USBIA Spotlight
Tom Grady: Taking Advocacy Online

A pandemic is not going to keep Tom Grady from effectively and enthusiastically promoting brain injury issues and awareness in the state of New Jersey. The Director of Advocacy and Public Affairs for the Brain Injury Alliance of New Jersey (BIANJ) has found new ways to connect with the community and lawmakers as well as the greater population. “I think we’ve adapted well,” he says. “We’re taking every precaution necessary not to be part of the problem, but part of the solution. We went virtual and that resulted in doing everything virtually, including our annual gala fundraiser and annual seminar. I think the whole virtual platform gives people more of an opportunity to get involved that otherwise wouldn’t. People who can’t drive, for example, get a link and jump online and can be part of a support group.”

The Cranford, New Jersey native has a passion for networking among lawmakers and citizens, particularly in brain injury awareness. He suffered a brain injury himself as a 10-year old child. The terrible headache and stiff neck he experienced while playing in the snow one morning in January 1981, led to a spinal tap that revealed blood in his central nervous system, indicating that there was bleeding happening. A series of tests led to a diagnosis of a ruptured arteriovenous malformation, meaning a bundle of malformed blood vessels had weakened over time and burst. Two weeks in the hospital and two surgeries later, he recovered and now, even 40 years later, he has minimal side effects.

Hospital to School Transition Following TBI: The Importance of Educator Training
by Melissa McCart and Doug Gomez

The transition from hospital to school is a key factor in the educational success of students with traumatic brain injury (TBI). Few studies have examined what transition services look like, how they are delivered and how they are received by educators. A recent study examined this issue to identify themes in parent perceptions of the hospital to school transition (Todis et al. 2018). The authors conducted interviews with the parents and educators of 21 students with brain injury about their perspectives of the return to school experience. From these interviews, two major themes emerged: (a) provision of hospital-school transition services are inconsistent and (b) teachers lack sufficient awareness of and training in TBI to implement hospital recommendations. Hospital to school transition communication consisted of either some brief communication, reliance on parents for communication, or in some cases, no communication at all between the hospital and school.

Statements such as these were indicative of parents’ experiences:
“I don’t think there was a lot of communication between the hospital and the school. I think it was, here’s our [hospital’s] recommendations and then you do with them what you’re going to do. And that is just the end of it. We’re done, you know, he’s out of the hospital now. And then the school was like, I think, looking at the recommendations, but what I found over and over and I still find to this day is that we’ll make recommendations and then it falls flat on its face and nobody is following through on the recommendations.”

Unfortunately, even in cases where there was adequate implementation of some type of hospital to school transition protocols, most educators remained unaware of students’ needs and how to meet them. This exemplifies the need for training for educators that extends beyond hospital to school transition.

“One of my child’s teachers said, ‘I just got so frustrated with him because I just showed him yesterday and he did just fine and today he doesn’t know how to do it.’ Well, hello? It’s a head injury! I think they just looked through the information I gave them from the hospital like they were looking through a magazine. Just kind of thumbing through it.”

“The teachers] never got the copies [of recommendations from the hospital]. I told them all about it, and I said, ‘It’s in his file.’ . . . They were like, ‘This is the first we’ve heard of it.’ And I’m like, ‘You need to look in his file.”
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Coincidentally, that same year, 1981, the Brain Injury Alliance of New Jersey was founded by a group of parents looking to advocate for their children who had suffered brain injuries. In an even more incredible coincidence, in late 2002, while Tom was unemployed, his mother saw an ad seeking an advocacy director for BIANJ. Having spent several years working in constituent relations for members of the New Jersey legislature, it seemed like a good fit, so Tom sent off his resume, thinking he was applying for the Business and Industry Association of New Jersey.

He was surprised and confused when an HR person contacted him from the Brain Injury Association of New Jersey, as the Alliance was previously known. Identical initials aside, Tom’s experience with governmental relations, advocacy, and his own brain injury experience led to a perfect match and now nearly 19 years later, he is well known in the state for his staunch support of the brain injury community.

