

December 25, 2013

New Tests for Brain Trauma Create Hope, and Skepticism

By **KEN BELSON**

Revelations in recent years that thousands of former football players might have severe brain trauma from injuries sustained on the field have set off a rush in the medical community to seize the potentially lucrative market for assessing brain damage. But experts say claims regarding the validity of these assessments are premature and perhaps unfounded.

Most researchers believe that C.T.E., or chronic traumatic encephalopathy, the degenerative brain disease found in dozens of former N.F.L. players, can be diagnosed only posthumously by analyzing brain tissue. Researchers at [U.C.L.A.](#) have developed a test they assert might identify the condition in a living person by injecting a compound that clings to proteins in the brain and later appears in a PET scan. But some are skeptical.

“There has really been so much hype surrounding C.T.E., so there is a real need for making sure the public knows that this type of science moves slowly and must move very carefully,” said Robert Stern, a professor of neurology and neurosurgery at Boston University School of Medicine and a founder of the [Center for the Study of Traumatic Encephalopathy](#). He is part of a group that is developing a different biomarker to identify tau, the protein that is a hallmark of C.T.E.

“My fear is the people out there who are so much in need, scared for their lives and desperate for information, it might give them false hope,” he said.

The debate over the scientific validity of such brain exams was [highlighted recently when Tony Dorsett](#), a Hall of Fame running back for the Dallas Cowboys, and several other prominent former players said they were found to have C.T.E. after taking the experimental test developed by U.C.L.A. Dorsett, 59, told CNN that “they came to find out I have C.T.E.” and that his memory lapses, short temper and moodiness were “all because of C.T.E.”

Despite what was widely reported as a diagnosis, the experimental test is perhaps years from gaining federal approval. An antidote is even more remote because C.T.E. is a degenerative condition with no known cure.

That is why neurologists, researchers and bioethicists question whether the doctors at U.C.L.A. and at TauMark, the company with the exclusive license to commercialize the test, may leave some former players and their families with false hopes or undue worry.

For instance, the [website for TauMark](#), which has helped find retired players to take the test, states that the test could soon provide a “clinical diagnosis and summary.” One of the doctors backing TauMark called the test “the holy grail of C.T.E.”

“I can see getting awareness and publicity, but this sounds like putting the cart before the horse,” said Dr. John Morris, a professor of neurology at Washington University School of Medicine in St. Louis. “In theory, they’ll be useful. But we don’t know for an individual, does this mean inevitably they will dement? We just don’t know.”

The scan for tau is far from the first test promoted as a new window to an emerging medical problem. An array of medical experts is now developing and marketing treatments for former players that include vitamin regimens, strict diets, testosterone treatments and other therapies.

Bernie Kosar, a former Cleveland Browns quarterback, has said that he received oral and intravenous treatment for brain trauma from Rick Sponaugle, the director of the [Sponaugle Wellness Institute](#) in Palm Harbor, Fla. Dr. Daniel G. Amen, the founder of Amen Clinics Inc., said this year that he had developed “an interventional strategy” that would “reverse brain damage” in athletes.

The search for remedies to the long-term cognitive problems associated with concussions and chronic brain trauma has received great attention not only because N.F.L. players are involved, but also because the health of millions of young football players could be at stake. The N.F.L. is spending tens of millions of dollars on research into concussion-related ailments.

The ability to diagnose C.T.E. in living players also has potential legal and financial consequences as former players fight for insurance coverage, workers’ compensation and other medical benefits well after they received their injuries.

A successful test to identify C.T.E. in living patients could also provide a big payoff for its inventors and rights holders. The tests cost as much as \$15,000, but the price would presumably fall as more people signed up for them.

The retired players tested at U.C.L.A. said they did not pay for the test. Financing for the first group of tests was paid in part by the [Brain Injury Research Institute](#), whose co-founder Julian Bailes co-wrote [a study on the FDDNP biomarker](#).

But quick fixes in medicine are rare, even when fortunes are being spent developing solutions. For C.T.E., which still lacks a clinically accepted diagnosis among living people, let alone a biomarker approved by the Food and Drug Administration, the answers are even more elusive.

“The condition is very much under debate,” said Dr. John Trojanowski, a researcher at the Perelman School of Medicine at the University of Pennsylvania. “We need to be patient to get more research to determine what statements we can make about football players’ pathology.”

Bob Fitzsimmons, a director at TauMark, said he believed that the publicity around his company's biomarker had been fueled by the news media. "We're well aware of the rush to have stories and a magical cure and diagnosis, and the media tries to get the jump on that," he said. "But science takes time, and that's what we're trying to do."

The doctors developing the test declined to discuss what they had told the players, citing doctor-patient confidentiality. But they stressed that their research was still in its infancy — only nine former players were known to have taken the test so far. Many more participants are needed to "get a better understanding of what the test results mean," Dr. Gary Small, the professor at U.C.L.A. leading the research effort, said in an email.

He declined to confirm any details about the tests, including the identities of the players, and said the players who discussed their tests had done so on their own. Early this year, Small and other researchers [published the results of the tests](#) given to the first batch of players in the American Journal of Geriatric Psychiatry.

"We appreciate the enthusiasm about the test, but we are still in the early stage of investigation," he said in an email.

It is unclear whether the players were given advice regarding public statements about the test. But their appreciative statements in the news media, which amounted to an endorsement of the test, were as effective as any news release or journal article in creating interest. More former players have reportedly inquired about taking the test after comments made by Dorsett and by other players, including the Hall of Famer Joe DeLamielleure and the former All-Pro defensive lineman Leonard Marshall.

Many in the news media have done little to scrutinize the athletes' claims. Words like diagnose and biomarker have precise medical meanings that can be misleading when incorrectly used, said Gary Schwitzer, the publisher of [HealthNewsReview.org](#), a blog that tracks medical reporting by the news media.

The results of an experiment, for instance, are not a diagnosis, which conveys a definitive answer, he said. A biomarker is a value that can serve as a reliable substitute for identifying a disease, not evidence of the disease per se.

Schwitzer and several doctors who study cognitive issues said that the research at U.C.L.A. was important and even promising, but far from definitive. Yet many players have suggested the test is conclusive. For instance, Marshall, who played 12 seasons for the Giants, the Jets and the Washington Redskins, said he had the third highest of the four levels of C.T.E.

"I kind of knew and had an idea that I was up against something that was pretty serious, but I had to check it out," he said, adding that he experienced "fogginess" and short-term memory loss. "The test, it's extremely definitive: I have C.T.E."

Some medical experts question the utility of biomarkers to identify C.T.E., Alzheimer's disease and other ailments despite the vast sums spent to develop them. While a negative test might confirm that a patient does not have a

disease, a positive does not ensure he or she has it, will develop it or will ever experience symptoms like memory loss or dementia.

The skepticism, though, appears not to have slowed the spending on biomarkers and the search for solutions to sports-related [head injuries](#).

“It’s because the issue is so prevalent in our everyday culture that we’re even talking about this,” said Dr. Alexander Powers, an assistant professor of neurosurgery, pediatrics and orthopedics at Wake Forest Baptist Medical Center in Winston-Salem, N.C.

“Name any other disease in which a new diagnostic test has been developed and only tested in five patients, yet it garners front-page headlines,” Powers said. “If tomorrow a new breast cancer diagnostic study was announced, we wouldn’t talk about it on a national level until it was validated through rigorous scientific review. Truthfully, from a scientific point of view, we need to do more.”