GAME CHANGERS

HOW dramatic brain discoveries are influencing America’s most popular sport

UNDER THE MICROSCOPE, the tan image with brown splotches resembles a burned map, its edges singed and riddled with dark squiggles that shouldn’t be there. This is a piece of brain from a 45-year-old man: former National Football League linebacker John Grimsley, who suited up for the Houston Oilers for nine years and absorbed at least 11 concussions during professional and college play.

In the years leading up to his death, Grimsley had changed. He became forgetful and scattered, quick to anger, flying into a rage over household garbage, certainly not the man Virginia Grimsley had married. When he forgot about the engagement party for his son and future daughter-in-law, Virginia knew something was gravely wrong. “We’d been talking about the party every day for the past week,” she said at the time. “I was shocked.”
ANN McKee, a School of Medicine associate professor of neurology and pathology, slips the sliver of brain from the microscope and pulls another from a wooden tray of slides. In the viewfinder, there are brown commas, tangled grammar everywhere. “This is his frontal cortex,” she says. “This is the part responsible for insight, judgment, and intellect. It’s completely congested and filled up with tau, an abnormal protein that forms tangles that strangle and destroy brain cells.”

In February 2008, Grimsley, an outdoorsman who’d grown up with guns, shot himself in the chest while cleaning his firearm. Police ruled his death an accident. A week later, when McKee looked at his brain, she found the congestion, evidence of chronic traumatic encephalopathy (CTE). It was her first discovery of the degenerative brain disease in a former professional football player. As an Alzheimer’s researcher based at the Veterans Affairs Medical Center in Bedford, Mass., she had seen CTE in the brains of boxers—she knew the condition as dementia pugilistica, more commonly known as punch-drunk syndrome. She’d also read about it in battered wives. Conventional wisdom held that if you avoided the ring and abusive husbands and always wore a helmet, you’d be OK.

“When I showed the results to my brother, who is also a doctor and played football, he said, ‘You’re going to ruin football,’” recalls McKee, a diehard Green Bay Packers fan, with Brett Favre bobbleheads on her shelf to prove it. “I definitely felt we were opening a Pandora’s box.”

But far from ruining the sport, McKee and her fellow codirectors of BU’s Center for the Study of Traumatic Encephalopathy (CSTE) are credited with helping make the gridiron safer, not only for exceptionally well-paid athletes, but for the millions of kids who strap on helmets and pads and emulate their idols.

“What BU brought to the table was an explanation for some of the bizarre behavior we’d seen in a number of players whose lives were cut short, many because of suicide or what were thought to be accidental injuries,” says Kevin Guskiewicz, chair of the exercise and sport science department at the University of North Carolina and author of a 2003 study linking concussions in retired NFL players to clinical depression.

At the time of McKee’s discovery, Grimsley was the fifth former NFL player diagnosed with CTE. The untimely deaths of the others often followed years of strange behavior. “Iron Mike” Webster of the Pittsburgh Steelers, felled by a heart attack at 50, took to living in his truck and at train stations and tazing himself to relieve back pain. Steelers lineman Terry Long, 45, killed himself by drinking antifreeze. Philadelphia Eagles defender Andre Waters put a gun to his head at age 44. And 36-year-old Steelers lineman Justin Strzelczyk died in a high-speed police chase.

For years, the NFL downplayed the link between head blows on the field and brain damage later in life. The league’s medical advisor had this to say about Guskiewicz’s 2003 findings: “When I look at the study, I don’t believe it.”

Then, in the middle of the 2009–2010 NFL season, the $8 billion-a-year industry appeared to run a single reverse. It
The TV networks, which draw several hundred million viewers a season, have toned it down, too. Punishing hits are considered too valuable (to both the game and the media) to take time off the field, now ride the bench after a head injury. Independent neurological experts, rather than team trainers or NFL doctors, now decide when they can return. Every locker room in the league is hung with new posters that spell out the dangers of brain injuries and the steps to take if symptoms appear. And more changes may be in store. The league is considering eliminating the three-point stance and reducing full-contact practices.

At the same time, the league began broadcasting public service announcements during games warning young football players about the dangers of head trauma. Off the field, the leaders of the league’s 15-year-old Mild Traumatic Brain Injury (MTBI) Committee, which had assailed studies linking head injury with CTE, were forced out, and the committee’s research was abandoned. In March 2010, it was replaced with the entirely new Head, Neck and Spine Medical Committee, populated with neurosurgeons, retired players, and former critics, including Guskiewicz.

