



Touched by TBI

How their son's traumatic brain injury changed Joan and Tom Nielsen's lives

In 2008, Marc Nielsen was a 24-year-old man on his way to professional success. He had already been promoted twice during his two years at John Hancock Financial Service, the large Boston insurance firm, following his graduation from Boston University in 2006. He had recently applied for another career-advancing position at the urging of one of the company's vice presidents.



Joan and Tom Nielsen, whose son Marc became a TBI survivor in 2008. The accident changed all their lives in unforeseen ways. Tom is now the Vice President of the BIAAZ Board of Directors.

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But on July 11, 2008 Marc sustained a traumatic brain injury (TBI) when he fell down 21 concrete steps leading to a subway stop (known locally as the underground T) in downtown Boston.

It was a life-changing accident, but not just for Marc. Tom and Joan Nielsen, Marc's parents and post-accident caregivers, now face a very different retirement from what they had previously envisioned.

A World Away

Tom and Joan Nielsen lived in Bangkok, Thailand when they got the phone call informing them of Marc's accident. Joan screamed and handed the phone to her husband.

The neurosurgeon introduced himself and told Tom two things: that Marc needed a surgery he may not survive and, even if Marc did live through surgery, he "might be a vegetable" for the rest of his life.

"So in 20 seconds we went from knowing nothing to knowing our son had had a horrific brain injury and that the prognosis was very dismal," Tom said.

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The Brain Injury Alliance of Arizona (BIAAZ) is a nonprofit organization dedicated to preventing brain injuries and to improving the lives of individuals with brain injuries through prevention, education, information, and community support.

From Executive Director Carrie Collins-Fadell

Even though we are quickly roaring through the summer months, things aren't slowing down at the Brain Injury Alliance of Arizona (BIAAZ).

The board of directors passed a new strategic plan that will provide a roadmap for the direction of the organization. The plan assures our continued success while positioning us to take advantage of exciting new opportunities.

In our continued quest to be a resource for professionals, we also hosted a Professional Network Meeting for BIAAZ professional members at which Dr. Pamela Klonoff, of the Barrow Neurological Institute, discussed the lessons learned in the Department of Economic Security's Youth Transition Program. We are also preparing for a signature BIAAZ event, Kamp Kan Do, a camp for brain injury survivors. Plans to fill the campers' days and nights with camp fire songs, fishing, star gazing and horseback riding are under way by the talented BIAAZ staffers.

I am particularly proud of July's BIAAZ newsletter. It features some incredible stories of families coming together to not only survive together as a family after a brain injury, but to thrive together. In this month's edition of the Noggin you'll meet our incredibly dedicated BIAAZ Board Vice President, Tom Nielsen and his family. Tom has served in upper management positions with several international corporations. He and his wife Joan lived in Bangkok, Thailand when one phone call from a hospital in Boston changed his family's life forever.

You'll also hear about what teenager and traumatic brain injury survivor Kyra Richards is up to this summer. She's a BIAAZ member who suffered a traumatic brain injury as a result of a car accident when she was only a few days old. Her mother, Bridgette, was in the same car accident and was soon faced with the reality of caring for an infant with a TBI while healing from a TBI herself. She raised Kyra with the mentality that she can do anything she sets her mind to. Kyra will be taking that strong will with her this summer to Missouri for a very special competition.

We'll also talk about staying safe in the summer heat and tell you about our Secrets of Healthy Living Summer Series. Finally, we're excited to introduce a new section that highlights brain injury specialists. This month speech pathologist Beth Lynch explains what she does to help brain injury survivors, many of whom are BIAAZ members. Thank you for being a part of the BIAAZ family and best wishes for a safe and happy summer!



Growing up a survivor:

Kyra Richards hopes to increase TBI awareness at competition



Bridgette Ratliff, left, and her daughter Kyra Richards, nominee for the state National American Miss pageant. Both are TBI survivors.

Kyra Richards is an elegant 14-year-old with a soft voice, gentle smile and natural grace. It's easy to see why she was nominated for the state National American Miss pageant by an anonymous teacher, coach or mentor. Far less noticeable are the minor mobility issues Kyra has with the right side of her body, the result of a brain injury she received when she was only a week old.

The accident occurred on July 27, 2000 after Kyra's mother, Bridgette Ratliff, and Kyra's father took the newborn to a hospital in Houston, Texas for a precautionary fitting for a sleep apnea monitor. The family van broke down on Beltway 8 during the return trip.

