

# 2019 ANNUAL REPORT

# CONCUSSION LegacyFoundation





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### **LETTER FROM LEADERSHIP**

Through more than a decade of education, research, and advocacy, the Concussion Legacy Foundation has changed the global conversation on the problems of concussion and CTE. In that time, achievable solutions for both patient health and public health have become clearer.

In 2019, we updated our mission statement to capture the three areas of focus that will create the sustainable change needed.

First, our mission is to "support athletes, Veterans, and all affected by concussions and CTE."

Concussions and CTE can be overwhelming to fight alone. We launched the CLF HelpLine (pgs. 22-23) to provide urgently needed one-on-one support, resources, peer-to-peer mentors, and medical referrals to patients and families.

Project Enlist (pgs. 34-35), our program to accelerate the study of CTE, TBI, and PTSD in military Veterans by increasing the rate of brain donations, recruited a record number of Veteran brain donations and pledges.

Second, our mission is to "achieve smarter sports and safer athletes through education and innovation."

Our award-winning Tackle Can Wait (pgs. 10-13) campaign and PSA, built on data from our groundbreaking brain bank study (pg. 27), was seen more than 1 billion times and delivered a lifesaving message for parents: wait to enroll your children in tackle football until age 14 and you should dramatically decrease their odds of developing CTE.

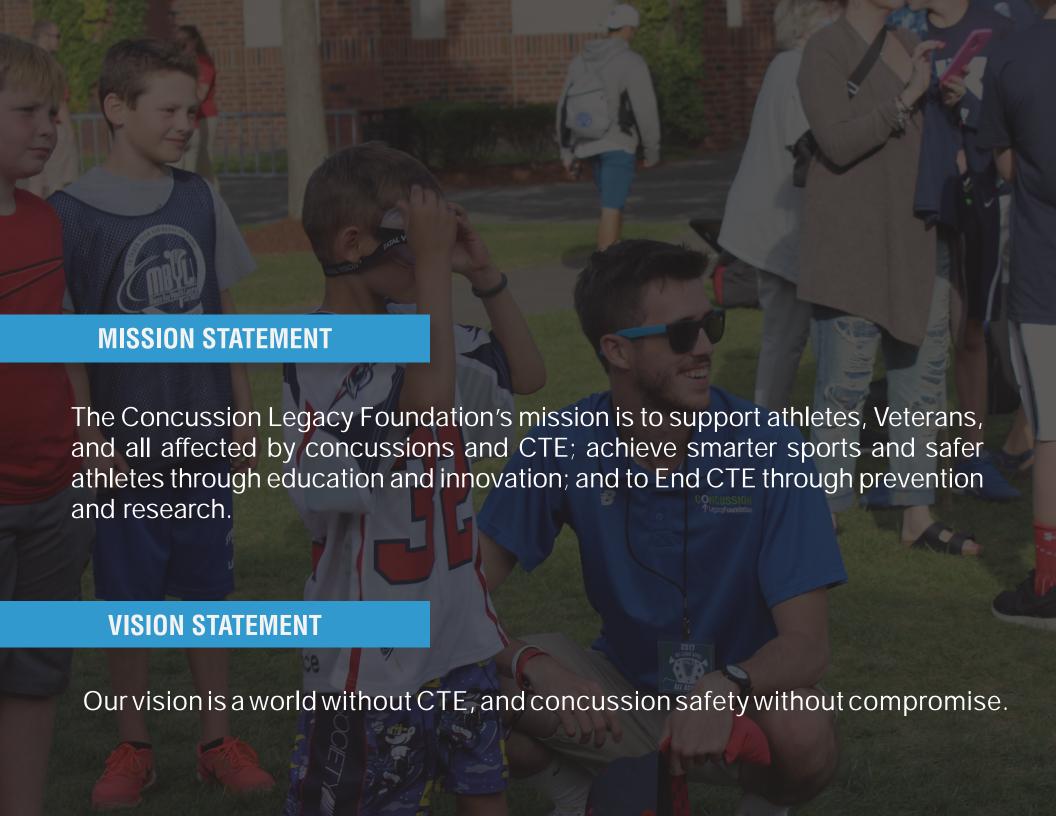
Third, our mission is to "End CTE through prevention and research."

Our 2018 investment in the CLF Global Brain Bank paid off in just one year by changing the conversation on CTE in Australia (pgs. 28-29). In December we welcomed our newest member, the University of Auckland in New Zealand, which we anticipate will change the global rugby conversation.

Thank you for helping the Concussion Legacy Foundation. With your support, we will continue to make progress toward smarter sports, safer kids, and a world without CTE.

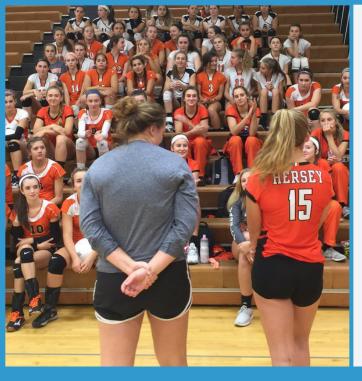
Sincerely,

Christopher Nowinski Co-founder and CEO Robert Cantu Co-founder & Medical Director John Corcoran President, Board of Directors









### The Team Up Speak Up Speech:

- 1. "We're a team and teammates look out for each other.
- 2. A teammate with a concussion needs your help.
- 3. I expect you to **SPEAK UP** to a coach or an athletic trainer if you think a teammate has a concussion."



