

BU ADRC Bulletin

The Bi-Annual Newsletter for the **Boston University Alzheimer's Disease Research Center**
Funded by the National Institute on Aging

About Us

The Boston University Alzheimer's Disease Research Center (BU ADRC) aims to reduce the human and economic costs of Alzheimer's disease through the advancement of knowledge. We conduct cutting-edge Alzheimer's research and provide education about aging and dementia to professionals and communities in Boston and beyond.

In This Issue

Seven out of ten patients with Alzheimer's are cared for at home, making caregiving a very important aspect of Alzheimer's disease. Caregivers selflessly assist their loved ones every day, and we thank you for the hard work you do.

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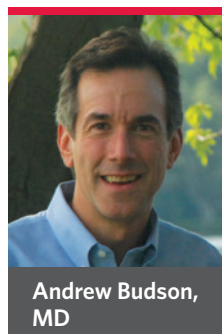
2021 CTE Conference

Six Steps to Managing Alzheimer's Disease and Dementia – A Guide for Families

"CAREGIVING IS hard. It's hard whether you're caring for your spouse, parent, grandparent, sibling, other family members, or friend. Even if you had an extra 10 hours each day to do it, it's hard to manage all the problems that come with dementia. And caring for a loved one with dementia can sometimes feel like a long, lonely journey."

As a sequel to their 2017 book *Seven Steps to Managing Your Memory: What's Normal, What's Not, and What to Do About It*, BU neurologist **Andrew Budson** and BU neuropsychologist **Maureen O'Connor** have published a new book, *Six Steps to Managing Alzheimer's Disease and Dementia: A Guide for Families* (Oxford University Press, 2021).

The book offers several different tips for managing difficult behaviors. Start with reviewing the 4 Rs: reassure, redirect, relax, and reconsider. **Reassure** refers to using words and body language that let the person with dementia know that everything is OK. When you **redirect** your loved one, you change the focus and direct them from the upsetting or counterproductive event or environment to something else. This change may be accomplished by taking your loved



Andrew Budson,
MD

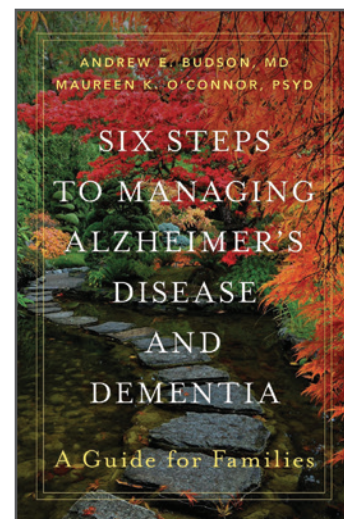
one into a different room, starting a fun conversation or activity, pointing out something interesting, or giving your loved one a novel, interesting, comforting, or well-loved object. **Reconsider**: It is important to consider your loved one's perspective. Their experience of situations might be very different than you might imagine. **Relax**: of course, it isn't always easy to relax your posture, uncross your arms, loosen your hands, and speak calmly and reassuringly. Remaining relaxed in the face of aggressive, agitated, embarrassing, and irritating behaviors is hard for everyone.

Dr. Maureen O'Connor answered a couple of questions related to the book.

Q: Many caregivers feel like they need to do everything for their loved ones with dementia by themselves. Is this the best way to approach caring for someone with dementia?

A: There is no way any one person can provide care alone. We talk to our caregivers about ways in which they can build a care team. A care team can include friends and family, healthcare providers, and even neighbors and other community resources.

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Note from the Director

Dear ADRC Community,

Wherever you are reading this, we want to send a warm welcome to each of you. As we approach the holiday season, we thank you for your support that has facilitated our pursuit of research and educational breakthroughs, and enhanced patient care at the Boston University School of Medicine Alzheimer's Disease Research Center (ADRC). This fall, our center remains resilient and productive, with the faculty and staff of the ADRC busy and hard at work supporting the wide variety of Alzheimer's disease (AD) related research and community-building efforts at the ADRC.



Neil W. Kowall, MD

The BU ADRC continues to focus on cutting-edge research, proactive community engagement and training of the next generation of AD researchers. Major new BU ADRC research initiatives include studies on repetitive head injury and risk for Alzheimer's disease and Alzheimer's disease related disorders (ADRDs) including Chronic Traumatic Encephalopathy (CTE); advanced neuropathology; genetics; biostatistical modeling; biomarker discovery; and molecular profiling.

The BU ADRC has been highly scientifically productive, contributing > 430 original scientific reports to the literature since 2015.