Tom also serves in a governmental relations and advocacy capacity with the United States Brain Injury Alliance. His liaison work with the Council for the Head Injured Community (CHIC) serves as a platform for anyone impacted by brain injury, including survivors, family members, clinicians, and caregivers. Members can bring their issues to the forefront to be addressed from a grassroots perspective, working with members of the legislature, other non-profit organizations, or the helpline, if it is a specific personal issue. His work in public policy and government relations involves advancing certain proposals and preventing other proposals that could undermine the brain injury cause. For him, this means monitoring legislation of interest, corresponding with lawmakers to express the view of the Alliance, testifying before committees, providing counsel on how to interact with elected officials, research, and more, or “the nuts and bolts,” as Tom puts it.

“I learned a long time ago that relationship building is a really good thing,” he says. “Before you want people to do something for you, build those relationships, because it makes it easier to get what you want to get done, done from a public policy standpoint. But I have learned in my almost 20 years here that people on both sides of the aisle are very supportive of this cause. It’s really a non-partisan issue and a lot of people get that.”

March is Brain Injury Awareness Month across the United States and one of Tom’s top focuses is the virtual Brain Injury Awareness Day, which he says took place online last year with successful results, educating elected officials and staff about brain injuries and what the organization does. “Most importantly, it gives an opportunity for people impacted by brain injury to have first-hand interaction with elected officials whether or not that official is their representative. It gives a face to brain injury, which I think is a good thing,” he says.

March also marks the beginning of the budget season process for the Garden State, and BIANJ keeps a handle on what is happening to make sure funds aren’t being cut. One of the projects supported by these funds is a program that offers community services to people impacted by brain injury through five broad areas: advocacy, education, information and resources, support services, and outreach. Last year the Alliance requested a sensible $140,000, which is a relatively small amount, according to Tom. Fortunately, they were awarded $280,000. “Go figure,” says Tom. “I must have a magic wand or something.” Without a guarantee that the same funds will be available this year, Tom must remain vigilant with each step in making sure the funding request is properly submitted to New Jersey Governor Phil Murphy’s budget proposal. If the proposal is not included, Tom has all the right connections in the legislature to put in a budget resolution to request to keep the funds in.

For the USBIA side, Tom is involved with the Congressional Brain Injury Task Force Day, which takes place annually to try to get more members of the United States House of Representatives and Senate involved in the task force. They act as a clearinghouse to disseminate important brain injury information to other elected officials. “Brain injury is not a partisan issue,” Tom emphasizes, sharing that lawmakers from both sides of the aisle are members of the task force, which is chaired by Representatives Bill Pascrell (D-NJ) and Don Bacon (R-NE). “One of our key aspects for USBIA is to get more members involved and be part of the team to address brain injury on a national perspective.”

But that’s not all that’s keeping Tom Grady busy these days. An educational conference for first responders is planned, with the idea to teach police, firefighters, and EMTs about brain injury so if they come in contact with someone with a brain injury, they can identify the issue. “Someone with a brain injury can be perceived as drunk, mentally ill, or violent, and that obviously can escalate into something that is not good. So, the idea is to educate to protect both the citizen and officer.”

On top of special projects, Tom has ongoing governmental relations duties. “We monitor at least 50 different pieces of legislation that can come up at any time for a hearing,” he says. “Not all of them are directly linked to brain injury but could enhance the cause. So, I’ll go on record with our position and make sure that members of that specific committee are aware of our position.”

Tireless in his endeavors for both BIANJ and USBIA and juggling important details at both the state and national levels, Tom relies on his organizational and oratory skills as a Toastmaster to help him get the right message across. At their meetings, members of the public speaking organization Toastmasters International give speeches that are critiqued by fellow members, and structure and succinct wording comes highly valued. “Every time I do a speech, at least one person tells me it’s very well organized. It’s one of my...
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members of the New Jersey Congressional Delegation to become members of the Congressional Brain Injury Task Force. "It's as legalese as you can think," Tom admits. "But whenever I see something that I write become a legal document from the state legislature that's definitely an accomplishment."

