

BRAIN INJURY SPECIALIST

Silent Epidemic

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If we collectively want to eliminate the Silent Epidemic moniker from our vernacular, then we must arm ourselves with knowledge about brain injury. Let's begin by taking a moment to examine the phrase "Silent Epidemic" and most importantly, the implications of remaining silent. An epidemic is defined as "affecting or tending to affect a disproportionately large number of individuals; excessively prevalent." By virtue of this definition, one would expect widespread understanding of brain injury, given its pervasiveness. Yet, this really is not the case.

If you compare the incidence of other maladies such as breast cancer and heart failure to TBI, it is hard to understand the general public's lack of knowledge, given TBI's higher relative rates of incidence and prevalence (see sidebar for definitions).

Figure 1 presents the overall incidence and prevalence of TBI₁, Breast Cancer₂ and Heart Disease₃. Figure 2 presents death rates for TBI₁, Breast Cancer₂ and Heart Disease₃, and Figure 3 presents incidence rates per 100,000 people for TBI₁, Breast Cancer₂ and Heart Disease₃. These figures highlight that while other diseases or conditions may have lower or equivalent rates of incidence, prevalence or death, many have a higher public profile. I would argue that the lack of public knowledge lies not solely in the breadth (or amount) of the general public's knowledge of brain injury, but also in its depth (or quality) of understanding.

Today, brain injury is a topic discussed in the popular press more than ever. Just last month, on both ESPN and ESPN Radio, there were stories regarding the NFL's (mis) handling of athletes with concussions. The nightly news is even more profound in its coverage of soldiers returning from Iraq and Afghanistan with brain injuries.

A particularly disturbing fact is that TBI is now considered the signature injury of the Iraq war. Words like "polytrauma", where soldiers return with brain injuries along with a host of other injuries like amputations, burns, auditory and visual impairment, post traumatic stress disorder, spinal cord injury and depression, have begun to seep into our collective vocabularies. The breadth of information is increasing—and that is a good thing. But I am not ready to declare success because I believe the depth of knowledge has yet to keep up.

Many of you will recall the news of CBS anchorman Bob Woodruff who was critically injured by a roadside bomb in Iraq in January, 2006. Woodruff was embedded with troops when their convoy was hit. It was widely reported that he suffered serious injuries, including a traumatic brain injury. As time passed, fewer news cycles reported on Woodruff and his cameraman Doug Vogt, who was also injured. While some of that may be due to privacy concerns for these gentleman and their families, some was surely due to the fact that newer stories started to take precedence.

To the general public, Bob Woodruff's story was a sound bite amidst the constant bad news that permeates our coverage of this conflict on television, radio and the Internet. For those familiar with the recovery process after TBI, there was a tacit understanding that Mr. Woodruff and his family had a long road ahead of them. I am quite sure the general public did not lay claim to such knowledge.

So as my argument goes, such stories have certainly increased the breadth of knowledge—more people are aware of

Epidemiology – The branch of medical science dealing with the incidence, distribution & control of disease in a population₄.

Incidence – The number of cases of a disease having their onset during a specified period of time. It is expressed as a rate and is a measure of morbidity₄.

Example – Every year in the U.S., 1.4 million people sustain a Traumatic Brain Injury₁.

Every year in the U.S., 506 people per every 100,000 sustain a Traumatic Brain Injury₁.

Prevalence – The number of cases of a disease present during a particular interval of time₄.

Example – In 2005, there were 5.3 million people living with a brain injury in the United States₅.

TBI as a substantial issue—but the depth of knowledge is still lacking. Few are aware of the often debilitating or life long consequences that come with brain injury. For the silent epidemic to no longer be silent, we need to increase both the breadth and depth of understanding. How do we make this happen and why is this so important? Let me tackle both separately.

How do we increase the public's knowledge of the consequences of ABI?