Beyond these scientific accomplishments, our center continues to grow and expand in its vision, leading innovative efforts in genetics, bioinformatics, and novel biomarker development, among other areas. We greatly appreciate the support of the National Institutes of Health, which funds major research efforts of our center, as well as individual donors dedicated to ending Alzheimer's disease.

Thank you for your continued support of our center and its mission, as none of our efforts would be possible without the dedication of our patients and their families. BU ADRC continues to have a bright future, with many new investigators joining our team who are part of a myriad of projects furthering the understanding and treatment of Alzheimer's disease and Alzheimer's disease related disorders.

Thank you for your interest and support of the Alzheimer's Disease Research Center at BUSM.

Sincerely,

A handwritten signature in black ink, appearing to be 'Neil W. Kowall'.

Neil W. Kowall, MD

ADRC Director

Professor of Neurology and Pathology

Q: I know that dementia caregivers often feel like they can't take time away from their loved ones to do things for themselves. What are your thoughts about that?

A: We tell caregivers, "You can't pour from an empty cup!" It's very important for caregivers to make time to take care of their own physical and mental health, socialize, exercise, and engage in enjoyable activities. If a caregiver is not caring for themselves, they won't be able to provide the best care for their loved one.

Below you will find the table of contents illustrating each of the Six Steps discussed in this book.

Step 1: Understand Dementia

- 1 What is dementia?
- 2 What is Alzheimer's disease?
- 3 Which other disorders cause dementia?

Step 2: Manage Problems

- 4 How to approach problems in dementia
- 5 How to manage memory problems
- 6 How to manage language problems
- 7 How to manage vision problems
- 8 How to manage emotional problems
- 9 How to manage behavioral problems
- 10 How to manage sleep problems
- 11 How to manage problems with bodily functions

Step 3: Ask About Medications

- 12 Which medications can worsen thinking, memory, behavior, or function?
- 13 Which medications can improve thinking, memory, behavior, or function?

Step 4: Build Your Care Team

- 14 Why and how should you care for yourself?
- 15 How do you build your care team?

Step 5: Sustain Your Relationship

- 16 Why is it important to sustain your relationship?
- 17 What are some ways to sustain your relationship?

Step 6: Plan for the Future

- 18 How to plan for the progression of dementia
- 19 How to plan for the end and beyond

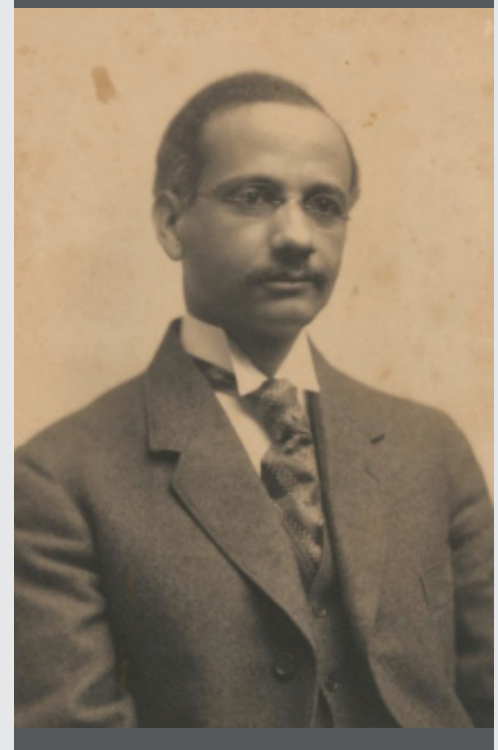
Six Steps to Managing Alzheimer's Disease and Dementia is comprehensive yet written in an easy-to-read style, featuring clinical vignettes and character-based stories that provide real-life examples of how to successfully manage Alzheimer's disease and dementia.

If you would like to learn more about the Six Steps to Managing Alzheimer's Disease and Dementia, check it out from your local library, bookstore, or online bookseller.

Celebrating the Life and Legacy of Solomon Carter Fuller, MD

Save the Date:

Feb. 17, 2022, 9 am-5 pm



PLEASE JOIN us for a virtual celebration honoring the life and legacy of Solomon Carter Fuller, MD, the first Black man to graduate from Boston University School of Medicine (BUSM) in 1897. A renowned psychiatrist, neurologist, pathologist, and educator, he worked with Dr. Alois Alzheimer and practiced in the Boston area before joining the BUSM faculty in 1919. Upon his retirement from academic medicine in 1933, he was appointed Emeritus Professor of Neurology, and continued in private practice for many years.