While Bridgette and Kyra's father waited for a tow truck, Kyra's father changed the baby's diaper. Bridgette, preparing to nurse Kyra, sat sideways in the back of the van with her feet dangling over the street. But just as Kyra was handed to Bridgette, a Ford F-250 pickup truck, whose driver was high on meth, slammed into the back of the van. The van crashed into concrete barrier. Police later estimated the truck had been traveling between 95 and 105 miles per hour when it hit the van.

Kyra was thrown between the back and middle seats, hitting both of them before being tossed around on the floor

boards. The infant spent the next 10 days in a Newborn Intensive Care Unit, or NICU, for severe intracranial bleeding and seizures. Fortunately, doctors did not have to operate to relieve pressure on Kyra's brain.

"The report I got from the hospital was that her head swelled up immediately," Bridgette said.

Reluctant to do anything overly invasive, doctors advised Bridgette to watch and wait.

Impacts

Before long, the impact of Kyra's brain injury to manifest. When she was about eight months old, Kyra would only use her left hand to eat. If Bridgette put food on the right side of the high chair tray, Kyra would reach across her body to get to food placed on the right side. Babies don't show preference at that stage of development, so Bridgette knew something was wrong.

As she grew, more issues began to surface. When Kyra crawled, she would keep her right arm bent and tucked up under her "like a little injured wing," Bridgette said.

When Kyra began to toddle, she veered strongly to one side. She was also nearly legally blind in one eye.

The mobility issues impacted Kyra's ability to learn daily life skills. Although she instinctually wanted to potty train, the lack of mobility in Kyra's right arm made it difficult to pull pants up and down.

"So I knew she needed help I couldn't provide; I didn't have the education or the resources to give her what she needed," Bridgette said.

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THE GAVEL

BRAIN INJURY SURVIVOR LEGAL ISSUES



Victims of TBI Are At The Back of the Line

By Ray Norris

Ray is a partner at Gallagher & Kennedy P.A. in Phoenix, Arizona. Ray specializes in catastrophic personal injury cases, with particular expertise in brain and spinal cord injury, along with medical malpractice, products liability, wrongful death and mediation of disputes. He also conducts trial preparation and jury selection focus groups. The views expressed in this article are Ray's own.

According to the Centers for Disease Control and Prevention the most common cause of traumatic brain injury (TBI) for people between the ages of 5 and 64 years old is motor vehicle crashes. If the survivor is not at fault, they may be able to assert a claim for damages.

Unfortunately, the chance of ever obtaining a recovery that fully compensates the victim for all of their damages is highly unlikely. First, an estimated 22 percent of Arizona drivers have no insurance at all. Without insurance, the person will almost certainly have no assets with which to pay a verdict against them. Second, even among those with insurance, very few people have the adequate insurance limits necessary to pay the damages of a catastrophically injured person.

The minimum insurance limit in Arizona is \$15,000 per person. In many cases, that may not even pay the cost of transport to the hospital from the accident scene, let alone years of medical treatment, the following lengthy rehabilitation, and (often) the loss of wages for the rest of the victim's life.

Even if the brain injury survivor *is* successful in recovering some compensation (which almost certainly will be for less than the total losses suffered), many survivors are shocked to discover state governments, the federal government, health insurance companies, hospitals and other health care providers usually have to be paid first. In other words, when the check clears the bank, the victim goes to the back of the line and waits while attorney's fees, including costs advanced by the attorney in prosecuting the case, and medical bills paid by various insurance plans deduct a portion of the settlement first. If you are starting to feel like the Colorado River at its terminus in Mexico, you are not far wrong.

For example, let's say that "Bob" works for a large corporation here in Phoenix. One of his employee benefits is health insurance. While driving home from work one day, Bob suffers a serious brain injury when a car runs a red light and smashes into the side of his car. Bob is in a coma for several weeks; he is in the hospital for months, he is in an inpatient rehabilitation facility for about a year. His medical bills, paid by his employer's policy, amount to over \$1.5 million. Bob is no longer employable. At the time of the crash, he was making \$100,000 per year.

Bob was somewhat lucky in that the person who ran the red light had a \$500,000 insurance policy on the car. But, Bob's total damages exceed many millions of dollars and it is likely that the other driver's insurance company will pay the policy limit without having to file a lawsuit.

Even though Bob's lawyer should only take a relatively small fee for helping Bob and his family through this process, in some cases the employer's health plan would be entitled to get the rest of the settlement, *leaving Bob with nothing*. Not sure how any fair minded person could think that is justice but reported cases which say just that exist.