For families and survivors—your stories are compelling, and they need to be told. As the saying goes; brain injury doesn't discriminate. But for a variety of reasons, we don't expect harm to come our way. Our psyches have built in protection systems allowing us to see the world through rose-colored glasses. Studies that have compared depressed people to "normal" people have shown that depressed people may actually have

Figure 1. Overall Incidence and Prevalence for TBI, Breast Cancer & Heart Disease

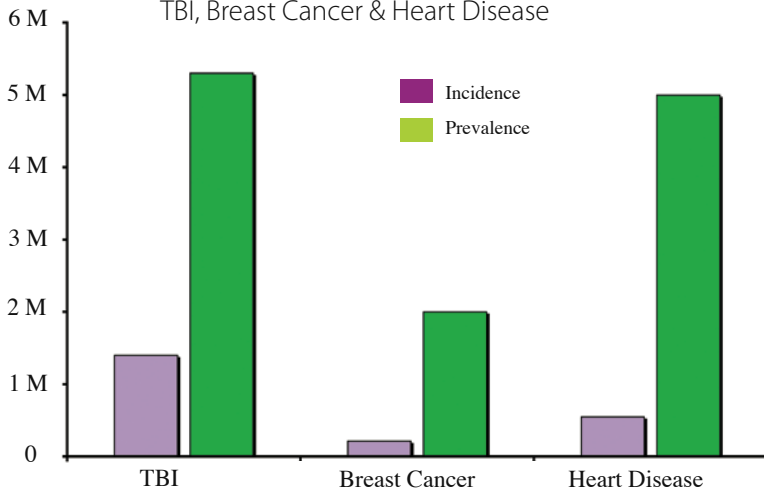


Figure 2. Overall Death Rates for TBI, Breast Cancer & Heart Disease

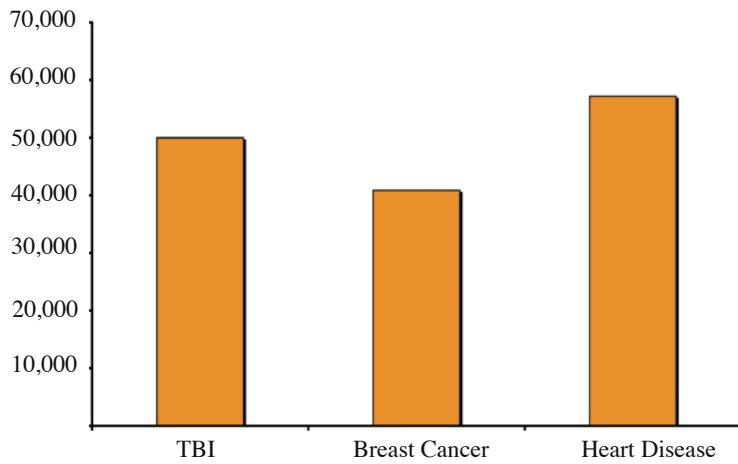
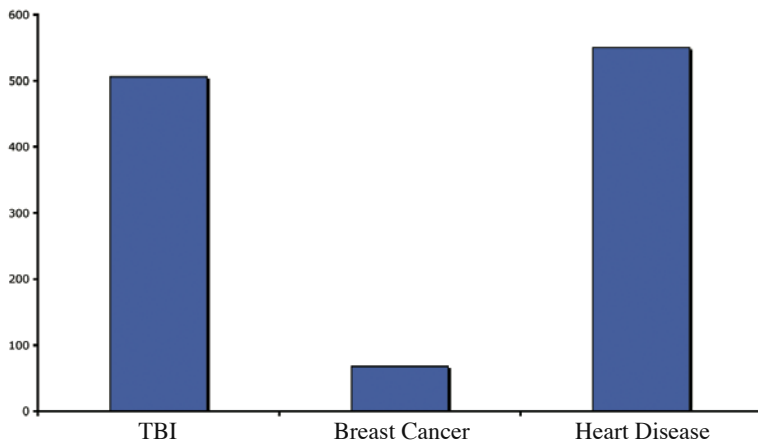


Figure 3. Overall Incidence per 100,000 People for TBI, Breast Cancer & Heart Disease



a more accurate view of the world. This implies that non-depressed people utilize some protective factor to shelter oneself from the pain of reality. Perhaps this is a case where the truth may in fact hurt. Akin to this protective factor is the widely held idea that bad things won't happen to me—they happen to other people. There are at least 5.3 million people currently living with a brain injury who likely believed that it wouldn't happen to them. They are evidence that this theory is a bad theory.