The daylong event is sponsored by the BUSM Departments of Neurology, Psychiatry, Pathology, Diversity & Inclusion Office, and BU Alzheimer's Disease Research Center.

Boston University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

This activity has been approved for AMA PRA Category 1 credit™.

Study Finds Brain Lesions on MRI Linked to Years of Playing Football

CERTAIN MARKERS of injury to the brain's white matter, called white matter hyperintensities, can be seen on brain scans. A new study finds that brain scans taken during the lifetimes of athletes in contact sports, compared to changes in their brains at autopsy, showed that white matter hyperintensities were associated with neuropathological changes. The research is published in the November 24, 2021, online issue of *Neurology*[®], the medical journal of the American Academy of Neurology. The first author of the study was Madeline Uretsky, MS, who is the coordinator of the brain bank used to conduct this study. **Michael Alosco, PhD**, of the Boston University School of Medicine was the senior author.

The study also found that white matter hyperintensities were more common in athletes who played contact sports longer or had more head impacts during their careers. White matter hyperintensities are areas that appear bright on magnetic resonance imaging (MRI) scans. They are common in people as they age and with medical conditions like high blood pressure.

"...white matter hyperintensities might capture long-term harm to the brain in people who have a history of repetitive head impacts"

study author Michael Alosco, PhD

"Our results are exciting because they show that white matter hyperintensities might capture long-term harm to the brain in people who have a history of repetitive head impacts," said Dr. Alosco. "White matter hyperintensities on MRI may indeed be an effective tool to study the effects of repetitive head impacts on the brain's white matter while the athlete is still alive."

The study involved 75 people who were exposed to repetitive head impacts and had reported symptoms. This included 67 football players plus eight other types of athletes in contact sports like soccer and boxing, or military veterans. Of the football players, each of whom played an average of 12 years, 16 athletes played professionally and 11 played semi-professionally.

All donated their brains to research after their death in order to advance research into the long-term effects of repetitive head impacts. Researchers then looked at medical records, including scans which were done while the athletes were still alive. Participants had scans taken of their brains, on average, at age 62. The average age of the athletes at death was 67.

Of the participants, 64% were judged to have had dementia prior to death. This was determined by a discussion with their loved ones. Autopsies showed that 53 people, or 71%, had chronic traumatic encephalopathy (CTE). CTE is a neurodegenerative disease associated with repetitive head impacts, including those from football, that can progress to dementia.

After examining the brain scans, researchers found that for every unit difference in white matter hyperintensity volume, there was about twice the odds of having more severe small vessel disease and other indicators of white matter damage, as well as three times the odds of having more severe tau accumulation in the frontal lobe of the brain. Tau protein accumulation in the brain is a biomarker for progressive brain diseases like Alzheimer's disease and CTE. Researchers also found that higher amounts of white matter hyperintensities were associated with more years of playing football.

When it came to completing daily tasks, greater amounts of white matter hyperintensities were associated with higher scores on a questionnaire about performing daily tasks that was completed by caregivers of the brain donors.

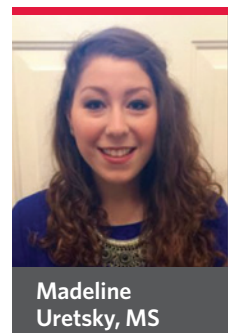
"There are key limitations to the study, and we need more research to determine the unique risk factors and causes of these brain lesions in people with a history of repetitive head impacts," Alosco said.

Limitations of the study included the use of MRIs obtained for clinical, not research, purposes, and that participants were mostly older, symptomatic, male, former American football players.

The study was supported by National Institute on Aging, National Institute of Neurological Disorders and Stroke, Boston University Alzheimer's Disease Research Center, Department of Veterans Affairs, the Nick and Lynn Buoniconti Foundation and Boston University's Clinical & Translational Science Institute.



Michael Alosco,
PhD



Madeline
Uretsky, MS

BU ADRC Happenings

Welcome – The Boston University Alzheimer’s Disease Research Center (BU ADRC) and its affiliate, the Chronic Traumatic Encephalopathy Center (CTE Center), would like to extend a warm welcome to new faculty members and employees:

BU ADRC Staff

Andrew Nguyen, Project Manager, was born and raised in California. He went to UCLA for his undergraduate studies and came to Boston for graduate school and got his MA from Boston University in 2013. From there, he worked at an assisted living facility, working with persons with dementia, where he eventually became the Director of the Memory Support Unit. Andrew wanted to pursue a more research-oriented career and was able to find a position with Dr. Maureen O’Connor’s project, where he currently is now.