But, he says, his biggest success came in his first year with BIANJ, with his involvement in a bill that would increase the number of available slots for people with traumatic brain injuries to receive Medicaid services they would not otherwise receive in a home or community-based setting. At the time, there were only a maximum of 250 slots available. Tom focused on speaking to legislators and staff across the state in attempt to garner support for the number to be expanded to 300. The budget was signed into law with funding for the requested 300 slots. For the budget season the following year, he spent time advocating to make sure those additional slots stayed in Governor Codey's budget. "Lo and behold, when the budget bill was released to the public to read, there was funding for 350 slots. He threw in an additional 50 slots, so I'm not going to argue. That first year I really busted my hump to make that happen. That policy stayed in effect for 10 years. Then the whole Medicaid waiver system was changed, but for 10 years, that resulted in $76 million being appropriated for that purpose."

He finds his inspiration in Kendra, his wife of nearly 11 years. "No question about it," he says. "Especially after almost a year of being quarantined, we get along. It works. Fundamentally, we relate to each other. And as long as I vacuum once in a while, I think I'm ok." Kendra is also one of the people he says he admires the most, along with his father, a retired police officer who prudently taught Tom to get to the bottom of a matter; his mother, who bravely fought breast cancer and conveyed the importance of being happy and successful, "in that order", Tom recalls, even when it is challenging; and his uncle, a research scientist who studied how pollutants affect human health, in particular the dust and debris from the collapsed Twin Towers on 9/11. "I could write a book about who in my life inspired me for different reasons," Tom says. "I'm very blessed in that way."

In addition to his Toastmaster activities, Tom is a fitness enthusiast who consistently finds time to exercise, especially walking and going to the gym, sometimes twice a day, even during Covid. "I feel better when I do it. It's a nuisance at times, but what's the alternative?"

He is also an avid chess player, playing at the beginner to intermediate level, "Chess helps with strategic thinking, but when my brain is spent, I like to make small meals, and I find it relaxing." Tom looks forward to getting back into golf in the spring and enjoys the nostalgia of playing retro Atari games.

“Personally, I’m probably more productive here [at home] than at the office,” he admits. “It’s less communting time, and this is my third or fourth meeting of the day. In the past, I couldn’t be in meetings that happen in different places around the state and take place one after another.”

Tom Grady’s dedication to the brain-injury community has continued throughout the pandemic with a full calendar of events, consistently managing public policy issues, and finding opportunities to advocate for survivors, caregivers, and clinicians.

“What I find humbling,” Tom says, “Is that when you hurt your brain in a major way, you are hurting every aspect of your being really – mentally, physically, emotionally, spiritually, financially. Every which way you cut it, it can impact you in a very negative way, or it can empower you. It’s a powerful concept, the brain. It has the ability to make or break you.”

Tom Grady is Vice Chair of the USBIA Public Policy Committee. If you would like to know more about volunteering for the committee you can contact Carrie@biaaz.org or call/text 520-310-3301.
Brain Injury and Criminal and Juvenile Justice: A Challenging Problem with Implementable Solutions
by Judy L. Dettmer, Director for Strategic Partnership, National Association of State Head Injury Administrators

The prevalence of TBI in the general population is alarming, with approximately 8.5% having experienced a TBI. However, it is staggeringly problematic in the criminal justice population. The incidence of TBI history in incarcerated populations is reported to range from 41-51% 1,2,3 to as high as 82%. Individuals with a TBI report a greater number of incarcerations than individuals without a TBI and inmates with a TBI have a higher rate of disciplinary actions while incarcerated4,6. There is some indication that TBI increases the risk for recidivism after release from correctional settings6.

More than two million people are currently under the supervision of courts, jails, and the Department of Corrections and approximately 95% of them will be released at some point7. Given that 41 to 82% of these inmates and probationers have a history of TBI and are therefore at greater risk for poor community outcomes, it is critical to address TBI in the justice system. There are tangible steps that can be taken to increase the likelihood of successful outcomes for this population.

1. Implement a universal screen for lifetime history of TBI.
   • Recommended screening instruments include the Ohio State University Traumatic Brain Injury Identification method, Traumatic Brain Injury Questionnaire, and for school aged youth, the Brain Check Survey. These instruments can be administered by criminal justice staff and are free to use.
   • If there are not enough resources for universal screening upon entry into the system, screening should be prioritized based on gender, substance abuse history, behavioral health conditions, and exposure to adverse childhood experiences.

