

TBI NEWS & VIEWS



PERSONAL PERSPECTIVE: RICHARD ANDERSON – CALLED TO BE AN ADVOCATE

In August 2004, I sustained a traumatic brain injury (TBI) while on a family vacation at the Jersey Shore. To this day, my short-term memory has limits. I struggle with finding the right words to express my thoughts and emotions. And, I no longer have the ability to taste and smell. I am sharing this because looking at me, you might not know I have a brain injury. These challenges are what we call “invisible losses.”

Despite these challenges, I try and help other individuals with brain injury by increasing awareness of TBI and advocating on behalf of the TBI community. I am a volunteer board trustee of the Brain Injury Alliance of New Jersey (BIANJ) and a member of the Kessler Foundation TBI Consumer Advisory Board. My wife Rose and I are also members of the Council for the Head Injured Community (CHIC) sponsored by BIANJ.

Currently, more than 5 million people living in our country have disabilities resulting from brain injury. The financial costs are staggering — \$35 billion annually, which includes medical costs as well as costs associated with lost earnings and social service needs. Persons with severe brain injuries, like me, face 5 to 10 years of intensive rehabilitation, including speech, physical, cognitive, occupational, psychiatric, emotional, and behavioral therapies.



In most cases, a brain injury is not an event that heals and goes away. It becomes a chronic condition, and one may need assistance and advocacy for the remainder of their lives. The only cure for brain injury is prevention. Public awareness is critical to our efforts to prevent brain injuries and maximize the recovery process of all individuals affected by TBI. My calling is to increase awareness about brain injuries, to advocate for individuals with brain injury, and to help others understand what it is like to live with a brain injury.

I often listen to the song “I Dreamed a Dream” from the Broadway musical “Les Misérables.” Although some consider the lyrics sad, I find it to be a passionate song that inspires and motivates me. I had dreamed of different

dreams before I was injured, but now I have a new dream. And, it is coming true as I help others live again. Join me in fulfilling my dream of a brighter future for everyone living with brain injury by raising awareness of the impact that brain injury has on individuals, their families, and our society. ■

For more information on how to get involved, please contact:
Brain Injury Alliance of New Jersey
www.bianj.org
(732) 745-0200

Council for the Head Injured
Community (CHIC)
bianj.org/chic/
Tom Grady, Director of Advocacy
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RESOURCE REFRESH

Tristate Advocacy Project: Helping Patients Gain Access to the Care and Coverage They Deserve

By Sarah Thomson, Research Assistant, Center for Neuropsychology and Neuroscience, Kessler Foundation



After a traumatic injury, caregivers and patients are left with a common, yet challenging question: now what? Adjusting to life after a traumatic injury comes with its own set of complications, but the financial burden of rehabilitation and inpatient care makes this adjustment even more difficult. Patients often don't know what questions to ask or how to find resources that will allow them to live on their own and maintain their quality of life. With the help of organizations like the **Tristate Advocacy Project**, patients can gain access to the support and guidance they need, free of charge, throughout their recovery.

The Tristate Advocacy Project is a privately funded advocacy organization that helps patients and families gain access to helpful financial resources after their injuries. Founder Cindy Clarke lost her father to a C1-C2 spinal cord injury in 2002, and as a caregiver, she struggled to navigate the complexities of the U.S. healthcare system. Because she had a particularly difficult time getting accurate and consistent information from government agencies,

Cindy decided to start an organization that would aid patients in identifying and utilizing available funding resources. Patients could then afford the necessary rehabilitation and support services to maximize independence after their injuries.

The organization she founded assists children and adults with traumatic brain injuries, spinal cord injuries, cerebral palsy, and burn-related injuries. The Project's advocates are available to provide consultation and support starting when patients receive treatment in acute care facilities. During this early phase of recovery, the organization serves as a mediator between the physicians advising longer inpatient stays and insurance companies pushing for early discharge. By advocating for the patient in the acute care phase, the organization can negotiate extended inpatient recovery time and increased coverage of rehabilitation services.

After patients leave acute care facilities, advocates determine patient eligibility for government benefits and provide expert insight into completion and submission of applications

for Medicaid, Social Security, and disability benefits. Advocates are well versed in submitting successful appeals and can help patients get the coverage and compensation to which they are entitled. If a patient isn't eligible for government benefits, advocates analyze all other potential sources of funding. They put patients in touch with personal assistance programs, housing programs, and loan programs in the community to help alleviate the financial burden of in-home care and home modifications.

