

Craig Sears: A Voice for TBI

Sarah Jane & the PABI Plan

The Sarah Jane Brain Foundation is one of the leading organizations dealing with Pediatric Acquired Brain Injury (PABI) throughout the nation. The foundation is named after 6-year-old Sarah Jane Donohue who was shaken by her baby nurse when she was only 5 days old. She suffered 3 broken ribs, both collarbones and received a severe brain injury. Sarah Jane's father, Patrick Donohue is spearheading a 4 phase program to pass a national comprehensive continuum of care model system for PABI patients. Patrick's goal is to have this pending legislation signed into law by Sarah Jane's 4th birthday in June 2009. As a brain injury survivor, and a Voice for TBI, I will do whatever I can to make this happy.
- Craig sears



If you are wondering why the Sarah Jane Brain Foundation and friends are devoting day and night to help children and young adults who suffer from the #1 leading cause of death and disability, Please take just 5 minutes out and read my story then share your thoughts with as many people as you can, by doing this you will raise awareness of TBI and in turn someone else who experiences this could get the help and understanding they so deserve. (Chances are someone you know has experienced something very similar)

My Name is Craig Sears, I am a survivor of Traumatic Brain Injury this event changed each and every single aspect of my life, forever. Being someone that lives with a brain injury my journey made me all-too familiar with the difficulties of individuals and families working through the arbitrary system of care. For years, I felt as though no one else knew what I was going through, but believe me; Traumatic Brain injury survivors almost ALWAYS experience the same things.

"DON'T 'EVER' GIVE UP; KEEP IT SIMPLE & EZ DUZ IT!"

Today more awareness has occurred, but there is still much to learn, much like no two brain injuries are alike. The learning impact between different students will also not be alike.

A traumatic brain injury is not a mental illness, it is an injury "Injuries require care, care that we all need, care that this plan can provide!

This is my personal experience about what happens when brain injury goes untreated

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It was July 9 1987. It was a beautiful Connecticut summer afternoon and I was out riding my motorcycle. I had just turned 20, and had a lot going for me. I was making a very good life for myself. I had a great family and a good job in construction and as a part-time mechanic. I was making good money for a kid my age. I had a great girlfriend and lots of friends. I had two cars and lived in a nice condo right on the water. I was living the American Dream. I'll leave that up to you to fill it in because I had everything a man could have possibly wanted — and in a heartbeat it was all gone.

As I was coming up over a hill, there was a car going the wrong way and I was unable to stop. We collided. I was thrown an estimated 40 feet into on-coming traffic. I landed headfirst into a curb. I have no memory of the next six months. That period of time is a black hole in my life. I was in and out of a coma, undergoing multiple surgeries. From there I was transferred to a rehabilitation center. While I was in this treatment center, I had to relearn everything about life down to using the bathroom on my own. There, I was fighting against the physical pain and the pain of not knowing who I was. Then one day they decided to transfer me out to a locked, mental health ward in Bridgeport, Connecticut where I was constantly put in four-point restraints and forcefully drugged. (I was told there were no other services offered for people with traumatic brain injury.) After being in the mental health ward for nine months, I began to regain some memory and I knew this wasn't for me! Keep in mind traumatic brain injury is not a mental illness.

So I started to call around to town officials and state government offices to ask them how to get out of the ward. The ward was holding me against my will and I knew I didn't need to be there. I did know that I needed help in other areas because of my brain injury but I also knew I was not mentally ill. After getting through to the Connecticut Governor's office and sharing my story with one of his representatives, they got a hold of the hospital and set up a jury room filled with my family, doctors, and a representative from the state office. All the while, I was saying that I wanted out of the ward. In order to be taken out of there, I had to have a place to go and my only option was my family and I did not want to burden them with the pain that I was going through.

I ended up in a one-room efficiency apartment. At the time, the building was a major drug trafficking building with rats, roaches, and prostitutes. There was no other place for me to go, no help at all; my family had tried everything to get me help. There were no group homes, no programs, no services offered, nothing. I still did not know how to do the basic functions of life so I would wander the streets trying to regain some kind of memory. I would watch other people to see what they were doing, how they were acting in order to regain memory of anything that I knew how to do before the accident. I knew at that time this was not who I was.

