



TBI News & Views is published tri-annually by the Northern New Jersey Traumatic Brain Injury Model System (NNJT BIS) for people with traumatic brain injuries (TBI) and their families. The NNJT BIS is funded by the National Institute on Disability, Independent Living and Rehabilitation Research (grant #90DPTB0003) and is a collaborative effort of Kessler Foundation, Kessler Institute for Rehabilitation, University Hospital, Hackensack University Medical Center, St. Joseph's Regional Medical Center, Morristown Medical Center, and Jersey City Medical Center.

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TRAUMATIC BRAIN INJURY FACT SHEETS

The Model Systems Knowledge Translation Center created a new fact sheet that suggests strategies caregivers can use to manage stress. The fact sheet can be found by scanning the QR code on the right.



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PERSONAL PERSPECTIVE

Never Take for Granted

By Debbie Grosser

How many times in our lives have we thought or uttered the words, "I will never take anything for granted"? As a 10-year survivor of a near-death accident and a traumatic brain injury, these words have become more meaningful to me than any others. In August 2011, I fell down a steep flight of stairs, fractured my skull and suffered severe damage to my brain. My condition was so perilous that the organ donation team was called before I even arrived at the hospital.

I survived thanks to God, my excellent neurosurgeon, and an amazing critical care nursing team. Although I have very little memory of the accident and the days that followed, I retained all my cognitive abilities. Since my fall, I have undergone 21 surgeries due to the severe injuries I sustained to my skull. Realizing I had an amazing story to tell, I wrote and published my memoir, *Never Take for Granted*.

Before my injury, I was a successful Wall Street analyst for 30 years. I traveled the world, was an avid triathlete, and even completed an Ironman in Lake Placid in 2005. My life was turned upside down in a split second. My journey over the past ten years has included every emotion under the sun—anger, guilt, depression, and finally, gratitude.

My recovery began at Kessler Institute for Rehabilitation in West Orange, NJ. I arrived there in a wheelchair, with no memory of what it felt like to walk. When I left seven months later, the physical therapists had me running again (with handheld assistance). They showed me that my body still remembered the mechanics of running!

After leaving Kessler Institute, I stayed with my brother and his wife before moving into a one-bedroom apartment in Garden City, NY. I lived there until December 2013 when I suffered a grand mal seizure. I was in and out of several long-term care facilities for the next few years. Since 2016, I have resided at Gurwin Jewish Nursing & Rehabilitation Center in Commack, NY. It was not an easy transition to accept because I was so independent previously. However, God had other plans for me.

While at Gurwin, I formulated the idea for writing my memoir and interviewed almost every employee. I also created the Deborah F. Grosser Foundation to fund cutting-edge research into the causes and treatments for TBI. The COVID-19 pandemic afforded me the time to finally finish my book. When it was completed, I decided to direct all proceeds



Debbie Grosser at the 2005 Ironman Competition in Lake Placid

"My journey over the past ten years has included every emotion under the sun—anger, guilt, depression, and finally, gratitude"

— Debbie Grosser

to my 501c3 foundation for TBI research as a way to give back.

It's been a long road and a very difficult journey, but I have truly learned to never take anything for granted. ■

RESOURCE REFRESH

Rate and Review Accessibility to Local Businesses with AXS Map

By Jeannie Lengenfelder, Assistant Director, Center for Traumatic Brain Injury Research, Kessler Foundation

Do you want to visit a new store, but aren't sure how accessible it will be? Or perhaps you are planning to meet a friend for dinner in an untried restaurant, but are concerned about the amount of noise or lighting you'll encounter? AXS Map may be able to provide the information you need.

AXS Map is a crowd-sourced tool for sharing reviews on the wheelchair accessibility of businesses, buildings, and other places. The tool gets better as more people input their reviews. AXS Map has won several awards including the da Vinci Award from the National Multiple Sclerosis Society and a charitable grant from Google.

AXS Map uses a basic ranking system when reviewing a location. Here are some examples of the criteria AXS Map provides for its ratings:

- Entrance – Are there steps or a ramp for access? If not, is there a second entrance? Is there reserved parking?
- Interior – Is there room to move around inside? Is there an elevator? Are there tables at an accessible height?
- Restroom – Do the restrooms have large enough stalls and swinging doors? Are there accessible sinks for wheelchair users?
- Other – Are there other important accessibility features to share? Are the rooms too bright or too dark? Is the location very noisy?

If your neighborhood establishments aren't reviewed on AXS Map, you can create a group to conduct a "Mapathon." Using the AXS Map mobile app, groups of people can compete in different teams to review and rate businesses and buildings in their communities. You can either start your own Mapathon or join an upcoming one in your area. Since 2012, there have been AXS Mapathons in over 300 cities!