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The doctor asked for permission to operate which Tom and Joan immediately granted.

“I told him, 'You treat him like he's your own child,'” Tom said.

Granting permission for surgery so quickly proved to be a crucial decision instrumental in Marc's remarkable recovery. Later, the parents would learn from the neurosurgeon that many brain injury patients lose precious minutes and even hours while family members are tracked down so permission to operate can be given.

Marc entered the operating room with several advantages on his side. He was young, there would be no delay in operating and, as it happened, the entire neurosurgery team had just finished a case and was already assembled at the hospital.

With little more the parents could do from twelve time zones away but wait for the next flight to the United States, Tom and Joan went into their son's bedroom and prayed. Joan emailed and phoned friends and family, asking for their prayers and support as well.

As their only adopted son underwent brain surgery, Tom and Joan began a 30-hour flight, including a six-hour layover, to Boston. In the meantime, Joan's brother flew from his home in Arizona to be at his nephew's bedside.

When Tom and Joan finally walked in to the waiting room at Boston's Beth Israel Deaconess Medical Center, they found it filled with Marc's coworkers and friends, at least 20 young people who Tom said “were basically in residence” at the hospital during the first few weeks of Marc's recovery.

Marc ultimately required two surgeries and had two strokes in the immediate aftermath of his accident, but eventually recovered into a very high-functioning TBI survivor. Still, the accident left Marc with visual impairments, executive dysfunction, short-term memory loss and the loss of feeling and minor mobility issues in his left hand.

Steep Learning Curve

Like many family members and caregivers of survivors, Tom and Joan scaled a very steep learning curve about brain injury, rehabilitation and all the peripheral issues that caregivers of brain injury survivors face.

“I didn't even know what a TBI was, I had to look it up,” Tom said.

After 12 days in the hospital, five days of which Marc was in a coma, the parents faced the first of countless difficult decisions they would make over the next several years. When Marc was released from the hospital, he couldn't walk, talk or eat on his own.

“He was an infant in a 24-year-old's body,” Tom said.

They needed to find a rehabilitation hospital for Marc, and quickly.

“They gave us a list of three and said, 'These are all good, which one do you want to use,'” Tom said. “We didn't have a clue.”

After preliminary interviews and assessing who even had room, the parents transferred Marc to the Spaulding Rehabilitation Hospital.

“I didn't even know what TBI was, I had to look it up.” ~ Tom Nielsen, whose son, Marc, sustained a traumatic brain injury after falling down 21 concrete steps

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Marc's recovery journey had begun, but Tom and Joan faced a long road of uncharted territory.

Split lives

For 12 years prior to their son's accident, Tom and Joan lived full, happy lives in Bangkok. After the accident, Tom had to return to work in Thailand and Joan stayed in Boston to be with Marc during his recovery.

Neither of the parents were prepared for a multi-year journey.

"Tom and I didn't know, we thought he's going to be back to work in six months," Joan said.

For the next three years, Tom would spend five weeks in Bangkok and then three weeks in Boston to be with Joan and Marc, continuing to work while in Boston. Meanwhile, Joan helped Marc to slowly regain his lost cognitive skills. She bought grade school workbooks to help re-teach Marc basic Math and Language skills and worked with her son daily.

"Tom and I didn't know, we thought he'd be back to work in six months." ~ Joan Nielsen on her son Marc's TBI

Marc spent the first three months of his initial 18 months of rehabilitation as an in-patient. He spent the next 15 months as an outpatient living with Joan in a rented, furnished apartment in Boston.

Though Marc continued to show improvement, it was a lonely, difficult time for the parents. Boston was Marc's home, not theirs, so they were without the immediate support of nearby family or friends. Joan and Marc had a place to live, but it was not home for Joan.

Eventually, Marc required advanced cognitive therapy. Tom and Joan found themselves choosing between a facility in New York City or the Center for Transitional Neurorehabilitation at Barrow's Neurological Institute in Arizona.

Faced with driving in Arizona or commuting in New York, the parents chose Arizona. It was not a place they had ever imagined they would live. Prior to the accident Joan and Tom had even traveled around the United States to get a feel for places they might want to live after Tom retired. Arizona, with its relentless heat, had not made the cut.

But in February 2010, Marc entered a 6-month program at Barrow's. Again, Joan accompanied him, driving a rental car for 18 months and living in a rented furnished apartment.

"We never thought we'd be here that long," Tom said. "This was not the place we were ever going to retire."