### **TEAM UP SPEAK UP**

Team Up Speak Up is our national concussion awareness program designed to mobilize athletes in the fight against concussions.

This unique and innovative program was launched in response to studies revealing that standard concussion education, which asks players to self-diagnose their concussion and remove themselves from the game, is ineffective in changing behaviors. Team Up Speak Up, built on the bystander intervention model, uses a train-the-trainer approach to teach coaches how to give an effective speech to their team that reframes concussion awareness as being a good teammate. Players are told that a player with a concussion needs help, and a good teammate will speak up to the coach or athletic trainer if they suspect a concussion in a teammate.

### 2019 Highlights:

Participation from 300+ organizations representing 6.25M athletes

Participation in all 50 U.S. states and 21 NFHS state high school associations

# 2019 Major Participating Organizations:

















### **2019 National Governing Body Partnerships**

Team Up Speak Up Weeks











USA Hockey Oct. 20-26





The Concussion Legacy Foundation is leading a global conversation about reforming youth sports to remove repetitive head impacts. In January 2018, we launched Flag Football Under 14, a multi-year campaign to educate parents on the risks of tackle football before 14 and suggesting they choose flag football instead.

In October 2019, we timed the release of our "Tackle Can Wait" campaign with a major new study from the VA-BU-CLF Brain Bank (pg. 26). "Tackle Can Wait" consisted of a Telly-Award-winning 30-second public service announcement (PSA) and Webby-Award-nominated microsite (pg.11).

A special thanks to marketing agency Fingerpaint, who created and executed the campaign pro bono. Angela Campigotto-Harrison was the lead creative from the Fingerpaint team. Her father, Joe Campigotto, was diagnosed with CTE after his death in 2016.

The study revealed that the link between tackle football and CTE may be stronger than the link between smoking and lung cancer. That comparison inspired the viral hook of the PSA that shows youth tackle football players – with smiling encouragement from coaches and parents – smoking cigarettes while playing. The video's voiceover, narrated by a child, leaves adult viewers with a compelling question: "You wouldn't let me smoke. When should I start tackle?"



# fingerpaint



The PSA was directed by award-winning filmmaker Rebecca Carpenter (left), who lost her father Lew Carpenter to CTE in 2010. It received over 700 million impressions in the first week and inspired feature segments the TODAY Show, The Doctors, and three separate Fox News debate segments. It was also covered by CNN, NBC News, and hundreds of local news outlets (pg. 12).



Parents are hearing the message. Primarily due to our CTE awareness efforts, over the past five years, youth tackle football participate is down 17.4% while flag football is up 38.9%. In 2017, flag football became more popular than tackle football for children, and the gap continues to grow every year.

### **Tackle Can Wait PSA Highlights**

>1 Billion Impressions from television, print, and digital reach

Two Telly Awards Gold, Promotional Video, Sports Silver, Promotional Video, Nonprofit







## Concussion PSA compares youth football dangers to smoking

Everybody seems to be having fun when the kids are playing football in the PSA, until one boy is thrown to the ground. Then, the coach starts handing out cigarettes.

YAHOO!