BU ADRC Research Education Component (REC) Scholars

The REC Scholar Program supports exceptional junior investigators at Boston University in their development into independent Alzheimer’s disease (AD) researchers. This program is intended to support AD training for individual researchers and to facilitate development of skills in basic, clinical, and translational research. This year we were able to bring on five trainees to the program.

Lola Baird, Polytrauma/TBI Program Coordinator at the Veterans Affairs Boston Healthcare System, has worked as a Social Worker at the VA Hospital in Boston since 2021. Her goal is to use research to better understand the effect of structural disadvantages—such as neighborhood violence—on health outcomes, with the goal of creating innovations and interventions that are meant to mitigate the impact of such structural disadvantages. When she is not working, she spends most of her free time with her two kids (ages 4 and 2) and husband.

Phillip Hwang, Postdoctoral Associate, is a neuroepidemiologist from Seattle, WA. His research interests are examining modifiable lifestyle factors for dementia across the life course. He also has an interest in studying TBI and CTE. In his free time, he tries to go outside and explore new trails with his wife and dog or play the violin or guitar with other musicians. Hwang’s research goal as part of being in the REC Scholar program is to use neuropsychological measures from the Framingham Heart Study to identify and predict cognitively resilient individuals.

Diana Anderson, Post-Doctoral Fellow, VA Boston Healthcare System, and Instructor of Neurology, BU School of Medicine, is a board-certified healthcare architect and internist. She calls herself “dochitect,” combining educational and professional experiences

in both medicine and architecture. She completed a geriatric medicine fellowship at the University of California, San Francisco, and is now pursuing further training in cognitive neurology and research at VA Boston. Her research goals as a REC Scholar include studying the impact of residential and community-built environments on mental and social health outcomes for older adults with and without cognitive impairment. In her free time, Diana enjoys running, kayaking, and writing.

Ryan Andrews, Research Scientist, Department of Epidemiology, BU School of Public Health, is a Research Scientist in the Department of Epidemiology at the Boston University School of Public Health. He did his postdoctoral work in causal inference methodology at the Leibniz Institute of Prevention Research and Epidemiology – BIPS in Bremen, Germany. Prior to that, he completed his PhD in Mental Health at Johns Hopkins University, where his thesis focused on cardiovascular pathways involved in dementia etiology. As part of the REC Program, he is working on implementing advanced statistical methods to characterize how social networks can affect research findings in neuroepidemiology. In his free time, he enjoys reading and trying to find the best burger in Boston.

Byron Aguilar, Research Scientist, BUSM Pharmacology & Experimental Therapeutics; Health Science Specialist, VA Bedford, grew up on a tropical island (Guam) and made his way to Boston to enjoy the snow and has been told that he doesn’t know what awaits him. During his free time, he tends to his indoor succulent garden, plays tennis, and explores the city. As a Medicinal Chemist, Byron’s goal is to establish collaborations for drug development research for Alzheimer’s disease and related dementias.

REC Alumnus Update

Robert W. Turner II, PhD, Assistant Professor at George Washington University and Former Boston University REC Scholar, is currently working on how caregiving for dementia patients affects the physical and brain health of black male caregivers.

Black male dementia caregiver burden: stress-related cognitive dysfunction, and physiological and psychosocial measures

PI: Robert W. Turner II, PhD : The objective of this research project is to evaluate the effect of dementia caregiving
Sponsor Name: NIA : stress on cognitive function in adults. While interest in this issue has increased in
Award Number: K01AG054762 : recent years, sparse literature exists on adult Black males as primary caregivers of a person with dementia, a growing subpopulation particularly vulnerable to various forms of stress. Knowledge about the cognitive health of adult Black males’ primary caregivers will allow for the healthcare system to better support this group that will be paramount in caring for a growing number of older individuals with dementia. To accomplish this goal, there are two research aims that combine instruction with established scholars in human aging biomarkers and conducting a pilot study. Cross-sectional data will be collected using a multi-method approach that consists of cognitive function and stress-related physiological and psychological measures, and in-depth interviews. The two research aims will enable Dr. Turner to integrate and apply knowledge gained through the proposed training and research activities by creating a more robust portrait of stress factors that may impact the cognition of adult Black male primary caregivers of a person with dementia. The approach used in this project addresses: a) which aspects of cognitive performance are affected by caregiver status and stress, and b) which stress-related physiological and self-rated psychological measures may mediate the caregiver effect on cognitive performance.