Since April 2010, NFL commissioner Roger Goodell, who took the helm in 2006, has made it his mission to lobby for youth concussion legislation in all 50 states. The same month, the NFL surprised researchers at the Center for the Study of Traumatic Encephalopathy—which had become one of the league’s most persistent critics—with an unrestricted gift of $1 million for further CTE research. It also promised, along with the NFL Players Association, to encourage active and retired players to donate their brains to the BU center. The last time football had seen radical morphing was in 1905, when President Theodore Roosevelt summoned a handful of college presidents to the White House after 18 on-the-field deaths, leading to the invention of the forward pass and creation of the National Collegiate Athletic Association (NCAA).

“The culture was markedly different four years ago,” says Peter Keating, a senior writer at ESPN the Magazine. “Concussions at all levels of play were just ‘dings.’ Hits to the head were just another kind of hit. And players were ‘warriors’ who were supposed to walk it off. People had a sense that there was something different about injuring your brain and injuring your forearm or knee, but they didn’t know how. The culture was to play through it, shrug it off.”

Look closely at a football game this year, and several changes are apparent. Star quarterbacks, who were once considered too valuable (to both the game and the media) to take time off the field, now ride the bench after a head injury.
At 29, Nowinski couldn’t help but wonder about his future. He knew all about the force of helmet-to-helmet contact and wrestling moves like the Dudley Death Drop, how the brain smacks against the cranium after the body stops moving. He knew about the stretched nerves and release of proteins that take over healthy cells in the parts of the brain responsible for judgment, impulsivity, memory, mood, and cognition. And he knew about the depression and the dementia. “I assume at some point I’m going to have to deal with this,” he says. “I just use it as motivation to keep working hard and keep working fast.”

Nowinski also knew that to make his most persuasive case about the dangers of head injuries in sports, he needed science with a capital “S.” A handful of case studies wouldn’t cut it. In June 2007, he partnered with the elder statesman of concussion research, Robert Cantu, a neurosurgeon attached to Emerson Hospital and now also a MED clinical professor of neurosurgery, who wrote the original—and largely ignored—return-to-play guidelines in the 1980s. They formed the Sports Legacy Institute, a nonprofit brain trauma research outfit. Then one evening, Nowinski’s roommate returned from a lecture on the link between brain damage and Alzheimer’s. “He said, ‘Chris, you should check this guy out,’” Nowinski recalls. “So I met Bob and we sat down for an hour.”

Bob is Robert Stern, a MED associate professor of neurology and codirector of BU’s Alzheimer’s Disease Clinical and Research Program. After hearing Nowinski’s pitch to pair the Sports Legacy Institute with a high-profile university medical school, Stern signed on. Nowinski would supply the brains, literally. BU would supply the science. The University already hosted one of 30 federally funded Alzheimer’s research centers, had several brain banks, and employed one of the world’s foremost experts—McKee—on tau protein, the telltale marker of CTE. Stern didn’t have to ask her twice. The MED dean and several department chairs kicked in start-up money, and the result was CSTE, whose acronym would soon be cited by countless reporters around the country.

Stern makes it clear that BU was not the sole agent of change. Outspoken pathologists and doctors, a few dogged sportswriters, a self-critical NFL-sponsored study, and elected officials all started to push in the same direction.

July 2005
Researchers at the University of Pitts-
burgh publish the first finding of chron-
ic traumatic encepha-
lopathy (CTE) in an
NFL player’s brain.
The NFL demands a
retraction.

October 2006
Former professional
wrestler and Harvard
football player Chris-
opher Nowinski pub-
lishes Head Games:
Football’s Concussion
Crisis from the NFL to
Youth Leagues.

March 2007
The head of the NFL’s
MTBI Committee
leaves his post amid
controversy over his
lack of appropriate
medical credentials.
The league estab-
lishes the 88 Plan,
which provides funds
for former players
struggling with
Alzheimer’s disease
and dementia.

May 2007
NFL commissioner
Roger Goodell an-
nounces mandatory
neuropsychological
testing for all players
and a “whistle-blower
system” to report
coaches who force
concussed players to
return to the field.
and things began to move with the inevitability of a freight train. But CSTE was shoveling some serious coal in the engine room.

MORE WORRISOME FINDINGS
Once Stern, Nowinski, McKee, and Cantu, who jointly codirect CSTE, joined forces in September 2008, headlines soon followed. News about the damage found in John Grimsley’s brain was accompanied by the announcement at a press conference of a brain donation program, led by pledges from such notables as troubled former New England Patriots linebacker Ted Johnson, whose struggle with post-traumatic concussion syndrome has been painfully public, and female soccer star Cindy Parlow, who retired early with the syndrome.