Things began to improve. My mother got me a weight set, my father bought me a bicycle, and I started volunteering at St. Vincent's Hospital in Bridgeport. At the hospital, I could go into the physical therapy rooms and I could watch what they were doing for rehabilitation. Then I would go back home at night to do the exercises on my own in order to regain my strength and abilities. But I overworked myself physically so as time went on, I found that I was spitting out blood and my body was in terrible pain. A touch hurt. I didn't know better, I didn't realize I was harming myself rather than helping and improving. My mother had to take me many times to the hospital because I couldn't walk or move.

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Socially, things were awkward. One day after volunteering I was leaving the hospital and I saw a lady fall to the floor. My instincts were to grab a wheelchair and put her in it and run to the emergency department. Because I had ran to the emergency department, they called me the next day and told me not to return. I was crushed. There was a lot of other pain from being turned away ... people always assumed that I was drinking or using drugs because I would slur my words and my equilibrium was off because of my TBI. It became harder and harder to find where I fit in. After remembering little things from watching other people and always trying to look at the good things in life, I started wondering what it would be like to get out of where I was living in Bridgeport. I asked my family for help. They got me a different apartment. Every time I moved into a different place, I'd think it would help me by being in a better environment. I would temporarily feel like things were changing.

But I had learned a wrong way of thinking to solve my problems. I started drinking and getting into drugs. I thought it would help me cope with the pain by letting me forget all that I went through. Everything I had fought for, I started to lose. I found myself alone even more and getting into trouble, ending up in numerous mental health facilities all over the state because there is no help for TBI survivors. I continued to spiral down, and soon I wound up on the streets and homeless, and not long after that, in prison

I had several brushes with the law. While I struggled daily to live with my brain injury, I ended up with several minor arrests for public urination and things of that sort. The state of Connecticut did find a way to use my injury against me. It was a probation violation, for which I would ultimately receive a five-year prison term. I spent five years locked up in a level-four high-security prison where I received absolutely no help for my disabilities. I was locked in an 8'x 10' cell twenty-four hours a day surrounded by gang members, rapists, killers, and child molesters; all for peeing in a garage. Does that sound like justice to you? The police, the court, and the judge didn't know, care, or consider my TBI. And once behind bars, neither did the warden. I served five-years for what other people would sleep off overnight in the local lock-up, and then clear up with a brief court appearance. Again, there were no programs, no early release, or time off for good behavior. TBI or not, I served every measure of that sentence to the fullest. Common courtesy prevents me from sharing here. I will leave it up to your imagination to fill in the blanks. It was hell.

Somehow, I survived and was released in 2003. Once again I needed a place to call home. After nearly 20 years of waiting and being turned down, I turned to a local Congressman's office for help. Within two months, they cut through the red tape and I finally received recognition of my TBI. I was accepted into a HUD subsidized housing unit.

Life though continues to be a struggle. I have few options, and fewer choices. I am very uncertain of my future. I still want the American Dream, but it feels further away than ever. I want to be hopeful, but I know all too well how quickly good can go bad in life. So I try my best to help those with TBI get the help we need.

For myself, I wish that there was a national Pediatric Acquired Brain Injury plan in place for me. I wish that the state, doctors, nurses, all the cops, judges and people whoever had the power over me had a clue about Traumatic Brain Injury. I wish that when I needed it there were people to turn too an answers

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to the questions I didn't even know I had and the resources in place for me. If there had been such a plan in place, my life and my family's lives would be completely different today. - CS

My advocacy started as means to overcome my own difficulties. It's become my mission to make sure that no one else has to go through what I have.

“Insanity is not doing the same thing over and over again expecting different results; insanity is doing the same thing over and over again knowing full well what the results will be.”

I have since become a national voice for Traumatic Brain Injury TBI survivors speaking first hand with congressional leaders and working with advocacy groups such as Goodwill, the Brain Injury Association, Department of Social Services, and the New Haven Vet Center.