Kids shown smoking cigarettes in shocking new PSA

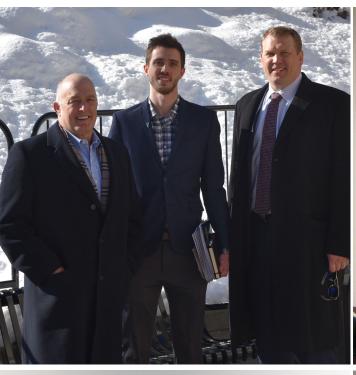


Concussion PSA compares youth football dangers to smoking

By JIMMY GOLEN October 10, 2019



New PSA warns parents to avoid youth tackle football by comparing it to smoking







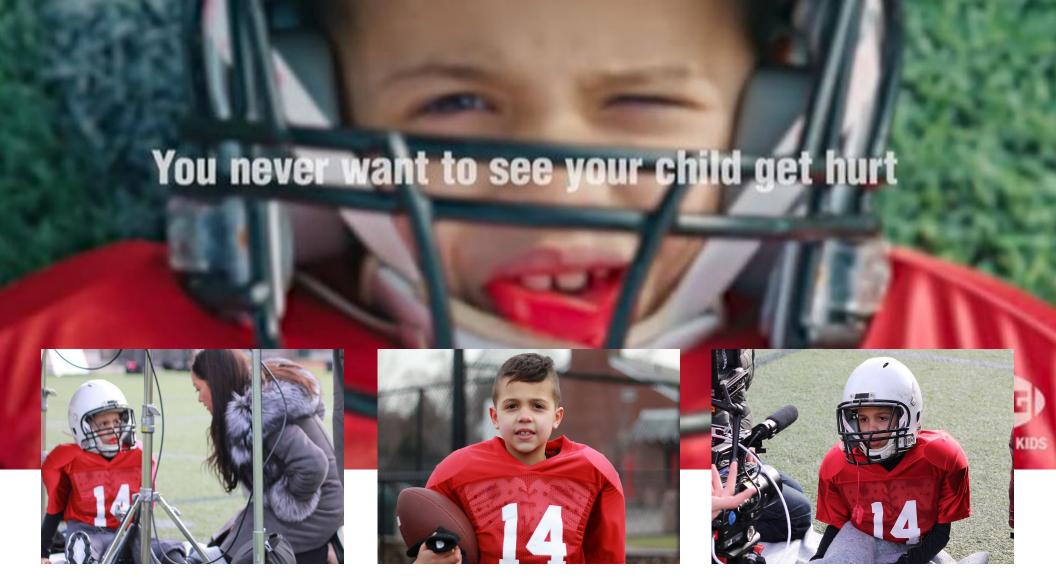


Tackle Can Wait bolstered CLF-supported legislative efforts to ban tackle football for children. Legislation has been introduced in California, Illinois, Maryland, Massachusetts, New Jersey and New York.

Former NFL player Pete Cronan joined CLF Program Coordinator Brandon Boyd and CEO Chris Nowinski, Ph.D. (top left, L-R) to educate Massachusetts state lawmakers on the risks of youth tackle football. CLF Board of Directors member Angela Campigotto-Harrison (top right), the creative vision behind Tackle Can Wait, testified in favor of a youth tackle football ban in New York, telling legislators the impact of her father's battle with CTE on his family.

"This disease destroys families from nearly every angle you can think of," she said.

New York Advisory Board (NYAB) member Dr. Erich Anderer (bottom left), Chief of Neurosurgery at NYU Langone Hospital in Brooklyn, testified in favor of the legislation in New York, saying the data we now have on tackle football and risk of CTE should spur action to protect children. NYAB member and former Harvard University football captain Brendan Bibro argued that a youth ban was good for tackle football and would increase high school participation.



You never want to see your child get hurt. But what if they're getting hurt in ways you can't see?

That's the question we asked parents in our second captivating PSA of 2019. The video, developed pro bono by the creative minds at PJA Advertising, showed a familiar scene in a youth tackle football game: a child takes a hard hit and lies prone on the ground as parents and coaches holler a mix of concern and encouragement for him to get up.

A child's voiceover gives parents the facts: youth tackle football players can take 500 hits to the head in a season. Research suggests these repetitive hits – even if they don't lead to concussions – can cause the brain disease CTE. More than 60,000 people watched the video and learned through the eyes of a child why Flag Football Under 14 is the best choice.



Concussion Legacy Foundation co-founders Dr. Robert Cantu and Chris Nowinski, Ph.D. are proud to serve as advisors to more professional and collegiate sports organizations than any concussion-focused nonprofit in the world. By working with professional and collegiate sports to educate stakeholders and set policy, CLF sets the example for high school and youth sports to follow.

### **ADVISORY ROLES**













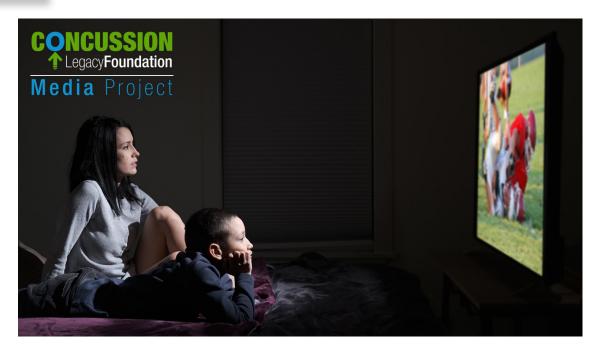




### **MEDIA PROJECT**

The CLF Media Project is the first and only concussion education program designed specifically for people in sports media. By training journalists on 22 lessons such as knowing their league's concussion protocols, accurately reporting on concussion signs, and retiring terms like "ding" and "bell-ringer", the Media Project gives sports media members the tools to inform their massive and hard-to-reach audiences about proper standards for concussion management.

The Media Project is divided into two parts: the Concussion Reporting Workshop, a curriculum for sports journalism programs at colleges across the country, and the Concussion Reporting Certification, a quiz for working journalists to get them up to speed on evolving concussion guidelines.





### 2019 Highlights

Concussion Reporting Workshop expanded to five new colleges

Taught at five of the top 10 journalism programs:
ASU, BU, Mizzou, Northwestern, Syracuse

Doubled the number of Concussion Reporting Certified Fellows (70)

## CONCUSSION REPORTING WORKSHOP



The Concussion Reporting Workshop was taught in **12 different** classes at eight colleges in 2019.

#### **Pilot Schools:**







New Schools in 2019:











# CONCUSSION REPORTING CERTIFICATION

Sports media professionals from some of the most recognized broadcast and print outlets are Concussion Reporting Certified:











THE ATHLETIC



More than 70 sports media professionals are Concussion Reporting Certified. Our new Certified Fellows cover football, baseball, baseball, hockey, and international sports.