2. For those with a history of TBI, implement a screen for cognitive impairment.
   • The gold standard for identifying cognitive impairment following TBI is a neuropsychological evaluation. However, given the reality of limited resources in the criminal justice setting, it is important, at minimum, to implement a free or low-cost screen that identifies impairment. Such as a neuropsychological screen or a self-report screen such as the Symptoms Questionnaire developed by MINDSOURCE within the CO Department of Human Services. The purpose is to start addressing the “now what?” question by drilling down on the areas where the person may require support, such as memory, organization, problem solving, etc.

3. When cognitive impairment is identified, provide strategies to support the individual.
   • The results of the impairment screen should be used to generate supports for the justice-involved individual.
   • Strategies should be targeted toward the identified impairment, be basic, and easy to implement.

4. Provide training to justice-involved individuals.
   • Evidence suggests that educating individuals with TBI about their injury is an important component of recovery4. The overall message of training for individuals with TBI is that, despite any impairment, they can implement compensatory strategies to be successful.

5. Provide training to criminal justice staff about the basic identification and management of TBI.
   • Criminal justice staff should have exposure to basic training about TBI to ensure they are effective at screening and supporting this population.
   • The message to convey is that it is not expected that the criminal justice staff “treat” the brain injury but rather that they provide support to the justice involved individual in the context of the brain injury.

Resources
A variety of resource related to brain injury and criminal and juvenile justice can be found on the National Association of State Head Injury Administrator’s (NASHIA) website.

NASHIA has also launched a Leading Practices Academy on Criminal and Juvenile Justice to support states in developing the infrastructure to support this population. More information can be found here.

References
New Year’s Eve of 2012 is a day I will never forget. My son Jericho was 3 months old at the time. I went to work leaving him in the care of his father. A few hours later, I received a phone call telling me my baby was unresponsive. When I got to the emergency room, I was greeted by a doctor who informed me that he had a subdural hematoma with midline shift, as well as rotation of the pons and midbrain. Her next statement dropped me to my knees: “We’re going to ship him out, but I’ll tell you right now, he probably won’t even survive the flight”. He had an emergency craniotomy when we finally got to Denver. He had survived the flight, and afterwards, they told me he lived through surgery but would probably never wake up. I was not feeling very hopeful.

My miracle baby woke up though. New Year’s Day, he opened his eyes and started trying to cough up the intubation tube. All his doctors were genuinely shocked. His official diagnosis was traumatic brain injury resulting in subdural hematoma from abusive head trauma. His father was arrested in connection with his injury.

We see a team of doctors at the acquired brain injury clinic at Children’s Hospital Colorado every six months. It was there that I met the Youth Education Liaison and she referred me to the Brain Injury Alliance of Colorado (BIAC). Jericho was having a hard time at school recently. Due to his meltdowns, he was being suspended a lot and I didn’t know who to turn to. When I contacted BIAC, they gave me a sense of comfort and hope I hadn’t felt in a while when it came to attempting to handle the resulting behaviors my son was exhibiting...I felt like I had someone on my side, and I knew that someone else understood brain injury and how it affects a person’s behaviors and abilities.

When I contacted BIAC, they gave me a sense of comfort and hope I hadn’t felt in a while when it came to attempting to handle the resulting behaviors my son was exhibiting. I realized that I was not alone in dealing with his school. I felt like I had someone on my side, and I knew that someone else understood brain injury and how it affects a person’s behaviors and abilities. The Youth Services Coordinator at BIAC has been the one helping me, and she has been amazing. She has really made me feel like my son and I matter, not just like we’re another case that hit her desk. I have also been informed that BIAC helps with many other things outside the school setting, and I’m sure that as Jericho gets older, we’ll need to utilize what they offer. It is so reassuring to know that help will be available to us when that time comes.

Brain injury has changed my family’s life forever. My daughter has also had her struggles as I’m sure many siblings of special needs kids do. My son defied the doctor’s predictions that he would not survive. We struggle every day with his problems, and I hope that one day, we can find a way to cope with them so that he can live a full and happy life. Either way, I know that him being alive, being able to run and jump and talk and laugh, is nothing short of a miracle.