Going through the aftermath of my Traumatic Brain Injury, I teamed up with The Sarah Jane Brain Foundation to help promote the need for a National Pediatric Acquired Brain Injury plan, a proposed system of care that would be universally accessible for all children, and their families, regardless of where they live in the nation. This coupled with the growing awareness that thousands of our troops returning from Iraq and Afghanistan too are suffering from Traumatic Brain Injury. This injury is being called the signature wound of these conflicts.

1993 – Present, I became a spokesman for Connecticut Brain Injury Association advocating for Connecticut's Acquired Brain Injury Medicaid Waiver, implemented in 1999. This waiver allows the state to permit organizations to provide non-medical services to people with TBI enabling them to live in the community outside of nursing homes and institutions.

2003 – 2008: Goodwill Industries of Western Connecticut - Programs & Services.

2004 – Present; Board Member, Survivor, Connecticut Traumatic Brain Injury Advisory Board.

2006 – Present. I am part of the State of Connecticut Department of Social Services' DSS attempts to make more awareness on brain injury for minorities and the underserved. DSS made a banner with a variety of cultures including myself and a child i.e.: shaken baby syndrome these banner is placed all over the state.

2008 – Present. I've really found my Voice for TBI. In January, I was approached by the Sarah Jane Brain Project. The Brain Project heard about me and my story, and they have since used that as part of a nationwide campaign to show an example of what can happen when brain injury goes untreated.

2008. through 2010. I appeared regularly on a talk show on Citizens Television, Inc. With the U.S. Department of Veterans Affairs New Haven Vet Center Readjustment Counseling Svc. Title of Show. The Sandbox Chronicles Getting the Word Out to Our OEF/OIF Veterans Recently as well, I have been asked by the State of Connecticut's Health Service Program Director for the Department of Corrections to assist with the re-entering for inmates with TBI as a peer support mentor. I can easily relate and help these inmates because I have been there; done that in the same system and process they are going through. I will be informing the inmates about what is available for after care re-entering into society. Cable News 12 did an editorial on brain injuries, featuring me. Cablevision editorials featured me as their

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Hometown Hero segment on my efforts to putting a voice to traumatic brain injury in hopes that it will help present and future people dealing with the challenges and changes of TBI.

In recognition of my years of TBI advocacy efforts; SJBFB has named me to the Family Committee of its National Advisory Board. "I was told by a lot of good people that I was kept around for a reason. Maybe this is it." The lives of all the Family Committee members have been directly touched by Pediatric Acquired Brain Injuries PABI. They are either PABI survivors like me, or parents of children injured or killed by a brain injury. Their combined experiences are helping to shape the Project's message, goals and policies.

2009. I've also taken part in their nationwide PABI Hero's Tour. In Boston, MA, New York, NY, District of Columbia, DC, Raleigh, NC, Helena, MT, Madison, WI, Lincoln, NE, Atlanta, GA, Miami, FL, Birmingham, AL, Pittsburgh, PA, Columbus, OH, Chicago, IL, Dallas TX, Denver, CO, Tempe, AZ, Los Angeles, CA, Seattle, WA "This is a blessing to me, it gives meaning to my many years of struggle". The purpose of the tour was to raise awareness and create philanthropy for local PABI families across the country. Each host institution listed in the tour schedule conduct a two-hour panel discussion surrounding one of the seven Categories of Care as outlined in the National PABI Plan.

On July 13, 2009, I also got to present my personal experience/story at the National Institute on Disability and Rehabilitation Research. While speaking with several U.S. Congressman's about my experience, and in hope to make a difference, I've even gotten to present my story at the US Capitol for the announcement of the PABI List of State Lead Centers.

2010. "Voice for My Child" I consider myself to be a very fortunate brain injury survivor and to be a "VOICE" for those forgotten children and families. Every 40 seconds an American child or young adult enters an emergency department suffering from a brain injury; the leading experts in our nation dealing with brain injuries have come up with a broad-based, bi-partisan plan to prevent, identify and treat our American youth with over 110 Members of Congress already endorsing it; however Democratic Congressman Frank Pallone from New Jersey and a few of his colleagues on the Energy and Commerce Committee refuse to even allow an up-or-down vote. Does Congressman Frank Pallone really not care about families who have a child or young adult suffering from a brain injury or is he so arrogant he thinks he knows better than the leading experts. In the months since then; I appeared regularly in Washington DC on Capitol Hill with Patrick and Sarah Jane Donohue giving my testimony on living with a Traumatic Brain injury. Etc