AJ Mleczko Griswold Commentator NBC Sports



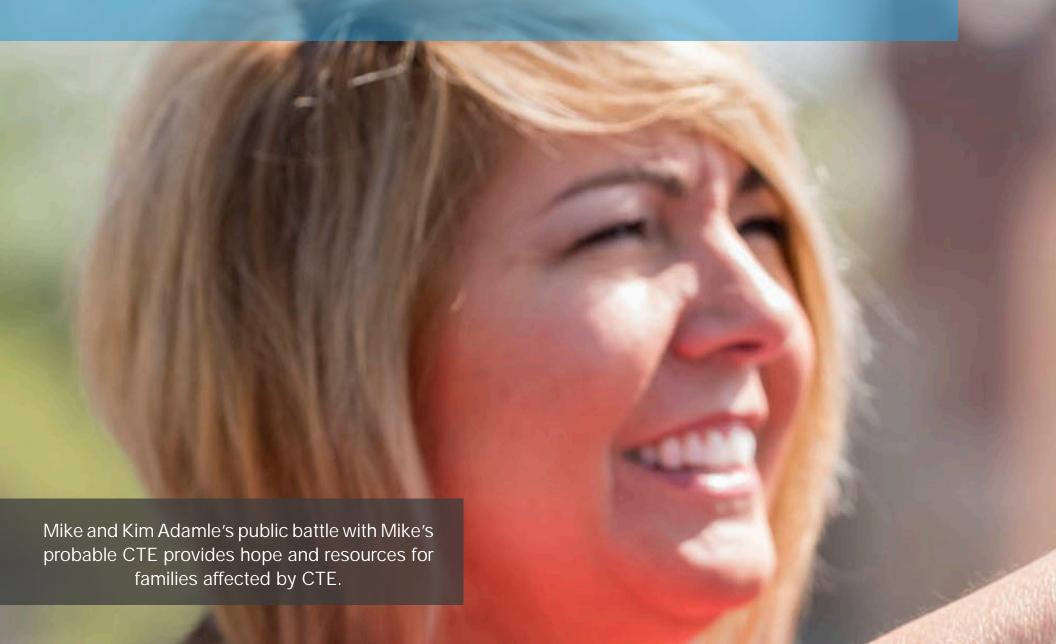
Michael Holley Host NBC Sports Boston



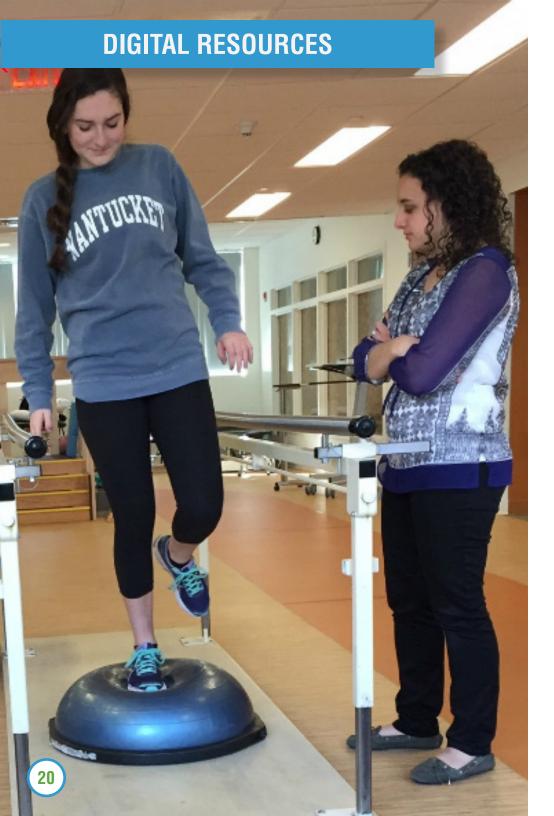
Mike Couzens
Play-by-Play
FSPN



# PATIENT & FAMILY SERVICES



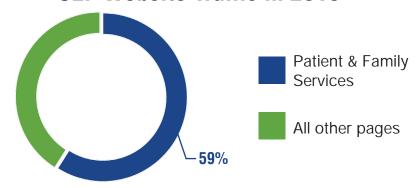




The Concussion Legacy Foundation is leading the fight against concussions and CTE and is dedicated to improving the lives of those impacted.

We have built an unprecedented web-based resource to help patients and families recover, cope, and maintain hope that better days lie ahead. Our Post-Concussion Syndrome (PCS) and Chronic Traumatic Encephalopathy (CTE) Resources pages account for the majority of our website visitors. When patients and families come to us looking for help, they find videos from experts, peer advice, explanations of treatments, coping strategies, and inspiring stories of recovery.

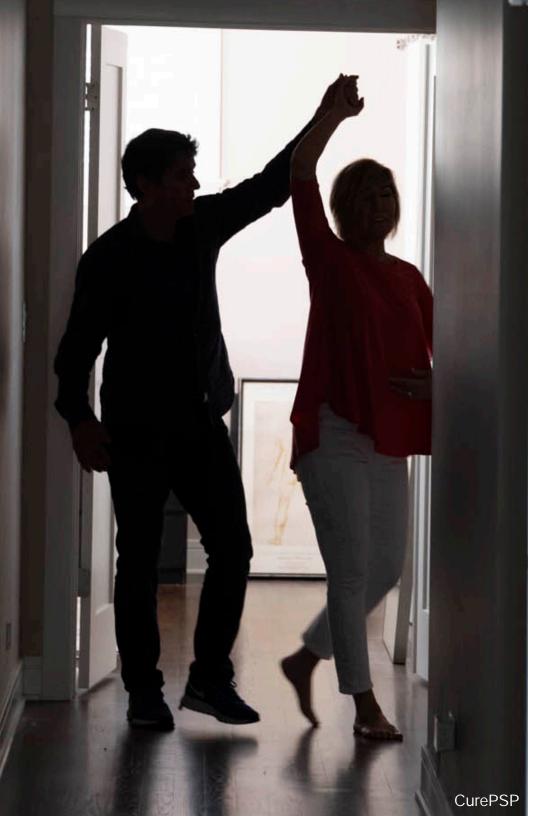
### **CLF Website Traffic in 2019**



### 2019 Highlights

150,000 views on Patient & Family Services videos

Top search rankings for: Chronic Traumatic Encephalopathy (1st), CTE (1st), Post-Concussion Syndrome (2nd)



