, portrayed by Albert Brooks, in reference to the immense popularity of the NFL.

Betraying both ignorance and arrogance, the NFL tried to force Omalu to retract his research, something a scientific journal would do only in the case of plagiarism or falsification of data. *Concussion* depicts that ill-fated attempt and Omalu's resultant indignation.

Unable to stop Omalu, the NFL, led by Commissioner Roger Goodell, then turned on its effective public relations machine.

As shown in the film, it also ignored Dr. Omalu, refusing to allow him to even enter the room at a league meeting held to discuss his findings. They were instead presented by Dr. Julian Bailes, a former Steelers team physician – played by Alec Baldwin – who had become convinced that football endangered players.

As *Concussion* depicts, Dr. Omalu and his wife were forced out of Pittsburgh. He took a job as the chief medical examiner in San Joaquin County, CA, but continued to press the issue of CTE.

You can watch the *Concussion* trailer in the video below.

CONCUSSION - Official Trailer (HD)



Mounting statistics

Concussion, for all its painful drama, actually takes a relatively mild approach. For example, it doesn't show all of the toll football took on Webster's body and mind.

Complementing *Concussion*, the award-winning *Frontline* documentary *League of Denial: The NFL's Concussion Crisis*, shows photographs from the Webster autopsy and delves more deeply into the science and politics of CTE. It originally aired in 2013 and replayed this month in anticipation of *Concussion*.

Two *League of Denial* collaborators, ESPN journalists Mark Fainaru-Wada and Steve Fainaru, have described the issues of CTE and football head trauma as a "public health crisis."

As noted in *League of Denial* and other media reports, NFL doctors and officials have consistently tried to downplay the CTE evidence. Among their claims: the number of dead players examined was too small to qualify

as scientific evidence, and some players endangered themselves with issues such as steroid abuse.

“You can’t go against the NFL,” says the real Dr. Omalu in *League of Denial*. “They’ll squash you.”

However, as *Frontline* revealed in [an online report](#) in September and in this month’s broadcast of its documentary, the statistics are now overwhelming: 87 of 91 NFL deceased players tested positive for CTE. That’s a rate of almost 96 percent. With semi-professional, college, and high school players included, the figure is 79 percent.

A young star retires

The *League of Denial* update highlighted the case of Chris Borland, a highly aggressive tackler for the San Francisco 49ers.

“I knew of CTE,” Borland said in an interview for the program. “I didn’t know what the acronym stood for. I started with Google searches. I started looking at things: what does this term mean? Where is the research done?”

Borland understands that as a player he was prone to both receiving and inflicting trauma-producing hits. “You understand on a certain level what you’re doing,” he said, “but you don’t know the science behind it.”

In March 2015 Borland spoke to Robert Stern, Ph.D., of the [Boston University CTE Center](#).

The documentary update cuts to an interview with Stern explaining that knocking heads in pro football is the “equivalent of driving a car at 35 MPH into a brick wall, a 1,000 to 1,500 times per year.”

After that call, Borland immediately retired from football.

“The idea that just the basis of the game, repetitive hits, could bring on a cascade of issues later in life, it changed the game for me,” he explained.

Is football safe?

Borland’s [decision](#) shocked the sports world.

Goodell immediately began damage control.

“I think our game has never been more exciting,” he said in a TV interview replayed by *Frontline*. “It’s never been more competitive. And I don’t think it’s ever been safer.”

“It’s dishonest, and I don’t think it’s responsible, to say that the game is safer,” Borland countered in the *Frontline* report. “I think that’s just not true, and the players themselves on the field know. I mean, they’d scoff at that. That’s not accurate.”

Borland recalled that the NFL’s own actuaries estimated that 30 percent of the league’s veterans would develop brain damage.

“I really don’t watch football anymore,” he said.

Concussion safety advocate [Chris Nowinski](#), a former Harvard University football player and professional wrestler, said of Borland’s retirement: “It really made me wonder: if every NFL player had the access to the information he has, would they make the same choice?”

You can watch a *Frontline* report on Borland in the video below.

Why the NFL Should Be Scared of Chris Borlan



Continued risks

A steady flow of other reports in 2015 further highlighted the risks of football.

In August, a research study underscored the growing concerns about the impact of youth football.

In November, lawyers for the thousands of former NFL players and families who were awarded a \$1 billion payout from the league for cognitive difficulties from concussion-related injuries returned to court to request an appeal so that CTE can be covered in the settlement. A decision on the appeal is expected in early 2016.

Also in November, the family of Pro Football Hall of Famer Frank Gifford, who died in August, revealed that he suffered from CTE and had shown signs of cognitive debilitation.

That month, continued weaknesses in the NFL's concussion policies became evident as several players suffered conditions but continued to play because they were diagnosed only after their games.

Refusing to back down

Contrary to *Concussion's* and Dr. Omalu's assertions that he discovered CTE, medical researchers have been investigating the disease since at least the 1940s.

At that time, they focused on the risks of boxing. It's no surprise that doctors and researchers have now found the disease in football players.

The themes of *Concussion* are deeply familiar to neurological disease communities. In the Huntington's community in particular, affected families, advocates, researchers, and drug developers witness both the majesty and delicateness of the brain on a daily basis. We seek badly needed treatments for an incurable disorder that disables people physically and cognitively, turning them into a mere shadow of themselves.

Although ignorance and denial might still lead some to view HD as some personality quirk – just as deniers of football trauma dismiss the link between head trauma and behavioral problems – the informed members of the HD community know that this medical condition can be explained by science.

Despite the campaign against him, Dr. Omalu refused to back down. He drove home how dangerous football can be. The film reminded me of my realization years ago that I could no longer watch football with a clear conscience. Now I rarely watch it at all.

Those affected by HD, Alzheimer's, Parkinson's, Lou Gehrig's, traumatic brain injury, and the myriad of other neurological and rare diseases should also not back away from their commitment to advocacy. Dr. Omalu's example gives us courage to keep fighting for a clearer understanding of these conditions, better care for those who suffer from them, and ultimately the development of effective treatments.

Click on the links below to read my previous reports about the concussion crisis.

["It's playoff time - and a reminder that brain health comes first"](#)

["Junior Seau, Super Sunday, and our most important national resource"](#)

["Finding America's passion: the NFL and Huntington's disease"](#)

Posted by [Gene Veritas](#) at 11:15 PM



Labels: [Bennet Omalu](#) , [boxing](#) , [chronic traumatic encephalopathy](#) , [Concussion](#) , [denial](#) , [Frontline](#) , [Huntington's disease](#) , [Mike Webster](#) , [National Football League](#) , [scientists](#) , [stigma](#) , [suicide](#) , [symptoms](#) , [Will Smith](#)

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