A New Home

Tom and Joan have since made a home in Arizona. Tom retired and became a Board Member of the Brain Injury Alliance of Arizona. He is now Vice President of the Board. The family has found a church that Joan said they like and Marc recently finished a vocational rehabilitation program with Rehab Without Walls.

Marc is now a very high-functioning survivor who can fix anything and is great with computers. He volunteers with the Tumbleweed Center for Youth Development.

However, the permanent impacts of his disability may keep Marc from ever returning to work, though Tom and

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Need support? BIAAZ facilitates several survivor and caregiver support groups that meet monthly throughout the Valley. Check out our Facebook page at www.facebook.com/BrainInjuryAllianceAZ for more information. Or, ask to subscribe to our e-Blasts by emailing info@BIAAZ.org.



SUPPORT

**Project
Independence &
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THE SECRETS OF HEALTHY *Living* SUMMER SERIES

Mind, Body and Music: Summer classes to focus on music therapy

Music therapy has an extraordinary ability to heal physical and psychological wounds. It can be especially beneficial for brain injury survivors and is often one of their more enjoyable rehabilitation activities.

That's why the Brain Injury Alliance of Arizona's annual Secrets of Healthy Living Summer Series will focus on music and art therapy. Each of the five free classes, part of Project Independence and Empowerment, will be led by Sally Niles, a board certified music therapist with 30 years of experience.

Every class will center on a fun, artistic activity that helps develop cognitive skills like memory and socializing. Activities will be adaptable to different abilities.

Sally said even just listening to music stimulates the memory and spurs conversations, both important cognitive skills. But adding an artistic component boosts the mental benefits of music because it incorporates more than one of the listener's senses.

"Art is a whole-brain activity," Sally said. "Multi-sensory experiences are always beneficial to the brain," Sally said.

And there's the spiritual aspect as well, Sally added.

"Creativity in itself makes you feel good," Sally said, and is a way survivors can "just express thoughts and feelings."

The first class, for example, will focus on [Zentangle](#), an activity during which a design is created through a step-by-step process that is simultaneously structured, yet fluid.



Sally Niles, board certified music therapist, will lead the five free classes in BIAAZ's Secrets of Healthy Living Summer Series.



"It's one little piece at a time," Sally said. "It's very free-flowing, there's no super rules, but you can learn to be more creative and artistic in your drawing."

The classes range from a Karaoke sing along to melding music and Tai-Chi and more.

The Secrets of Healthy Living Summer Series will be held in Classroom B, Second Floor in the Disability Empowerment Center at 5025 E. Washington Street, Phoenix 85034.

For more information, check our Facebook page [Events tab](#).

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Kyra began a physical and occupational therapy regimen that was folded into her normal learning and growing activities.

“It was simple things like holding both of her hands and letting her swing, to help stretch [the right arm muscle],” Bridgette said.

Another game involved a picking up a hula hoop and putting it down on to the floor to teach the muscle memory necessary for acts like pulling on clothes. Playing dress-up, especially putting on scarves and hats, was another fun way for Kyra to improve her fine motor skills.

But it wasn’t all fun and games.

“She would get frustrated and she would say, ‘I can’t,’” Bridgette said. “And the thing I always tried to teach her was that you can, you might need a little help but there’s nothing you can’t do.”

Although Kyra’s limited mobility isn’t evident in her face, it has impacted her speech. Even after a significant amount of speech therapy, Kyra still had difficulty articulating her needs, especially when she was upset.

That was when Bridgette first noticed her daughter’s artistic talent. To help Kyra express herself, Bridgette would give her daughter an art bucket full of crayons, paper and other items and say, “Show me how you feel.”

A well of artistic talent was unleashed. Kyra proved to be exceptionally creative and showed a natural skill with virtually any medium, from paints to modeling chocolate. After merely watching an episode of *Cake Boss*, Kyra discovered a love of artistic baking and made edible roses comparable to those found in a professional bakery.

Later, in school, Kyra would use her art skills as an alternative way to complete assignments.

Growing up post-TBI

Kyra said she didn’t have many friends in elementary school and spent most recesses by herself on the monkey bars.

It’s only been recently that she has been open about her brain injury, and finally telling her peers about it was difficult.

Though they meant well, friends began to offer an excess of help.

Before Kyra told her friends about her injury, she said many of them “thought I was a role model.” But afterwards “they thought I couldn’t do anything.”

Today, Kyra is on the volleyball team but has to serve differently because she can’t put her arm in the traditional serve. But Kyra’s sister, and some classmates, say Kyra is just “using it as an excuse,” Kyra said.