We also provide patient and family resources through social media, and we surpassed **70,000 social followers in 2019**. For those who depend on us during their recovery from long-term symptoms, we publish patient and family-focused PCS and CTE Resources newsletters. These **targeted newsletter lists are now nearing a combined 10,000 subscribers and grew more in 2019 than in the previous three years combined.** 

Video content remains a feature of our digital resources, and in 2019 our audience averaged nearly 4,000 minutes of viewing per week. New videos in 2019 included tips from medical experts on diet and exercise, advice for wives and families experiencing intimate partner violence, strategies for parents of children suffering from PCS, and advice on living with possible CTE from Mike and Kim Adamle (pictured left).











CLF has always provided one-on-one support to patients and families who reach out for help. But in 2019, as our web traffic continued to climb, inquiries began to outpace capacity. To ensure we could match demand, we created the CLF HelpLine, which provides personalized, one-on-one guidance and resources to those struggling with the outcomes of brain injury. Lingering concussion symptoms or possible CTE can be isolating, frightening and frustrating. With the CLF HelpLine, we have created a service to specifically support these individuals and families in their time of need.

The CLF HelpLine provides doctor and medical provider referrals, online and printed collateral resources for concussion, PCS and CTE, and a peer-to-peer mentor network to help struggling patients and caregivers maintain hope.

Due to the success of the HelpLine, we will grow this service in 2020 by hiring a full-time Resource Coordinator, investing in digital promotion to reach more patients, expanding the referral network, increasing our mentor capacity, and expanding our video library.

"Thank you so much for all your help... this has given me the most hope."

-HelpLine User from Atlanta, GA November 2019

"You were the only one that reached out to try and help me and I can't thank you enough for that."

-HelpLine User from Chicago, IL, December 2019

"After all these years of struggling, it's nice to finally have someone that understands."

-HelpLine User from Santa Barbara, CA August 2019



Former gymnast Erin Payne (right) was a CLF Help recipient and has excelled in her recovery from PCS. Now, she's a HelpLine mentor for Kylie, who is also battling PCS symptoms.

### **HelpLine By the Numbers**

80 Help requests per month since launch

At least one Help request in all 50 states

62% request help with long-term concussion symptoms

40% of inquiries looking for help for a loved one







The VA-BU-CLF Brain Bank, led by Dr. Ann McKee, remains the leading CTE research program in the world. CLF cofounded the brain bank in 2008 and continues to lead outreach and recruiting efforts. In 2018, the brain bank grew by 24%, adding 159 new donations to end the year with 825 total. The brain bank holds an astounding 70% of the CTE cases ever diagnosed worldwide.

than 70 publications and made dozens of unique discoveries. The prestige and success of the VA-BU-CLF Brain Bank would not be possible without the generous gift of brain donation made by our Legacy Families, pictured above at our most recent Family Huddle, where we invite our families to meet the research team and learn how their donation has advanced science.



In October, lead author Dr. Jesse Mez, senior author Dr. Ann McKee, and the brain bank team published a game-changing study that investigated the correlation between years of play of American football and the odds of developing CTE.

While we don't yet know a football player's absolute risk of developing CTE, we are beginning to understand relative risks.

The study of the brains of 266 football players revealed that the odds of developing CTE increase by 30% per year of play.

That means the odds for CTE double every 2.5 years and increase tenfold after nine years. To put it another way, any future high school, college, or NFL player who starts tackle football at age 5 will have 10 times the odds of developing CTE than if they started at age 14.

This data informed our "Tackle Can Wait" campaign (pgs. 10-12). CLF is committed to educating football parents and coaches how delaying the introduction of tackle football by just three years would be expected to prevent more than 50% of future CTE cases.



In 2018, CLF created the Global Brain Bank to recreate our successful partnership with Boston University in other countries. The mission of the CLF Global Brain Bank is to accelerate research by collaborating with leading scientists at brain banks around the globe to understand, prevent, treat, and eventually cure CTE and other consequences of brain trauma.

Our first collaboration was with Dr. Michael Buckland (above, center) and the Australian Sports Brain Bank at the University of Sydney's Brain and Mind Centre and Royal Prince Alfred Hospital, soon followed by the University of São Paulo Biobank for Aging Studies in Brazil.



The Global Brain Bank has paid immediate dividends. In June, Dr. Michael Buckland (above, left) published the first two CTE cases in Australian National Rugby League (NRL) history. The discovery quickly created a national conversation on the consequences of head impacts in Australian sports and sparked reforms to contact sports.

One of the diagnoses was of former NRL star Steve Folkes.

Folkes' family (above) met with Dr. Buckland and chose to share their story publicly.