2011. I am pleased to report that Congressman Leonard Lance (NJ-6) announced federal legislation to implement the H.R. 2600: National Pediatric Acquired Brain Injury Plan Act of 2011 at Overlook Medical Center on Thursday, June 30, 2011. Joining Congressman Leonard Lance Barbara Geiger-Parker (CEO of the Brain Injury Association of New Jersey) Alan Leiber (CEO of Overlook Medical Center) Patrick Donohue and his six-year-old daughter Sarah Jane the namesake of the Sarah Jane Brain Foundation, along with Traumatic Brain Injury Survivor Craig Sears and other families' advocates and professionals then again on Wednesday, July 20, 2011, H.R. 2600: National Pediatric Acquired Brain Injury Plan Act of 2011 Room HVC 214 in the Capitol Visitor Center, East Capitol Street NE, Washington, DC 20515.

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This act develops a seamless, standardized, evidence-based system of care that will benefit many American families whose children have sustained brain injuries; we applaud Congressman Lance and the other members of Congress for co-sponsoring this critically important, groundbreaking legislation. The PABI Plan Act would create a national network of 52 state Lead Centers of Excellence, one for every state, plus the District of Columbia and Puerto Rico, with the responsibility of implementing the PABI Plan on their own state's unique demographics, geography, laws, infrastructure, financing, and causes of brain injury without duplicating current practices.

In addition, this legislation will focus on individuals with a mild traumatic brain injury, which accounts for 80 percent of brain injuries each year, commonly referred to as concussions, as well as rural communities, which make up 25 percent of the population and have higher incidence rates of brain injuries. For example, the 52 state Lead Centers would help children suffering from sports-related injuries by providing additional information, resources and care.

For example, the 52 state Lead Centers would help children suffering from sports-related injuries by providing additional information, resources and care. I would like to point out that the federal government spends less than \$10 million a year on traumatic brain injuries -- a fraction of what is invested in research for other illnesses and diseases with much lower incidence of occurrence.

We were most impressed by the bipartisan sponsorship of the PABI Plan Act that included some of the most conservative members of Congress to liberal icons.

It's has been an honor and privilege to be a part of their historic and ground breaking work. CS

What I Value...

Faith, family, true friends, education, honesty, love, happy memories, good health, falling and then getting back up as a stronger person, not taking the small things for granite, finding inner peace and balance, and always remembering who helped me get to where I am now.

What I Leave Behind...

I hope my achievements in life shall be these; that I will have fought for what was right and fair, that I will risked for that which mattered, that I will have given help to those who were in need... that I will have left the earth a better place for what I've done and who I've been.

A great man once said...

"The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy."

The advice I would give to others is to share your story! The one and only way that a change is possible if enough people have become fed up. But if people don't come forward it will continue. The only way we can grow by letting people know we exist and we are fighting for everyone. Day after day I get emails about the horrible things that the U.S. are doing to brain injury survivors. They need to be stopped; we have rights for a reason, but the State's trample all over them as if they are immune to our

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constitutional rights. We plan on doing everything we can so we can all help each other. And with enough people complaining about the wrong, we can bring this information to the media as well as the United States. Lets finally put a stop to this, all it takes is spreading the word so let's stick together and start fighting back with the rights we are given.

"Someday everything will all make perfect sense. So for now, laugh at the confusion, smile through the tears, and keep reminding yourself that everything happens for a reason."

So make peace with your past, enjoy your present, and hope for your future!