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No diagnosis: Bridgette Ratliff’s TBI & how she coped

Bridgette Ratliff also received a traumatic brain injury when the driver of a Ford F-250 on meth, going at least 90 miles per hour, slammed into her minivan on Beltway 8 near Houston. The van was pulled over and waiting for a tow truck and Bridgette was getting ready to nurse 7-day-old Kyra so she was sitting sideways in the van with her feet dangling over the road.

The van was slammed into a concrete highway barrier. Bridgette was pinned between the van the barrier, crushing her leg and tearing tendons in her right ankle and left knee. Her feet were dragged so hard against the asphalt gravel was embedded in them.

Even more severe was the damage done to Bridgette’s brain as a result of the successive impacts. Since she was pinned when the van stopped moving, Bridgette was thrown upwards causing her head to slam into the van’s frame so hard her skull skin was torn open from the above her right eye to nearly the back of her neck.

“That was just from impact,” Bridgette said. “I wasn’t cut, I just hit the frame of the car hard enough that it split me open.”

Part of Bridgette’s orbital socket was crushed and to this day she is missing a chip of bone in her orbital lobe.

“The doctors had said that everywhere my brain had hit inside [my skull] it did damage,” Bridgette said. “The way they explained it was that it was like shaken baby syndrome.”

Bridgette was released from the hospital that same evening and given no information or guidance about brain injury.

During the following months, Bridgette helped Kyra’s older brother battle a serious form of cancer while caring for Kyra. So though she knew something was wrong, she didn’t have an opportunity to seek help.

“I found there were a lot of things that were just deleted, they were just gone,” Bridgette said.

She found herself having volatile, surprising reactions to events.

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The right to be reimbursed out of the settlement for medical expenses (also referred to as a “lien” on the recovery) varies from state to state and has become a very complex area of the law. In fact, in some of my cases I spend more time resolving the various lien rights that emerge than I spend resolving the underlying case.

Since a complete explanation of each type of lien is beyond the scope of this article, I’ll give a brief summary of the more common liens lawyers such as myself encounter.

Arizona Health Care Provider Lien

This is sometimes called a “balance bill lien,” but I like to call it the “Hey, my health insurance company, to whom I paid a premium for years and years paid my medical expenses” lien.

Pursuant to Arizona statutes §33-931, *et. seq.* any licensed health care provider may assert a lien for the difference between the amounts the health insurance carrier paid and the provider’s “customary charges” for the medical treatment.

Anyone who has ever received a bill from a hospital or doctor will notice there is the total bill amount and the amount paid by health insurance. The amount the insurance company pays is established in the provider agreement, an agreement between the insurance company and the provider. The provider is the person or facility that provides medical care to the insured. The patient’s health insurance policy states that payment by the insurance company is payment of the bill in full. So, if payment is payment in full, how does the provider get the authority to charge more when there is an injury and a settlement?

This lien is not a personal obligation of the patient, but is collected from any proceeds from a third party who was responsible for causing the medical bills to be incurred.

The upshot is the patient gets less money out of any settlement so the hospital gets paid its “customary” charges. Of course, what constitutes a customary charge isn’t uniformly established. A recent survey of charges by hospitals in Phoenix showed that what different hospitals charge for the same procedure varies wildly across the valley.



Federal ERISA Liens

In the example above, Bob’s large employer would most likely have had a health plan that qualified under the Federal Employee, Income and Retirement Security Act. Whatever the ERISA Plan pays for medical treatment, it is arguably entitled to be paid back 100 percent of what it paid out, regardless if the recovery was \$15,000 or \$15 million.

I have personally seen an ERISA plan attempt to insist that all of a policy limit be paid to them. In one memorable case, an ERISA plan insisted the \$50,000 policy limits be paid to them when an 11-year-old girl sustained a catastrophic brain injury in a car crash caused by an underinsured driver.

Some attorneys, myself included, have turned down cases where there was collectable insurance against the person who broke the law (the tortfeasor) because the ERISA plan refused to compromise and would have left the client with nothing out of the settlement.

Worker’s Compensation

If you receive worker’s compensation benefits for an on the job injury, and you collect from a third party responsible for your injury, you will have to pay back the worker’s compensation carrier for any benefits it provided.

AHCCCS

AHCCCS has an automatic statutory lien for payment of accident-related medical benefits. Statute and case law indicate the AHCCCS should compromise its lien when “fair and equitable” to do so.

Medicare

All past and *future* medical expenses paid or to be paid by Medicare must be reimbursed. Like AHCCCS, Medicare can waive or compromise its lien when equitable to do so.