"If his story can help some of his mates and then help more research then that's what we want out of it," said his daughter, Hayley Shaw.



In December we announced the **University of Auckland in New Zealand as the newest member of the CLF Global Brain Bank**.

The New Zealand Sports Human Brain Bank Initiative will be part of the University of Auckland's Centre for Brain Research, led by internationally recognized neuroscientist Distinguished Professor Sir Richard Faull (third from right). Former members of the iconic All Blacks, New Zealand's national rugby union team, pledged their brains as part of the launch, garnering front page coverage in the New Zealand Herald.

"This is a massive chance to try to understand what is happening with me. Our age group, if we don't start now they'll have no research to study, that's why I pledged."

JJ Williams
 Former New Zealand All-Black





#### **REVIEW**



Check for updates

### Management of chronic traumatic encephalopathy

Robert Cantuab and Andrew Budsonb

<sup>a</sup>Department of Neurosurgery, Emerson Hospital, Concord, MA, USA; <sup>b</sup>Department of Neurology, Boston University School of Medicine, Boston, MA, USA

#### **ABSTRACT**

**Introduction**: Chronic Traumatic Encephalopathy (CTE) is a neuropathological disease defined by perivascular hyperphosphorylated tau protein depositions in a patchy distribution at the depths of cortical sulci in the brain. Presently, in living individuals, it cannot be precisely diagnosed or differentiated from other neurodegenerative diseases nor are there treatments for the underlying disease process. There are non-pharmacologic and pharmacologic treatments for the symptoms of CTE that improve the quality of daily life. That is the primary focus of this review article that used Pub Med and other standard databases but drew heavily from the author's personal experience managing patients at risk for CTE.

**Areas covered**: The history and pathology of CTE, aiding the clinician diagnosing CTE as unlikely, possible, or probable in the living, and symptom treatment are the major areas discussed.

**Expert opinion**: Diagnosing CTE during life with sensitive and specific biomarkers is the next critical step and only then will its incidence and prevalence, risk factors, and clinical features due to tauopathy versus axonopathy or other features be known.

#### **ARTICLE HISTORY**

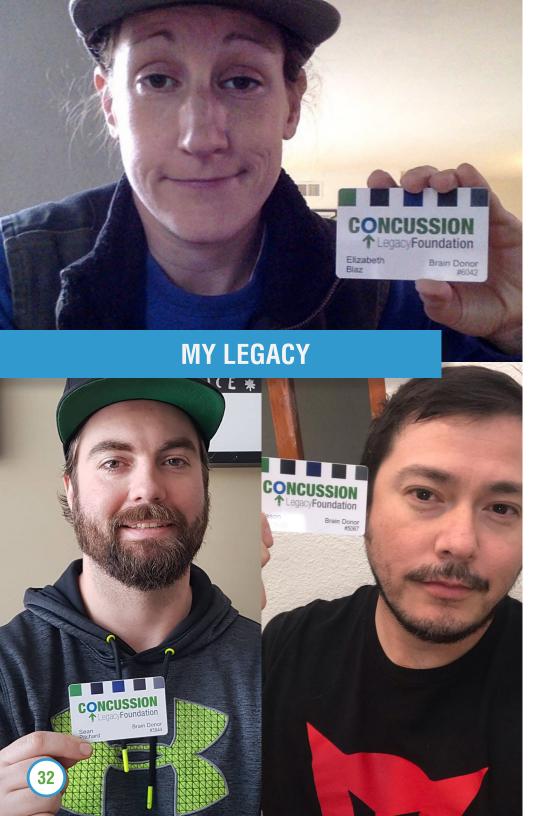
Received 1 April 2019 Accepted 17 June 2019

#### KEYWORDS

Chronic traumatic encephalopathy (CTE); cognitive; behavior/mood; ocular; vestibular; motor and exercise therapy; pharmacologic treatment of agitation; apathy; attention

Our medical director Dr. Robert Cantu co-authored the first publication on the *Management of Chronic Traumatic Encephalopathy*. While we cannot definitively diagnose CTE in living people, more doctors are recognizing patients with possible or probable CTE. **This publication provides the first guidelines for medical professionals for how to treat CTE symptoms**.





My Legacy promotes the CLF brain donation registry by acknowledging contributions to concussion and CTE research and ensures a bright future for the VA-BU-CLF Brain Bank. 2019 saw a record number of people from all walks of life pledge to donate their brain.

More than **6,000 people have taken the #MyLegacyPledge** to donate their brain. Each pledge receives their own customized brain donor card to acknowledge their contribution to accelerating concussion and CTE research at the VA-BU-CLF Brain Bank.

### 2019 Highlights

Record 1,678 pledges

Record 635 pledges from females

Record 354 Brain Pledge Month pledges

USWNT legend Michelle Akers' pledge covered in national news

"I'm donating my brain to the Brain Bank, and I hope that something good can come out of y'all having my brain."