The Tristate Advocacy Project serves patients in New Jersey, Pennsylvania, New York, Maryland, Delaware, Virginia, Florida, and Hawaii, and they are still growing. All of the Project's services are free of charge, and advocates devote the entirety of their time and resources to serving patients and families, making them a unique and valuable asset to the community they serve. ■

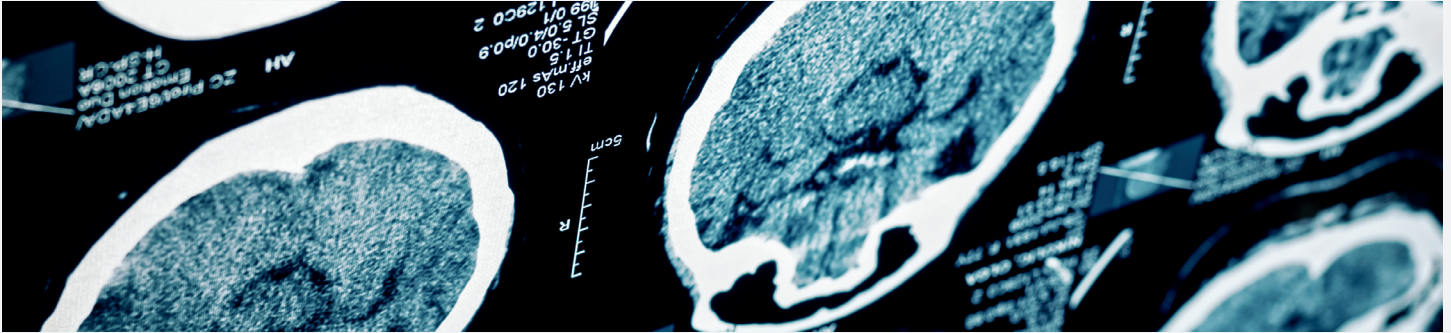
Tri-State 
Advocacy Project

If you or someone you know has recently sustained a traumatic brain injury, you can contact the Tristate Advocacy Project for assistance and consultation. To learn more, visit their website at tristateadvocacy.com or contact them directly at **1.877.774.6380**. Translational services are also available for non-English speakers.

EXPERT OUTLOOK

Helping Brain Injury Survivors Live Better Lives

By Lee Anne Mincolelli, Senior Nursing Assistant, Kessler Institute for Rehabilitation, West Orange



Lee Anne Mincolelli

My journey as a Certified Nursing Assistant (CNA) began in 2012 on the Traumatic Brain Injury (TBI) Unit at Kessler Institute for Rehabilitation (KIR). After managing a catering company for 20 years, I felt a calling to do something that would make a real difference in people's lives. Upon completion of my certification, my CNA instructor, who happened to be a registered nurse at KIR, recommended that I apply for a position on the TBI Unit.

To be honest, I was nervous. I had studied brain injuries, but to physically care for these patients was a whole

different story. But I was an open book, ready to write a new chapter in my career and fully engaged in learning all I could about my patients and their needs. The more insight I gained about brain injury and patient care, the more empowered I became. Slowly, the empty pages began to fill!

Now, I begin each day with a clear head and a focus on my patients' needs and goals. Some people may believe my job is just toileting, dressing, grooming, and feeding patients, or taking them to therapy sessions. But it goes far beyond that. I am their advocate, cheerleader, confidante, and companion. I listen to the concerns, their fears, and their hopes for the future. I may be their eyes, ears, or voice, and I also strive to be their trusted caregiver.

The complexity of how the human brain functions and the impact of a TBI challenges me every day to learn more. How the combination of care and treatment, therapies and medications, and a patient's personal drive can produce a positive outcome never ceases to amaze me. The success stories I witness every day continue to motivate me and make me proud to be part of our

patients' journeys. Likewise, I am proud to be a member of the Hospital Council, a Falls Prevention Advocate, and a member of Kessler Foundation's Stroll 'N Roll Planning Committee. Above all, I am so very fortunate to work with a dedicated TBI team. Our saying on the unit is simple: "TEAMWORK." We look out for patients, as well as one another.

I'll be the first to admit it's not always easy reporting to the unit for my shift. It can be very overwhelming. We care for a diverse patient population, not only in terms of age, ethnicity, gender, and socio-economic background, but also the type of injury which can range from stroke and motor vehicle accidents to gunshots, falls, viruses, tumors, and more. I've worked with patients from 16 years of age to 103, and each story is as unique as the people themselves. This level of experience continues to help me grow within the scope of my practice. And, I am grateful that my calling brought me here to Kessler where we work together and use the latest treatments, techniques, technologies, and therapies to give the patients and their loved ones the best possible rehabilitation experience. ■

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Editorial

Carolann Murphy Gail Solomon

SAVE THE DATE: Moving Forward: Improving Emotional, Physical, and Cognitive Health after Brain Injury

A consumer conference for individuals with brain injury, family members, and friends

Friday, September 27, 2019, 8:15am-3:00pm | Hotel Westminster, 550 West Mount Pleasant Avenue, Livingston, NJ

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Volunteers are the heart of research.

Kessler Foundation research helps people with disabilities live better lives.

Join our research studies at
[KesslerFoundation.org/join](https://www.KesslerFoundation.org/join)