There are some very good memoirs by people with brain injuries. Some of these include Kara Swanson's *I'll Carry the Fork*, Dr. Claudia Osborne's *Over My Head*, and Tricia Meili's *I am the Central Park Jogger*. But you don't have to write a book to tell your story—every day opportunities present themselves, and a message coming from someone who has been there is often the most powerful. Credibility is not in question—it's a given. Some Rainbow clients have spoken at local high schools, to let people know first hand the real consequences of drinking and driving. You couldn't hear a pin drop in a gymnasium full of teenagers. Personal experience is powerful and people will listen. In the spring of 2007, Bob Woodruff and his wife will air a special to present their story. I will be watching.

For professionals in the field, use every day opportunities to educate. Whether its done formally by speaking to a conference or to your local church group, or informally by talking to your neighbors about the newest concussion information or the benefits of side curtain air bags, (*I think my neighbor will buy her next car based solely on whether it has side curtain air bags*) there are countless opportunities.

At worst, we risk coming across as pious; at best our education may save a life, or prevent a brain injury. I think I'll take my chances at being perceived as self-righteous. It's that important. But why?

Why is increasing the public's knowledge of the consequences of ABI so important?

In a nutshell, it's all about funding. Prevention efforts require money. Research into neuro-protective factors requires money. Research to improve trauma care requires money. Rehabilitation requires money. Long-term care requires money. The Brain Injury Association of America estimates that of individuals with severe brain injuries, only five percent have the

Table 1

Budget 2006	Funding Amount
Federal Spending Budget ₈	\$2,500,000,000,000
Department of Health & Human Services	\$44,000,000,000
TBI Act ₇	\$14,210,000

funding needed to care for long-term treatment. I often wonder what percentage of that five percent is the result of our Auto No Fault system here in Michigan. We are blessed with a system that works.

In the year 2000, Traumatic Brain Injuries in the United States cost more than \$60 billion, and the expected lifetime costs were estimated at \$406 billion₆. The need for money is clear. Where it will come from is not so clear. A key point of departure for this discussion lies with the Traumatic Brain Injury Act of 1996; it focused on 3 key areas: Prevention, research and improved service delivery. It appropriated funds for the CDC to establish TBI surveillance and prevention projects, the National Institutes of Health to award grants for TBI research, and the Health Resources and Services Administration to

award grants for the creation of programs that provide comprehensive, coordinated TBI services for states₅. **Figure 4** presents the amount of appropriations by fiscal year₇.

To put this in context, in 2006 the annual budget for the United States included 2.6 trillion in spending dollars₈. The budget included \$4.4 billion for the Department of Health and Human Services, which includes the Centers for Disease Control, the National Institutes of Health (NIH) and the Human Resources and Services Administration among others₈. **Table 1** (above) presents this data. It is, as they say, the proverbial drop in the bucket.

When it comes to appropriations in Congress, the squeaky wheel gets oiled and numbers speak volumes. The more we can educate about the incidence and

prevalence of brain injury, the more people will understand that a disproportionate number of people are affected. **Figure 5** highlights the disparity that exists in NIH grant awards across different health issues₉. Again, despite the overall incidence of TBI relative to other health issues, the funding is disproportionately low.

We need to use these disproportionate numbers to show that TBI is grossly underfunded. We also need to ensure that we help people realize these “numbers” are far more than statistics used to get powerful people’s attention—they are all people. They are individuals with families who need more than good will gestures from politicians. They need the results of research that show best practices in trauma care. They need funding for programs that provide comprehensive, high quality care.