By that time, the NFL's MTBI Committee had backed off some of its rhetoric from the mid-2000s, when it described the first worrying studies as “purely speculative” and “seriously flawed.” But it still expressed doubts about the credibility of the brain research. In response to BU’s findings of a link between concussions and CTE, NFL spokesman Greg Aiello told the New York Times, “Hundreds of thousands of people have played football and other sports without experiencing any problem of this type, and there continues to be considerable debate in the medical community on the precise long-term effects of concussions and how they relate to other risk factors.”

Three months later, the CSTE team held another news conference, this time in Tampa, Fla., against the backdrop of the 2009 Super Bowl. McKee had found CTE in the brains of two more athletes. The first was former Tampa Bay Buccaneers offensive lineman and successful restaurateur Tom McHale, who had died of a drug overdose at 45. As Virginia Grimsley had done earlier, McHale's widow, Lisa, now the single mother of three young boys, took part in the announcement.

The second case described at the news conference was even more disturbing: the early signs of CTE had been found in the brain of an 18-year-old high school athlete, a football player who had suffered multiple concussions.

“This was earth-shattering,” Cantu says. “To see initial-stage chronic traumatic encephalopathy at that age is hugely worrisome. It’s something no 18-year-old should have.”

With more than 1.2 million teenagers playing football every fall, many through the independent, nonprofit USA Football, and several million preteens playing at the Pop Warner level, the weight of the message had increased exponentially. The CSTE team had known that it would. “The NFL made it about NFL players,” Nowinski says. “We made it about kids. We said this is not about what’s happening to grown men who make a lot of money. This is about one in eight boys in this country who play the sport and where everybody models what they do on the NFL. They have a responsibility, especially since they’re funding USA Football, to take care of them and acknowledge them. It was about changing the terms.”
In May 2009, the NFL invited McKee, along with other concussion researchers, to present her findings to the MTBI Committee in New York.

“I’m from a small town in Wisconsin,” she says. “NFL headquarters is on Park Avenue. You get photographed and IDed on the way in. You’re taken to this big mahogany boardroom with Vince Lombardi posters everywhere and a bunch of men sitting around a big table. I insisted Chris come. It was intimidating. I was the only woman. There was a lot of testosterone in the room. They were very skeptical. One of them said I was making up the disease. They were polite, but you felt like it was falling on deaf ears.”

Alan Schwarz, however, a freelance baseball reporter whom Nowinski first approached in 2007 with the Andre Waters story, had been capturing every word. He has since been hired by the New York Times, which kept the narrative on its front page, earning two Pulitzer Prize nominations along the way for Schwarz’s coverage. It wasn’t long before Bob Simon of 60 Minutes showed up at McKee’s office, followed by Malcolm Gladwell of the New Yorker. The issue had reached the water coolers.

THE LAST STRAW

In early October 2009, as BU’s School of Medicine was gearing up to host a conference on athletes and concussion at Gillette Stadium, in Foxboro, Mass., home of the New England Patriots, the results of a long-touted study commissioned by the NFL had leaked to the media. The research showed the prevalence of dementia, Alzheimer’s, or other memory-related diseases among retired players to be as much as 19 times higher than in the general U.S. male population. The league claimed the study was incomplete. Further findings, it said, would be needed.

“They had a very bizarre reaction,” Nowinski says. “They paid for the study, yet they tried to distance themselves from it. But you understand their position. The guys who commissioned the study are probably not the same guys who had to react to it.”

The study, conducted by the University of Michigan, helped prompt the House Judiciary Committee, headed by Michigan Democrat Frank Conyers, to order the first of several hearings on the subject. At the end of October 2009, Nowinski, Cantu, and McKee testified, along with dozens of other researchers, doctors, players, players’ wives and widows, league executives, and players’ union officials.

“They were a lot of ex–football players there,” McKee recalls. “The older ones reminded you of a neurology clinic. It was very sobering. You got the sense that this was mainstream.”

Stern believes that even as some in the NFL expressed doubts, Goodell and a few other league leaders had grasped the scope of the concussion problem before the hearings. In 2007, a year after Goodell took over, the league had established a fund for retired players struggling with dementia.

“Unfortunately, things were moving too fast and Goodell was made to look like a villain, when, in fact, he wasn’t,” Stern says. “He was stuck with having to deal with people who were still in important positions within the NFL, people who were the old guard. He wasn’t just going to undo things until he learned more.”

January 2009
CSTE announces two new cases of brain degeneration in deceased players, including one high school athlete who was only 18 years old.