> – Mark Henry WWE Superstar
>  CLF National Advisory Board

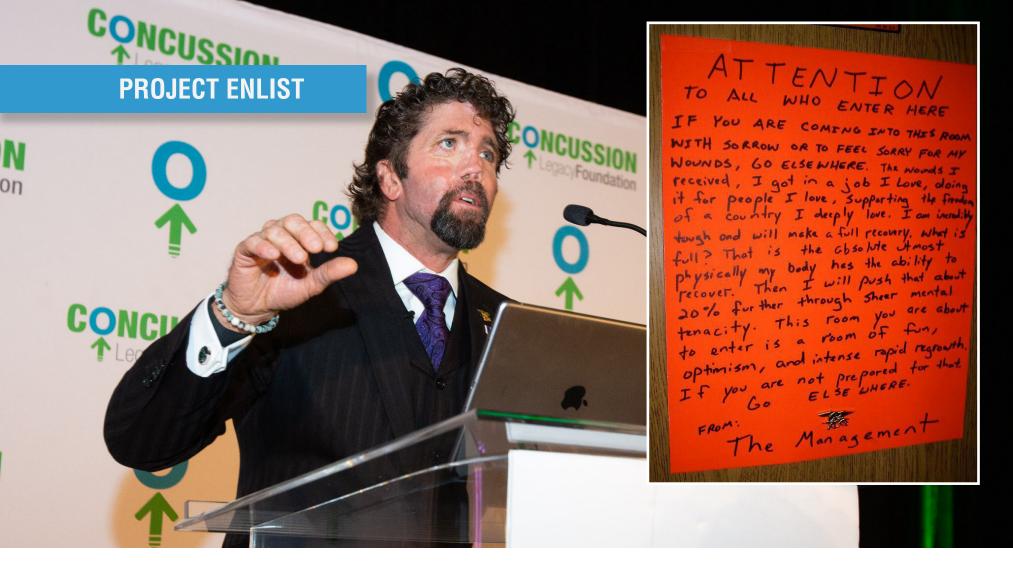


(L-R) Dr. Robert Stern, Michelle Akers, and Chris Nowinski, Ph.D., got together for a USWNT World Cup Watch Party in June. Dr. Stern is leading the S.H.I.N.E. study of Akers and her former U.S. Soccer teammates.

### S.H.I.N.E. STUDY

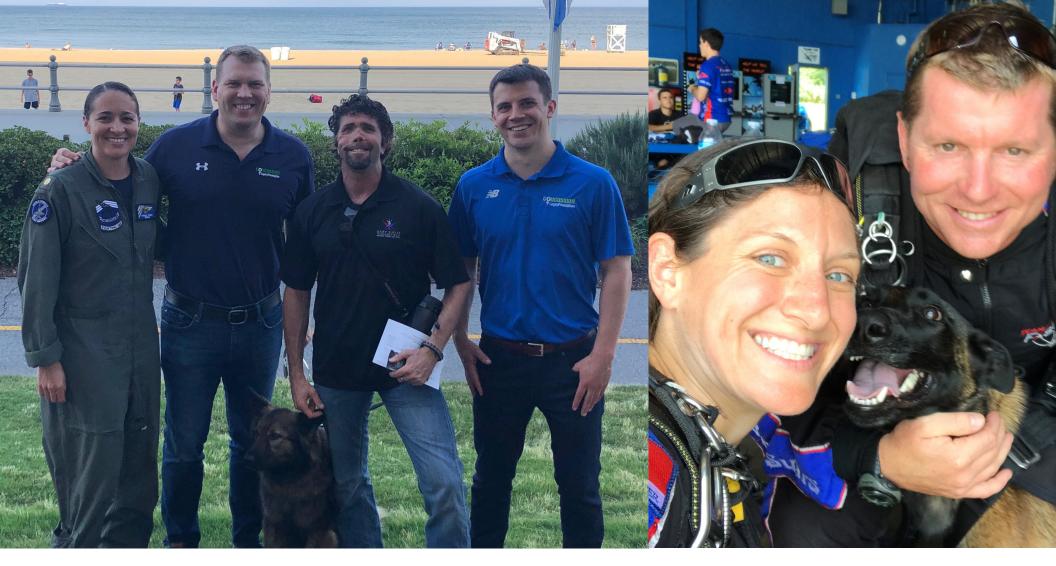
In June, we helped launch the first-ever study on the long-term effects of brain trauma in women's sports. In an exclusive story we placed with CBS News, we announced we were teaming up with U.S. Soccer icons Michelle Akers and Brandi Chastain for the S.H.I.N.E. (Soccer, Head Impacts and Neurological Effects) Study. Led by Dr. Robert Stern and Dr. Jesse Mez at Boston University Alzheimer's Disease and CTE Centers, the study will investigate the long-term neurological effects of playing soccer in 20 former elite U.S. women's soccer players.

As part of our dedication to shining a spotlight on female athletes, CLF was proud to commit \$100,000 to help fund the study alongside the National Institute on Aging. We are also leading recruiting efforts for the study with Akers and Chastain pro bono to enlist members of the legendary 1990s U.S. Women's National Teams. The study will evaluate their brain health as they age into their 50s. The former members of the U.S. Women's National Teams have been remarkably supportive and we recruited most of the study's cohort in just one month.



Project Enlist is our program to expand investment and research on TBI (Traumatic Brain Injury), CTE and PTSD (Post-Traumatic Stress Disorder) in military Veterans. This program acknowledges the incredible sacrifices made by those who have suffered injuries while in service to our country. These heroes deserve special attention for their service. Through Project Enlist, we are recruiting brain pledges from the military community to raise awareness of the need for additional investments in Veteran support services.