He is now 8 years old. It took me awhile to realize and accept a lot of things. I researched pediatric brain injury day and night for months after his injury. I struggled with accepting the whole situation. I had to accept the severity of his injury. I had to accept the fact that his own father, a man I trusted to take care of our child, could do this to my baby boy. I had to accept that even though my baby looked normal, considering how badly he was hurt, he would have challenges of one kind or another for his entire life. I had to accept that he would never be “normal”. As Jericho’s challenges arise, we have no choice but to cope with them. I continue to struggle with the guilt of feeling like I should have been there to protect him. Mothers are supposed to protect their babies. What hurts the most is that I will never truly know what occurred that day. His father will never tell me the whole truth and Jericho was far too young to have any memory of it.

When I contacted BIAC, they gave me a sense of comfort and hope I hadn’t felt in a while when it came to attempting to handle the resulting behaviors my son was exhibiting...I felt like I had someone on my side, and I knew that someone else understood brain injury and how it affects a person’s behaviors and abilities.
Denver is a step closer to funding an apartment complex that, according to those involved in the project, would be the first of its kind in the U.S.

On Wednesday, a Denver City Council committee approved $2.4 million that would help pay for construction and services for the 72-unit apartment complex on East Colfax Avenue. The complex would offer housing and services for low-income residents, including for people experiencing homelessness who have brain injuries. The full council will vote on the contract at a later date.

Valor on the Fax will be located at 7900 East Colfax Ave. on a city-owned parcel. Units would be reserved for people experiencing homelessness and people earning up to 30 percent of the area median income, which for Denver would be $21,000 for a single person.

City deputy director of housing opportunity Debra Bustos said in an interview with Denverite before Wednesday’s meeting that the complex was planned with community feedback.

“Any housing units that we can develop is healthy,” Bustos said. “This type of housing in particular is very valuable because this is the population that has the greatest need when it comes to housing. There aren’t a lot of options for people earning less than 30 percent of area median income.”

Brothers Redevelopment, which specializes in affordable housing, will build the complex. The city’s contribution, which would pay for construction and cover services at the complex like 24-hour front desk support and RTD passes for residents, is a fraction of the $23.6 million the overall project would cost. A majority of the money paying for the project will come from the state housing authority and federal low-income housing tax credits, according to a presentation given at the meeting.

Brothers Redevelopment President Jeff Martinez called the project unique, since the complex will partner with Brain Injury Alliance of Colorado to provide services for people living with brain injuries. Gavin Attwood, CEO at Brain Injury Alliance of Colorado, said studies have suggested that more than 60 percent of people experiencing homelessness have had a brain injury at some point. Attwood said this project is likely the first of its kind in the country.

Valor on the Fax will include 47 one-bedroom, 19 two-bedroom and 6 three-bedroom apartments. Residents would receive housing vouchers to help pay their rent.

The location where the complex will be built is currently vacant. The empty parcel will be sold to Brothers Redevelopment for $10, with the understanding that it will be turned into affordable housing.

Gavin Attwood, CEO at Brain Injury Alliance of Colorado, said this project is likely the first of its kind in the country.
It is a bittersweet moment when I recall trying to create normalcy out of a situation that didn’t even have ‘normal’ as part of its description.

You may be wondering where I came up with the title. As I was travelling on this often lonely and invisible caregiving journey, the focus was always on my husband and very few ever asked about me. I often felt as though my thoughts and feelings had to be swept under the rug.

I remember a counselor once said, “So Rosalyn, what are you going to do if you don’t move out of Vancouver?” That had been a desire of mine, because up to that point it had been over five years living in BC’s lower mainland with nothing to show for that time. In that conversation, there was nothing said about my husband looking at different work options.

It wasn’t until January 1998 that I finally “got into the saddle” and fully realized something was really very wrong and that he needed more help. To help me navigate this lonely and unknown journey, I used my research skills to find practitioners that could help my husband with his recovery. I spoke to anyone who would listen. I learned along the way to craft better questions to get the answers I needed as I connected the dots in providing the best care possible. Throughout the seven years from the accident to the court date, I managed my husband’s physical and mental recovery on a daily basis. During the court case, I realized I had sourced 73% of the medical professionals and practitioners that my husband saw to help him on his recovery journey. I was also always on the hunt for those who could help my husband.