Robert W. Turner II, PhD

Featured Study

Couples' Lived Experience: *understanding the lived experience of couples across the trajectory of dementia*

The purpose of this study is to learn about the experiences of couples, one or both of whom may experience changes in thinking and memory over 3 years. We are particularly interested in understanding how various aspects of their relationship changed over time and whether some relationship styles are better at supporting their health and well-being. Each member of the couple will be asked to respond to a series of questionnaires asking about relationship style, mental and physical health, social interactions, and cognitive function through video or phone interview every 6 months for 3 years. We are looking for couples, both members of whom are over the age of 65. You will be compensated for your time and will be invited to annual seminars for the study participants.



If you and your significant other are interested in participating, please reach out to Project Manager Andrew Nguyen at 617-358-6437.

Actively Recruiting Studies

AD = Alzheimer's Disease; MCI = Mild Cognitive Impairment

STUDY TITLE	STUDY DESCRIPTION	STUDY AGE RANGE	CURRENTLY RECRUITING
HOPE	HOPE is the main registry of participants. People who join HOPE attend a yearly visit in which their memory and thinking abilities are evaluated. Following their appointment, participants receive feedback on their results. They also participate in other BU ADRC-affiliated studies. <i>Locations in Boston and Needham.</i>	55+	Healthy adults, MCI, AD
AHEAD	A study to evaluate efficacy and safety of treatment with a novel medication called BAN2401 in participants with preclinical Alzheimer's disease, elevated amyloid, early preclinical Alzheimer's disease, and intermediate amyloid.	55-80	Healthy adults, caregivers
Brain Plasticity in Cognitive Aging	The overall goal of this research is to learn more about changes in the structure and physiology (function) of the brain that occur as people age and how these changes relate to cognitive (thinking) and other marks of brain health.	60-90	Healthy adults, caregivers
Chronic Stressor	This study assesses the relationship between chronic stress and cognition in older African American adults. <i>Located in Boston.</i>	55-75	Healthy adults
Diagnostic Test for Alzheimer's Disease	This study is testing whether it is possible to repurpose a diabetes drug called pramitide as a diagnostic test for Alzheimer's disease. Participants will undergo a PET scan, two infusions and several blood tests over the course of three total visits. <i>Located in Boston.</i>	60-90	Healthy adults, MCI, Probable AD
Digital Phenotyping	The purpose of this study is to better understand Alzheimer's disease and dementia through the use of technology like smartphone applications or wearable devices.	40-110	Healthy adults, MCI
FIND-CTE	The aim of this study is to develop methods of detecting chronic traumatic encephalopathy (CTE) during life and to understand the differences between CTE and Alzheimer's disease.	45-74	MCI, AD dementia
Effects of NR	The purpose of this study is to investigate an over-the counter vitamin B3 supplement often taken for the purpose of cognitive enhancement in those with MCI and AD.	55-89	Healthy adults, MCI, Probable AD
Lived Experience	This study is to learn about the experiences of couples, one or both of whom may experience changes in thinking and memory over three years.	65+	Healthy adults, MCI, Probable AD, Caregivers
Metformin in Alzheimer's dementia Prevention (MAP)	MAP is a research study looking at whether metformin can help prevent memory decline for people with mild memory concerns. The study is testing if this drug can help prevent a decline in memory and thinking abilities for people with mild memory problems. It is a randomized study in which you will take either metformin or a placebo.	55-90	Amnesic MCI

Interested? Contact the BU ADRC recruitment coordinator at 857-364-2140 or JoinADC@bu.edu

If you don't see a study that interests you right now, please check back on our website as we always have new studies starting.

www.bu.edu/alzresearch/research/recruiting-studies/

Participate in Research

We need you! The Center is currently recruiting adults with and without memory changes to participate in our research studies. We have many different studies for which you may be eligible.

We have several different types of ongoing studies at the ADRC. Each study has its own goals. If you are interested in participating in a study listed, please contact us at JoinADC@bu.edu or call us at **857-364-2140**.

Memory and Aging Studies: Our memory and aging studies help us learn about the changes that occur in people's memory as they age.

Clinical Trials: Clinical trials (or treatment trials) and prevention trials help determine if new or currently used medications can prevent Alzheimer's disease or slow its progression.

Genetic Studies: Our family and genetic studies look at the link between Alzheimer's disease and genetics; these studies help us understand genetic risk factors associated with Alzheimer's disease.