My Letter to President Barak Obama

Tuesday February 3, 2009

President Barack Obama
The White House
1600 Pennsylvania Ave NW
Washington, DC 20500

President Obama,

My name is Craig Sears, and I am a Voice for Traumatic Brain Injury and a TBI Survivor advocate from Connecticut. Brain injuries affect millions of Americans, young and old, male and female, and their families. Thousands of our Iraq and Afghanistan soldiers are suffering brain injuries while on the front lines. The most at risk however, are the millions of infants and children in this country. According to the National Center on Shaken Baby Syndrome in Ogden, Utah, hundreds of children in this country will suffer a severe or fatal head trauma as a result of child abuse this year. These deaths and injuries are completely preventable. I am joining in the support of one particular child's case, whose family members are trailblazing for new laws that will protect our children. Sarah Jane Donohue was shaken by her baby nurse when she was only five days old and suffers from Pediatric Traumatic Brain Injury - PTBI. Her father, Patrick, is organizing a nationwide effort to spearhead comprehensive legislative action to help all of Americas' children form this horror. I am appealing to you for your attention to this issue. National Pediatric Acquired Brain Injuries (PABI) plan has begun and Patrick wants to gain National support. As part of the Obama-Biden health care initiative, I urge you to include provisions that support the Sarah Jane Brain Foundation • 181 Broadway Suite 300 • New York, NY 10007 • (212) 201-0599 • www.TheBrainProject.org • Please read Sarah Jane's story and her father's plea @: www.myspace.com/sjbrainproject I wish to help in any way I can, as she is "America's Sarah Jane", representing ALL of our children...the already injured to abuse, and the still healthy children- not yet afflicted. Sincerely Craig Sears

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Some Brain Injury Facts:

Compiled from the Centers for Disease Control and Prevention
Source: (http://cdc.gov/ncipc/tbi/FactSheets/Facts_About_TBI.pdf)

What is a traumatic brain injury?

A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from "mild," i.e., a brief change in mental status or consciousness to "severe," i.e., an extended period of unconsciousness or amnesia after the injury. A TBI can result in short or long-term problems with independent function.

How many people have TBI?

Of the 1.4 million who sustain a TBI each year in the United States:

- 50,000 die;
- 235,000 are hospitalized; and
- 1.1 million are treated and released from an emergency department.

The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.

What causes TBI?

The leading causes of TBI are:

- Falls (28%);
- Motor vehicle-traffic crashes (20%);
- Struck by/against events (19%); and
- Assaults (11%).

Blasts are a leading cause of TBI for active duty military personnel in war zones.

Who is at highest risk for TBI?

- Males are about 1.5 times as likely as females to sustain a TBI.
- The two age groups at highest risk for TBI are 0 to 4 year olds and 15 to 19 year olds.
- Certain military duties (e.g., paratrooper) increase the risk of sustaining a TBI.
- African Americans have the highest death rate from TBI.

What are the costs of TBI?

Direct medical costs and indirect costs such as lost productivity of TBI totaled an estimated \$60 billion in the United States in 2000.

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What are the long-term consequences of TBI?

The Centers for Disease Control and Prevention estimates that at least 5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI. According to one study, about 40% of those hospitalized with a TBI had at least one unmet need for services one year after their injury. The most frequent unmet needs were:

- Improving memory and problem solving;
- Managing stress and emotional upsets;
- Controlling one's temper; and
- Improving one's job skills.

TBI can cause a wide range of functional changes affecting thinking, language, learning, emotions, behavior, and/or sensation. It can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.

More Brain Injury Resources:

Brain Injury Association of America
www.biausa.org
800-444-6443

Centers for Disease Control and Prevention
www.cdc.gov
800-311-3435

Defense and Veterans Brain Injury Center
www.dvbic.org
800-870-9244

Health Resources and Services Administration
www.hrsa.gov
301-443-3376

National Association of State Head Injury Administrators
www.nashia.org
301-656-3500

National Brain Injury Research Treatment and Training Foundation
www.nbirtt.org
434-220-4824

National Center for Medical Rehabilitation Research, NICHD, NIH
www.nichd.nih.gov/about/ncmrr
800-370-2943

National Institute on Disability and Rehabilitation Research
www.ed.gov/about/offices/list/osers/nidrr
202-245-7640

National Institute of Neurological Disorders and Stroke, NIH
www.ninds.nih.gov
800-352-9424

North American Brain Injury Society
www.nabis.org
703-960-6500

Social Security Administration
www.ssa.gov
800-772-1213

The Pediatric Acquired Brain Injury Plan & The Sarah Jane Brain Project
thebrainproject.org

Brain Injury Association of Connecticut
biact.org