There is another type of lien, but it is quite different. This is the “consensual” lien. As many brain injury survivors and caregivers know, insurance companies and AHCCCS do not cover many available treatments for TBI victims.

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Kyra uses art to help her express herself and communicate. She is painting a mural depicting her TBI recovery journey for one of her pageant projects.

Pageant plans

Being nominated for the state National American Miss pageant on July 18-19 is only the first step for Kyra. To compete, she needs to meet fundraising benchmarks.

Kyra plans to use the entire pageant process, including finding sponsors, to educate people about traumatic brain injuries. She is writing an introduction letter to prospective supporters explaining the challenges she's overcome. To thank people for donations, Kyra sends them a green ribbon pin she has made herself.

For her pageant project, Kyra plans to paint a 30-inch by 40-inch canvas depicting herself as a baby, young child and now to illustrate her brain injury journey. There's a spokesperson competition within the pageant Kyra hopes to enter as well, mainly because she plans to speak about her brain injury and how to prevent brain injury.

If Kyra wins the pageant, she will go on to represent Arizona in the national National American Miss pageant.

"I want people to know what I've overcome," Kyra said.

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"There were things that made me angry that didn't normally make me angry," Bridgette said.

Even now, Bridgette knows she's not who she was prior to the accident.

"I used to have a really good memory," Bridgette said. "If I met you, I would know your name and your face and your phone number forever."

Despite not having much formal guidance, Bridgette has found ways to cope with the impacts of her brain injury.

At work, to help with memory challenges, she keeps project folders and files neatly on her desk. Having them in sight serves as a reminder of what she needs to accomplish during the work day.

Still, it's been challenging.

"People in the work place are not very understanding about traumatic brain injuries," Bridgette said.

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In such cases, some health care providers are willing to agree to wait for payment of their bill for services until the case is settled. Such an agreement should be set out in writing and kept in the doctor's and lawyer's files. These liens often allow a patient to obtain much needed, but unaffordable, medical treatment.

In this case, the health care provider has every right to be paid for their services. However, these liens can be abused as well. A good lawyer will ensure the no one takes advantage of the brain injury survivor.

There are many other liens that operate more or less the same way. A listing of every possible lien is beyond the scope of this article, already longer than I intended. As Mark Twain said, "I didn't have time to write a short letter, so I wrote a long one instead."

Is there anything we can do? I think so. We need to let people who have not been through this process know just how unfair it can be. The average person has no idea how victims are sent to the back of the line. Our lawmakers will not change these laws unless we tell them they must.

Ghandi said the measure of a just society is how it treats its weakest members. When we allow rich corporations to take (an often huge) bite out of settlements intended to be compensation for lost wages, future medical care, etc. from people who have been catastrophically injured through no fault of their own, using Ghandi's measuring stick, we fall far short as a society..

Rehab Ready

Brain injury often introduces survivors and caregivers to a new array of health care providers who specialize in brain injury. Some of the specialties may be completely unknown or confusing to caregivers looking to find the right care for a survivor. For example, we've all heard of an ophthalmologist, but how is a neuro-ophthalmologist different? The Brain Injury Alliance of Arizona offers referral services to help people navigate these sometimes overwhelming choices. Here in *The Noggin*, each month we'll feature a brain injury specialist and explain what they do and the role they play in the recovery process.



Beth Lynch, MS CCC-SLP, CBIST

HealthSouth Valley of the Sun

Beth Lynch, Speech Pathologist

Despite what the name says, speech pathologists help brain injury survivors with far more than speaking out loud. In reality, speech pathology includes every aspect of communication, from a survivor's physical ability to speak to cognitive skills such as memory and reasoning.

"The role of a speech pathologist changes throughout the journey of a person with brain injury," Beth Lynch, speech pathologist at HealthSouth Valley of the Sun, explained.

Usually, a speech pathologist will enter a brain injury patient's recovery early on during the acute recovery phase.

The speech pathologist will first address physical concerns. They can assess whether a patient needs a tracheostomy, a surgical incision in the throat that allows patients with a windpipe or lung obstruction to breathe. Or, they may recommend a speech valve to help a survivor verbalize. Importantly, speech pathologists also assess a patient's ability to eat, drink and swallow.

"We want to make sure the patient is safe to chew and swallow foods and liquids," Beth said.

These examinations may take place at a survivor's bedside in their hospital room or at a rehabilitation facility, but generally happen fairly soon after the brain injury causing incident.