One of our military pledges is retired **U.S. Navy SEAL Lt. Jason Redman** (above). In 2007, Lt. Redman was severely wounded by machine gun fire outside of Fallujah, Iraq. While in the hospital, he posted a sign outside his door (above) that gained national attention for its inspirational message. Lt. Redman was the keynote speaker at our 2019 Concussion Legacy Gala, where he powerfully highlighted the challenges faced by our Veterans with brain injuries and voiced his support for Project Enlist so we can help our country's heroes.



A record 436 members of the military community pledged their brain to CLF in 2019 as part of Project Enlist. In June, we traveled to Virginia Beach for USO Warrior Week (above left), where we spoke with military Veterans about brain health and signed up new pledges for Project Enlist.

In December, we placed a cover story in The American Legion Magazine about one of our military brain donors. Nicole Condrey (left in photo on right) lost her husband, U.S. Navy Special Warfare Veteran Ron Condrey (pictured with

Nicole), to suicide in September 2018 after a three-year battle with depression, anger and impulsiveness. Nicole made the decision to donate Ron's brain to the VA-BU-CLF Brain Bank to support research that will help other Veterans. "Ron wanted to give back to Veterans in every way he could, so it was just a clear fit, something that could last," Condrey said.

The article sparked more than 200 military brain pledges to Project Enlist in the first two weeks after its publication.

### **COMMUNITY EVENTS**



Chicago sports legends joined Rob Johnson, Dr. Ann McKee, and Chris Nowinski, Ph.D., to honor Jane Mikita Gneiser and the Mikita Family with our Courage Award at the 2019 Chicago Honors. Mikita Gneiser is the daughter of Blackhawks legend Stan Mikita, who was diagnosed with CTE by Dr. McKee at the VA-BU-CLF Brain Bank.



(L-R) Tyler Maland, Brandon Drummond, Brandon Boyd, and Michael Burke participated in the Positive Coaching Alliance Stadium Stampede to raise awareness for Team Up Speak Up in July.



CLF co-founders Chris Nowinski, Ph.D. and Dr. Robert Cantu helped U.S. diplomat Mark Lenzi announce his brain pledge at our Boston Investment Community Breakfast in May. Lenzi suffered an unexplained brain injury linked to a mysterious weapons attack while working in China and has become an advocate for CLF Project Enlist (pgs. 34-35).



CLF Director of Family Relations Lisa McHale addresses the crowd at our 2019 Chicago Honors dinner.



WWE Superstars Mark Henry and Lacey Evans joined Chris Nowinski, Ph.D. at our 12th Annual Concussion Legacy Gala. Henry, who was named the World's Strongest Man in 2001, took the #MyLegacyPledge to donate his brain.



CLF Board member and Army Veteran Matthew S. Collier (left) and CLF Family Advisory Board member and former Army engineer Nicole Condrey joined Chris Nowinski, Ph.D. at USO Warrior Week in Virginia Beach to promote Project Enlist (pgs. 34-35).



Chris Nowinski, Ph.D. poses with NFL superagent Leigh Steinberg (center) and J.A. Adande. Adande is an advisor for the CLF Media Project (pgs. 16-17) and brought the Media Project's Concussion Reporting Workshop to his alma mater, Northwestern University.



Kim and Mike Adamle continue to provide hope for people living with possible CTE through the Mike Adamle Project: Rise Above. In June they helped raise over \$10,000 with a dance competition in Chicago.



From New Zealand, Chris Nowinski, Ph.D. reads headlines of new international brain pledges with Dr. Michael Buckland (pgs. 28-30).



Boston University lecturer and Pro Football Hall of Fame broadcaster Andrea Kremer co-taught the Concussion Reporting Workshop with Tyler Maland, CLF's Chief Impact Officer, in her class at BU. Kremer is an advisor for the CLF Media Project.





#### **CO-FOUNDERS**

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ROBERT CANTU, M.D.

Medical Director

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**KELLY DEAN** 

JOE CAIN

Development & Operations Manager

**Development Coordinator** 

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Chief Impact Officer

JULIA MANNING
Communications Manager

BRANDON DRUMMOND

Program Marketing Manager

MICHAEL BURKE Program Coordinator BRANDON BOYD

Program Coordinator

**BARRY FOVAL** 

Community Outreach Coordinator

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# **LEGACY: \$50,000 AND ABOVE**

Dennis M. and Lois A. Doyle Family Foundation Fingerpaint Marketing, Inc. Tom Gardner Mintz The Metro Foundation Oak Foundation WWE

# VISIONARY: \$20,000-\$49,999

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# **FINANCIALS**

PHRI IC	<b>SUPPORT &amp;</b>	OTHER REV	/FNIIF
I ODLIO			/LINUL

Contributions	\$2,569,050
Program Revenue	\$125,580

Total Revenue \$2,694,630

# **EXPENSES**

Programs	\$2,182,202
Administration	\$203,178
Fundraising	\$267,697

Total Expenses \$2,653,077

# STATEMENT OF FINANCIAL POSITION

Cash, Cash Equivalents and Investments	\$1,479,681
Property and Equipment	\$2,436
Other Assets	\$18,825

Total Assets \$1,500,942

\*Unaudited



# CONCUSSION LegacyFoundation