Caregiving Studies: Caregiving studies specifically focus on issues related to activities in daily life, such as driving, coping emotionally with caregiver activities, and support strategies for caregivers.

Imaging Studies: Our imaging studies help us learn how brain images can provide more information about diagnosing and detecting Alzheimer's disease. If we can identify changes that are occurring in the brain throughout the disease process, we can help diagnose and treat people with Alzheimer's disease as early as possible in the disease process.

BU ADRC Partnerships

Memory Sunday

Memory Sunday is an initiative of the National Brain Health Center for African Americans, a program of the Balm in Gilead. It is typically held every year on the second Sunday in June. The purpose is to raise awareness about aging, memory loss, and research opportunities. By using the power and influence of the Black Church, the message of Memory Sunday brings local and national attention to the tremendous burden that Alzheimer's disease and other dementias place on the African American family. Participating in this unique program is a way to include congregations in the science, research and caregiving of the Alzheimer's community. This includes discussion about ways to reduce the risk of developing Alzheimer's disease and support available for caregivers as well as raising awareness about the importance of research and participation in research studies. People of color are disproportionately affected by Alzheimer's disease but are underrepresented in clinical trials and Alzheimer's disease research.

The second annual Memory Sunday was held virtually in June as a designated Sunday within the Black faith community. We were able to reach more people this way and hope to expand our reach even further next year. **If your faith community would like to learn more, please contact Royisha Young, youngra@bu.edu or call at 857-364-2140.**



In the Community

Stay Connected with BU ADRC Virtual & In-Person Events

Community Events & Programs

The BU ADRC holds many educational events and programs for community members throughout the Commonwealth. We also conduct numerous educational activities for health care professionals. We can tailor each lecture and presentation to the needs of the audience. Join one of our virtual outreach events to hear more about managing your memories as well as hear from individuals who are currently enrolled in research studies, who will share their experience. If you would like to participate in one of our virtual events or would like to schedule a time for us to speak to your group, please email us at joinadc@bu.edu.

A Successful Walk to End Alzheimer's

Each year, our team looks forward to gathering to support the Alzheimer's Association Walk to End Alzheimer's. This year, we all supported a little differently. Our center and team members gathered independently, with our loved ones, to support the Greater Boston Walk to End Alzheimer's in September. We were also able to sponsor the walk and had our table featured. If you would like to gather with us next year, please email our Program Manager, **Samrana Bertrand**, at sbertran@bu.edu.

BU ADRC Student Ambassadors

The Boston University Alzheimer's Disease Research Center (BU ADRC) created the BU ADRC Student Ambassador Program, in which medical students, graduate students, and undergraduates interested in medicine completed a curriculum during the academic year that included six educational and three outreach events.

Activities included monthly dementia-focused didactic meetings, the BU ADRC monthly lecture series, community outreach events, and our BU ADRC Community Action Council meetings focusing on Black participant recruitment. This year we welcome more than 50 students to the program, and we opened it up to not only BU students but any student who is interested and goes to school in the Boston area.

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5th Annual Boston University CTE Conference

THIS YEAR we were able to bring back our Annual CTE Conference with over 170 registrants for a virtual experience. Held in October, the 5th Annual Boston University CTE Conference featured a conversation with former NFL player Jonathan Martin, who retired in 2015 after several injuries, mental health struggles, and suicide attempts. Presenters included faculty members from our center ([Ann McKee, MD](#); [Bob Stern, PhD](#); [Robert Cantu, MD](#); [Jesse Mez, MD](#); [Doug Katz, MD](#); [Lee Goldstein, MD, PhD](#); [Thor Stein, MD, PhD](#); [Kate Turk, MD](#); and [Michael Alosco, PhD](#)), as well as guest presenters, like Robert Turner II, PhD, of George Washington University School of Medicine & Health Science (former BU ADRC REC Fellow), who explored how racism and discrimination may influence diagnosis for Black former football players. The conference was designed for health care professionals and researchers, but was open to patients, families, and other members of the public as well.

The Concussion Legacy Foundation's Lisa McHale explored how CTE impacts families by interviewing three family members of former football players diagnosed with CTE, including the daughter of Atlanta Falcons star Tommy Nobis and the parents of former Dartmouth football player Hunter Foraker, who died by suicide at age 25.

The conference was organized to train doctors and other health care professionals on the latest advances in our understanding of CTE, including its pathology, pathophysiology, genetics, biomarkers, imaging, clinical syndromes, clinical criteria, differential diagnosis, impact on Veterans, implications for the family, and what it is like to live with or worry about the disease.