October 2009
Results of an NFL commissionersed study are leaked. They show a significantly higher incidence of Alzheimer’s, dementia, and other memory-related diseases among former NFL players. The U.S. House of Representatives Judiciary Committee holds hearings to examine the NFL’s alleged neglect of former players with brain injuries.

November 2009
NFL agrees to require independent neurologists, rather than league doctors, to treat players with brain injuries. NFL, along with the U.S. Centers for Disease Control and Prevention, broadcasts public service announcements warning youth of the dangers of head trauma.

December 2009
NFL publicly states its intent to give CSTE $1 million to fund its research.

February 2010
Eighteen more former and active NFL players agree to donate their brains to CSTE. They join 250 other athletes, 60 from the NFL.
HARD-KNOCK LIFE

BU researchers have found a link between repetitive head trauma and a new form of motor neuron disease similar to amyotrophic lateral sclerosis (ALS), or Lou Gehrig’s disease. The findings were published in the September 2010 issue of the Journal of Neuropathology and Experimental Neurology.

“The significance of this finding is that not all ALS-like disease attacks out of the blue,” says MED’s Ann McKee. “Sometimes it’s because of our choices in life.”

McKee and her colleagues discovered the new disease while examining the brains and spinal cords of 12 athletes stored in the CSTE brain bank. Each showed evidence of the neurodegenerative disease chronic traumatic encephalopathy (CTE), but two former NFL players—Wally Hilgenberg of the Minnesota Vikings and Eric Scoggins of the San Francisco 49ers—as well as a boxer, developed motor neuron disease late in their lives. Scoggins died in 2009, at age 49, and Hilgenberg in 2008, at 66. Both had been clinically diagnosed with ALS, although they also showed behavioral changes and cognitive decline, which is associated with CTE.

In the three athletes diagnosed with ALS, McKee found the abnormal protein TDP-43 in the brain and spinal cord in a unique pattern, along with deposits of an abnormal form of tau protein. Abnormal tau deposits, a marker of CTE, are not found in ALS.

The findings suggest that the motor neuron disease that affected the three athletes, while similar to ALS, represents a distinct disease never before described in the medical literature. McKee and her colleagues have named it chronic traumatic encephalopathy (CTEM), and believe that it is caused by repetitive head trauma sustained in contact sports such as football and boxing. CD

In November 2009, Goodell, in Boston for an owners’ meeting, asked Cantu to swing by for a private get-together. They talked for 90 minutes about ways to move the league forward on the concussion issue. Cantu stressed the importance of education at the USA Football level and of shutting down the MTBI Committee. Both have since happened.

“Goodell allowed for the appointment of some of the biggest critics to the new Head, Neck and Spine Medical (HNSM) Committee,” Cantu says. “Kevin Guskiewicz was a very vocal critic and had gotten into brouhahas with the original chairman. Now, lo and behold, he’s on the committee. To me, that shows great integrity. It’s pretty amazing the landscape today versus a few years ago.”

The HNSM Committee cochair, Richard Ellenbogen, a Seattle, Wash.–based neurosurgeon and longtime youth concussion awareness advocate, is now consulting with Cantu, who was appointed senior advisor to the committee.

“Bob Cantu has been one of the biggest names in concussion awareness and has been an amazing asset to all U.S. governors.”

THE REST OF THE ICEBERG

For Nowinski, McKee, Cantu, and Stern, the quarrel was never with the game of football, although they were accused often enough along the way of being “football-killers.” All of them are fans who hit the couch on Sunday afternoons. McKee is an NFL Network subscriber. Stern’s son played the game. “It was always about education and awareness,” Nowinski says.

McKee has since found CTE in 26 other brains: a hockey player, pro wrestlers, boxers, and college and semipro football players. She is also probing the brains of combat soldiers exposed to bomb blasts. “This isn’t just an NFL problem,” she says. “It’s an enormous public health problem.”

Beyond concussions, the CSTE crew has been exploring the cumulative damage caused by repeated, but less violent, head knocks on the field. The National Institutes of Health is currently reviewing a $9 million grant application the center has submitted to work on diagnosing CTE in living patients.

“The rest of the iceberg is a gazillion times bigger and scarier,” says Stern. “It includes everything from the linebackers in high school or Pop Warner who in every play in every practice and every game are hitting their heads. They might not be diagnosed with a concussion, but we’re talking 500 to 1,500 times a season whacking their heads. Even in something like soccer, we have no idea what those repetitive, very mild, nonsymptomatic headings cause. That’s the stuff we’re trying to understand.”