The success of AXS comes from its users rating and reviewing businesses and buildings all over the world. Currently AXS Map lists over 12,000 registered users with maps in over 100 countries. ■



AXS MAP was developed by AXS Lab, a non-profit organization which engages individuals and organizations that strive for inclusion and accessibility through media, technology, and stories. It was founded by Jason DaSilva, a writer, director, producer, and disability rights activist. His Emmy award-winning film, *When I Walk*, follows his seven-year journey with multiple sclerosis.



AXS Lab



AXS MAP

EXPERT OUTLOOK

Mentors: A Light Through the Fog

By Carole J. Starr

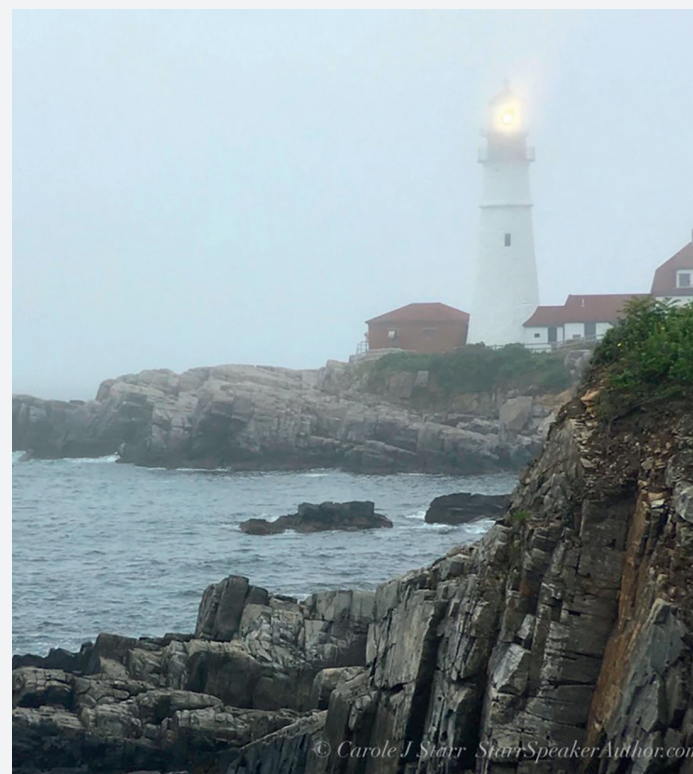
Coping with the life-changing challenges of brain injury can feel like we're lost in a murky fog: stranded, closed in, cut off, and disoriented. When we can't see where we're going, it's easy to lose our way.

However, many people help traumatic brain injury (TBI) survivors find their way, including medical professionals, family, friends, peers, and mentors.

TBI survivors who have successfully navigated through their own fog can become mentors, otherwise known as beacons, to individuals at an earlier stage in their journey to recovery. Beacons can comfort, guide, inspire, and help others cut through the fog of TBI.

My mentor was a beacon to me. Until I met her, it seemed like no one else understood the loss or fears I felt. She validated my feelings and my TBI experience at a time when I struggled to describe it. **Beacons comfort: they show that we are not alone in our challenge.**

I was amazed at the way my mentor described her brain injury challenges freely and without embarrassment.



Portland Head Light—Cape Elizabeth, Maine

She showed me how to manage symptoms and encouraged me to focus on what I could do. Her example was a light when the fog of my injury overwhelmed me. **Beacons guide: their lived experiences illuminate our path forward.**

Seeing what my mentor had achieved showed me that it was possible to create a meaningful, productive life after brain injury. Through her example, I began to believe that even though my life was forever changed, it could still be good. **Beacons inspire: they model what is possible.**

My mentor passed away in 2014, but her legacy lives on. I am now a mentor, author, and speaker, just like she was. Once we've found our own way through the fog, I believe we have a responsibility to become beacons for others who share our challenges.

If you're a survivor lost in the fog of TBI, know that you are not alone. Beacons are out there.

To all the TBI beacons who spend time comforting, guiding, and inspiring others on their path to recovery, thank you. You do make a difference! ■

The unyielding, jagged rocks surrounding Portland Head Light in Maine remind me of the hardness of life with TBI and the resilience it takes to face TBI's challenges. While reflecting on my own journey through the TBI fog, the lighthouse beam inspires me to think about people as beacons—individuals who use their TBI experience to illuminate the challenge and light the way forward for others.

Carole J. Starr is a brain injury survivor, national keynote speaker, author of the award-winning book *To Root & To Rise: Accepting Brain Injury*, and the founder/facilitator of Brain Injury Voices, a survivor volunteer group in Maine.