Caregivers are often backstage, working to help the star performers (the people who have sustained a traumatic brain injury) shine.

The level of stress experienced by the family members of patients who have TBI is such that professional intervention is appropriate, even after 10-15 years after the injury occurred. It is not the severity of the injury, but the nature of the injuries, which determines the level of stress (Verhaeghe, S. 2005).

Some of the thoughts and concerns I mulled over during this time included striving to stay positive and being proactive throughout this entire experience. I wanted to grieve, but never felt like that was allowed. I often felt like I was flying by the seat of my pants, while at the same time walking on eggshells. It was sad and scary to watch my husband struggle on a daily basis with what used to be very simple tasks for him. Conversations were tough as he got lost in conversation. He couldn’t remember what he had said or what someone had said to him and he would forget the main point he was trying to get across. He would persevere, continuing to repeat himself.

These were some of the things I was dealing with on a fairly regular, or even daily, basis. He would take everything I said very literally and would be very critical of most anything I would say. Even if he asked me how I was feeling or was asking about an event in the past, I would give my answer and then he would proceed to tell me how he would do it differently. In conversation, there were often huge pauses in the conversation, and he would be totally unaware of his tone of voice. What he was saying and his body language weren’t in agreement.

As you may guess, communication is quite a process when it comes to brain injury. Communication is also a huge part of our daily lives. It was very difficult to carry on an in-depth or lengthy conversation with Donald. Sometimes I would ask a question and there would be no answer. I was left to wonder if he heard me, or if he chose to ignore me. I would have to ask the question again, only to get “I don’t know”. Sometimes he started a sentence and stopped mid-sentence and then I would wonder if I should wait, should repeat what he said and add ‘what’?, or I should simply say, “uh huh?” To this day, I wonder if we will ever be able to share in-depth conversations again without very frequent and long pauses. Another emotion was frustration. It came along with washing dishes. Let’s suffice it to say

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I would rather do all the laundry, than the dishes. One physiotherapist couldn’t figure out why I always talked about it, and she got irritated with me. She didn’t understand that I had to make sure I was able to do the dishes and that was made a higher priority than my own exercise. I think she thought I was always complaining, but looking back now, I think I was simply reaching out. My husband didn’t seem to understand that I needed help. Getting help doesn’t mean one is a weakling, but rather that one is strong enough to say, “I need some assistance here and as a couple we could work as a team.”

Along with all these new emotions, I had a new list of roles in our marriage, which included financier, taxi driver, daily planner, case manager, public relations person, provider, role model and garbage man, not to mention “chief cook and bottle washer.” Some of these roles continue today.

I often felt like I was Snow White, and I was living with the seven dwarves. I have bought the book, Seven Dwarves and Snow White. This may actually be a useful tool for others in a similar role. I call it ‘The Snow White and the Seven Dwarves checklist. Is the individual with the TBI Sleepy, Dopey, Grumpy, Bashful, Doc (telling you what to do or being Mr. Fix It), Happy or Sneezy? Interestingly enough, the caregiver or spouse may not realize the role they are playing is crucial in getting their loved one better.

Looking back, I now realize that this has become a new way of life. I no longer sweep things under the rug because I care not only for my husband but for myself as well! This is a part of my life. I continue in the thick of things and while the struggles still come and go, like waves at the seashore, I continue to acknowledge my feelings and emotions and ride the waves of life.

Recommendations to address these issues identified in this study include more consistent and specific communication between hospital and school for all students with TBI, long-term tracking of the injury, and increased training of educators in how to meet the needs of students with TBI. The fact that many teachers remained unaware that students needed on-going support following TBI, even when transition support was provided, indicates the need for extensive pre-service and in-service training for educators. Additionally, educators report that they feel more confident in providing services to students when they have received training.

Resources for educator training:
- In the Classroom After Concussion: Best practices for School Success
- Oregon Resources for Educators
- Brainsteps