Figure 4. TBI Act Appropriations by Year

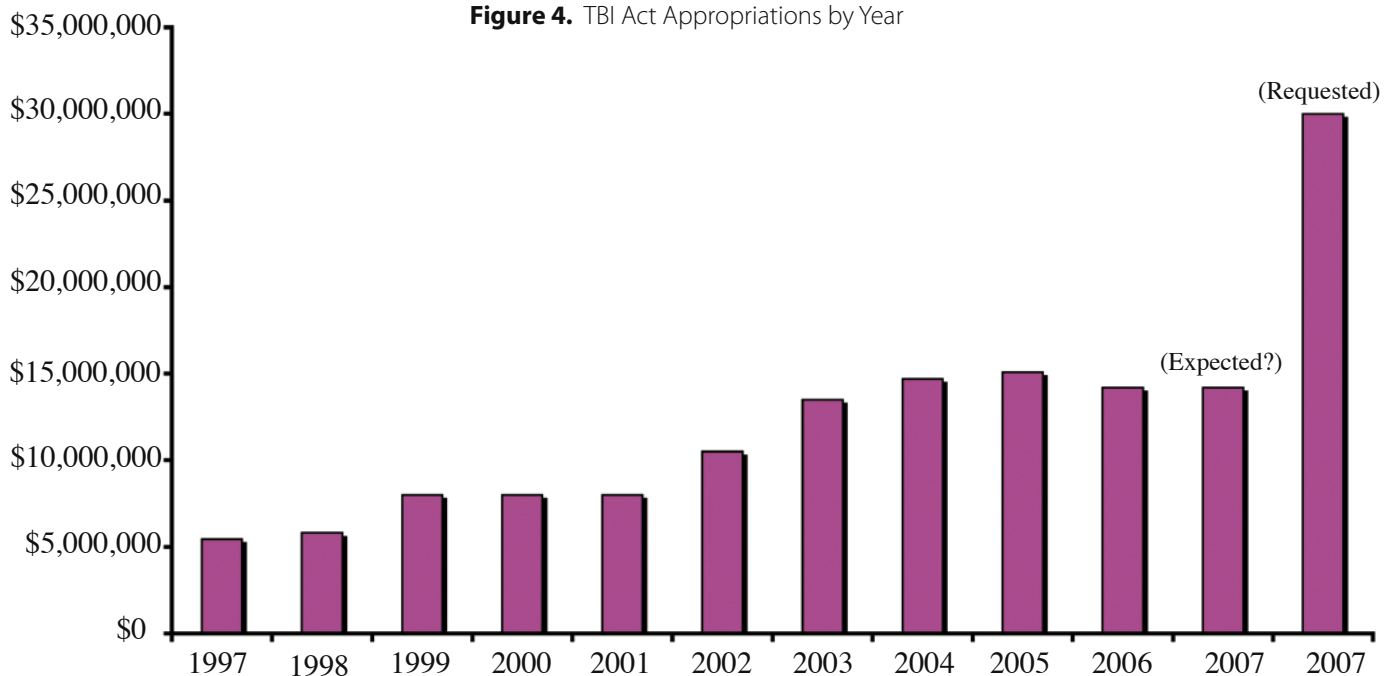
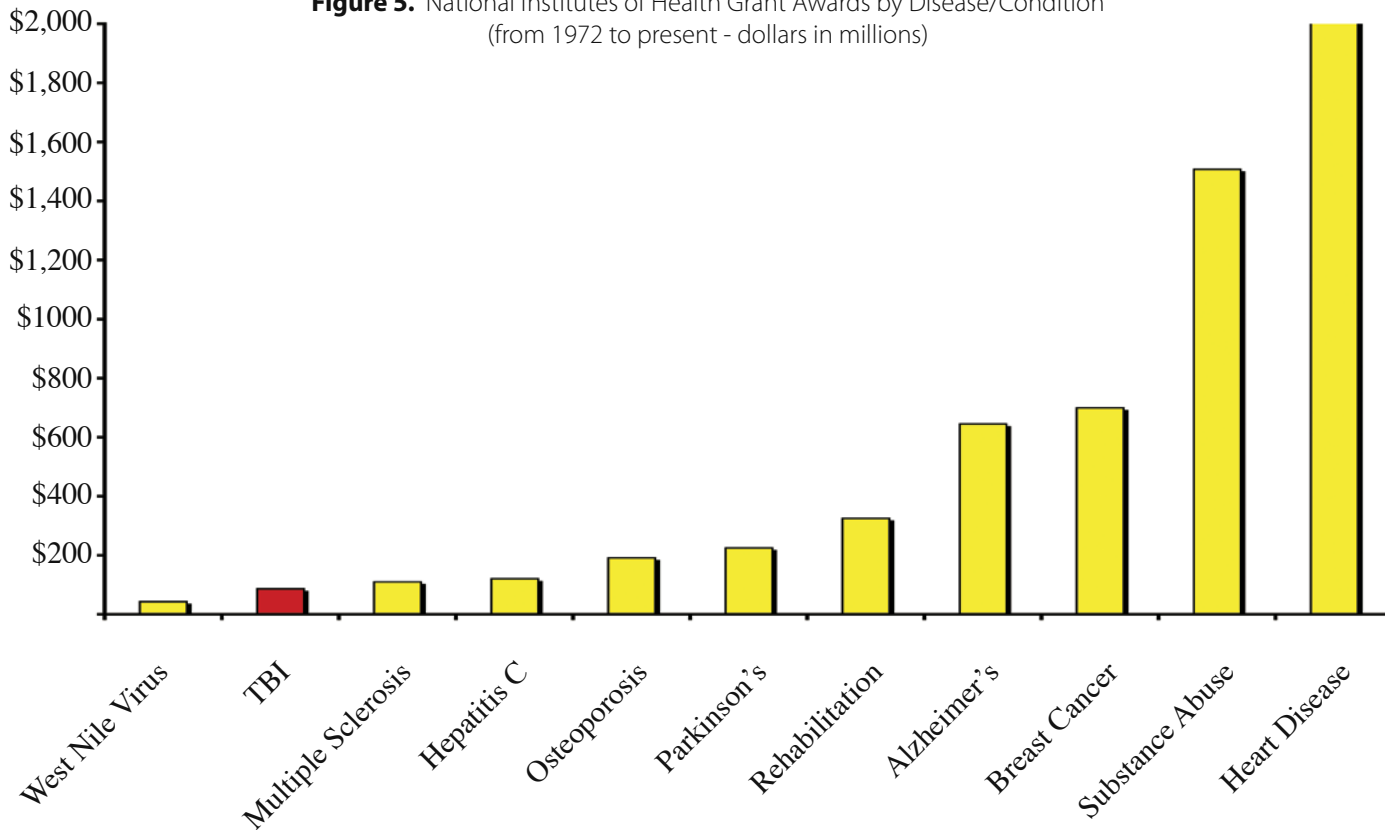


Figure 5. National Institutes of Health Grant Awards by Disease/Condition
(from 1972 to present - dollars in millions)



They need prevention programs that work and reduce the incidence and prevalence across all groups. They need research that examines ways to lessen injury effects and provide better long-term outcomes. They need funding that doesn't place the burden of care solely on families. They need care in settings of choice that are appropriate for individual needs.

The list of needs is long, but the silence can be broken. We need advocacy that is loud and consistent. You can write your Congressperson. There is a quick and convenient way to do this via the Internet. Go to: www.biausa.org/policy and legislation/legislative action center to find your legislators.

You can also support your local Brain Injury Association through volunteering or donating much needed money. I also strongly recommend supporting the Brain Injury Association of America. We need a strong and consistent voice holding Congress accountable to our constituents—individuals with brain injuries and their families, providers of care, and future brain injury survivors. This organization is committed to keeping brain injury awareness a constant. They are the voice in Washington that we all rely upon every day whether we realize it or not. They have strong leadership and are committed to ensuring that every dollar they spend is spent well, and they need our help to do that. Every dollar will count; whether you can afford \$1 or \$100, it will make a difference. Please consider helping this organization if you have the means. It may go a long way in stopping the silence. ♦

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