Later, during the rehabilitation phase, speech pathologists focus on "evaluating and treating communication and cognitive impairments," Beth said.

This can include everything from re-learning the right words to use to picking up subtle social cues during conversation.

Sometimes the need for a speech pathologist may not become apparent until after a survivor has finished a rehabilitation program. When subtle cognitive issues, sometimes missed by medical professionals unfamiliar with brain injury, begin to surface.

"Especially patients with higher-level deficits can fall through the cracks because they can hold conversations and appear OK to family and friends and unfamiliar health care providers," Beth said.

Caregivers or family members closest to the survivor, however, usually notice something is amiss, even long after the survivor is discharged from a rehabilitation program.

For example, a brain injury survivor may go to the grocery store to get three items but only return with one. Or he or she may forget appointments completely. The survivor may do very well at home but has difficulty focusing in other environments. They could have difficulty managing their finances. Verbally, a survivor may have trouble maintaining attention to long bursts of speech or, when they speak, communicate their needs but in a way that just doesn't quite make sense.

This decreased ability to pay attention, often accompanies with by a lack of organizational skills, can lead to frustrated outbursts from survivors.

A speech pathologist can help the survivor learn to cope with these cognitive changes. Therapy often include everything from setting up tasks of increasing difficulty to help the patient re-learn cognitive skills.

"We can work in steps to work up to the difficult task they're trying to complete in their daily life," Beth said.

Other therapy may include completing exercises, either in a workbook or on the computer, to exercise specific parts of the mind.

Speech pathologists are board certified professionals, so be sure to check credentials if you feel the need to or have questions about your provider's qualifications.

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Joan said Marc is looking for additional volunteer opportunities.

For all his ongoing challenges, “Marc never lost his zest for life,” Tom said. Marc is outgoing, extremely friendly, caring and can fix just about anything, Tom said.

Still, the impact of their son’s injury on Tom and Joan’s own lives is undeniable. Tom retired earlier than he planned. Joan finds she is less social than she used to be.

“I’ve really become a homebody,” she said. “I love being at home. It can be difficult to be around people. For a long time, all I could talk about was brain injury.”

And while many people their age are empty nesters who exchange stories about grandkids, Tom and Joan find themselves caring for their son again on a daily basis. The diverse experiences can make it difficult to find common social ground.

Fortunately, the close-knit family genuinely enjoys spending time together. The trio does everything together, from dinners out to vacations.

“Our whole life has changed because Marc now lives with us and our whole life pretty much revolves around him,” Tom said. “We’re not two people, we’re three.”

“Marc is a lot of fun to be around,” Joan said. “We enjoy each other’s company immensely.”

For all they’ve been through, Tom and Joan don’t have a trace of anger or bitterness over what’s happened. For that matter, neither does Marc. Rather, Tom and Joan said what they feel most is gratitude.

“Dozens of caring persons contributed to Marc’s rehabilitation, both in Boston and in Phoenix,” the parents said. “Hundreds more from around the world have lifted him up in prayer. For all we are so grateful.”



Staying safe in the summer sun

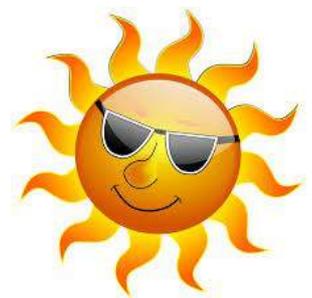
Already, temperatures have climbed into the triple digits and stayed there. With the increased heat comes an increased risk of [heat exhaustion](#) and [heat stroke](#). These conditions, caused by overlong exposure to high temperatures, can lead to a heart attack or even death if left untreated.

Below are some tips to keep cool – and safe – during the brutal Arizona summer.

- ◇ **Dress appropriately.** Wear loose, lightweight clothing that allows your skin and body to breathe, preferably cotton. And remember, covering skin protects it from harmful UV rays (though make sure these items are loose, light and billowy to allow air circulation). And try to wear a hat and sunglasses whenever possible.
- ◇ **Spritz or goop before you go.** Apply an odorless, light coat of high SPF sunscreen before going outside, even if you’re just going to be sitting in a car, and re-apply it throughout the day. This not only helps protect against UV rays and prevent skin cancer, but adds a (small) buffer between the heat and your skin.
- ◇ **Pay attention to your medications.** Some medications impact the body’s ability to stay hydrated and can make a person more susceptible to heat exhaustion and heat stroke. Be sure you’re aware of all the impacts of any medication you are on.

◇ **Bring water, or even just a chunk of ice.**

Never leave home without cold water at hand. If you’re going to be in and out of the car and running errands, try freezing water bottles or water a freezer-safe, reusable tumbler and bringing that as back-up hydration. It will melt into ice cold, refreshing water as the hours go by even if you leave the bottle in the car.



◇ **Work around the heat.** If you need to do strenuous activity, be outdoors or exercise, schedule these activities for the coolest parts of the day, early morning and late evening.

◇ **Know when to get medical assistance.** Heat exhaustion and heat stroke **are medical emergencies**. It can cause [multitude of symptoms](#) ranging from a *lack of* sweating to headaches. Be aware of your body and call for medical help when necessary.

◇ **Listen to your body.** If you feel like you need rest, rest. If you can’t get cool, find shade and get indoors as soon as possible. Take a cool shower if necessary or lie down with ice packs on your head, wrists and groin if necessary to cool your body’s temperature down.

Survivor Q & A:

Dee Farrand shares the highs and lows of recovery and why she won't let her injury define her

Dee Farrand was a young mother and recent college graduate when she suffered a serious injury in 1999 that left her immobile and unable to care for herself. She recovered and now gives back to the Arizona community as a social work professional, specializing in empowering people dealing with anxiety issues.



Tell us about yourself

I am a professional social worker. I have a Bachelors in Social Work and a Masters in Nonprofit Management. I have lived with a brain injury for the last 16 years. I was injured in August of 1999 when I was struck by a falling swamp cooler, having just completed my Bachelors degree the previous May. The accident not only left me with a brain injury but a broken neck and a dislocated right shoulder that eventually became 70% frozen. I am right handed, so I was not able to dress, eat, or bathe and with the balance issues from the brain injury I wasn't able to do much of anything unassisted.

What was your personal experience with recovery?

At the time I was injured they told me it would be catastrophic and I would not fully recover. At the one year point, they told me further recovery was not going to happen. I still had not regained my ability to read, I struggled with short term memory issues, mood swings, significant personality change, and had a pretty major identity crisis. I was told to accept this was my new normal and to go file for disability left the neurologists office so angry and dispirited! I have since recovered. But then I decided I would refused to accept that this was now my life. I live with some symptoms as a result of my accident. I have migraines and recently had my first cluster headache where I though I was having a stroke. I smell and taste things that are not real, I have ocular migraine and visual distortions, I have auditory photo sensitivity and still have memory issues. But I went on to earn my master's degree and am now opening a private practice. I did not let the injury rule my life. When I got home from the hospital my mom had to help me get dressed. Right then and there I decided that I was only in my thirties and this certainly was not going to be my life.

Was there someone there helping you during recovery or cheering you on?

I was very fortunate because my parents were retired and able to move in with me after my injury. Had they not been able to do that, my life would've gone in another direction. My mom moved in and helped me rehab and ran my house. She helped me maintain custody of my son who was 9 at the time. My father became my sons favorite person and they spend hours together working on my sons bicycle, working on my parents RV, which they parked at my house, and just talking. My father was a God send for my son who had to adjust to a whole new mom as a result of this accident.

How did you go about helping your son understand your injuries?

Initially I couldn't really help him through this because my rehab was all consuming.. After a few months, when it was clear that this was going to be a long-term journey to recover, I sat everyone down, including my son's father's side of the family, and had a frank talk about what life was going to look like during my recovery. I rallied the troops. Strangely out of this life-altering tragedy came some wonderful things. During my recovery my siblings made a point to come to my house and help out in whatever way was needed on Mondays. As I recovered and the visits became more of a social calling, we moved the visits to Sundays. Now every Sunday night my family gets together for tea. Out of a tragedy we formed a beautiful family tradition. And this tradition has now become the place where other family members can bring their own struggles and get the support from the family. We are a tight knit bunch and we are always there for each other.

How has being a TBI survivor impact the ways in which you serve your clients?

One of the primary ways it helps me is that I now have a unique perspective when it comes to letting a diagnosis define who you become. I work in the mental health field and there are a lot of diagnoses in the field. People can get trapped inside that. I like to challenge a client's perceptions of themselves. People are more than a diagnosis, that is just one page of the book that is their life. Also, since the people who rallied around me were key in my recovery, I have a keen sense that people need to have a community that supports them and challenges them. I have become adept at helping people create communities for themselves, even if they have no family in the area. Arizona can be transient and I like to help people look at creating the community that they need while are creating their new lives. I tell people, I create communities so everyone wins. Part of that is my private practice, creating safe spaces for people with anxiety.

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