

# What we don't know will hurt us

*Why diagnosing traumatic brain injuries on the streets matters*

BY STACY BROWNHILL  
CONTRIBUTING WRITER

James Smith is a 53-year-old Portland veteran who used to have a job he loved. After a car accident left him with traumatic brain and neck injuries in 2005, Smith lost his job, ran out of money and wound up on the streets. When Smith tried to apply for Social Security Disability Insurance (SSDI), he was denied three times because he was flagged as violent. He was loud, angry and high-strung — symptoms of traumatic brain injury, or TBI. For years, Smith sunk deeper into despair. This week, with the help of Portland law firm Swanson, Thomas & Coon and Central City Concern's BEST program, Smith won his second hearing. The benefits he was awarded will give Smith a house, health care and a new life.

If you read the article in our last issue "All in their heads," (Street Roots, May 27) you'll remember a similar story of Nick Patton, a homeless Portlander who was misdiagnosed with schizophrenia when he was really having seizures from a TBI that had happened years earlier.

People suffering from TBI, the so-called invisible disease, can seem angry, forgetful, antisocial and disinterested. They may slur their speech, talk too loudly and walk crookedly. In other words, it's easy to mistake people with TBI for being intoxicated, high, mentally ill, suffering from fetal alcohol syndrome or even averse to getting help. It's especially easy to make

This is the second report in our ongoing coverage of traumatic brain injuries among people experiencing homelessness.

those mistakes when the person is homeless and already burdened with stigmas.

In October 2008, Portland's Housing Bureau partnered with New York City-based Common Ground Institute to survey 646 homeless people on the streets of Portland. The resulting "Vulnerability Index" found that about half were medically vulnerable. One of the medical conditions PHB was curious about was traumatic brain injury; however, because TBI can be so difficult to correctly diagnose, the field was left "To Be Determined."

That same year, the city of Hamilton, Ontario awarded funding for a program that offered counseling and intensive case management to 176 chronically homeless men. Forty-nine of those men agreed to participate in a more in-depth pilot program that included advanced neuropsychological testing. A staggering 98 percent of men in the pilot program met the criteria for TBI.

Today, we're as clueless about TBI on the streets of Portland as we were three years ago. But TBI is causing a stir among scientists, social workers, city officials, the military and the NFL. What they're discovering is surprising.

## It can happen to anyone

Traumatic brain injury is indiscriminate, and it is the leading cause of death and disability in North America for people under 45, according to the Brain Trauma Foundation. There are an estimated 1.7 million deaths, hospitalizations, and ER visits related to TBI every year, according to the Center for Disease Control.

Treatment is expensive and complex. X-rays, CT scans and MRIs help confirm TBI, and individualized physical therapy, speech language therapy, occupational therapy, psychological therapy and social support are usually needed to stabilize a TBI victim. (Oregonian columnist Elizabeth Hovde was recently hospitalized for 36 days after a TBI and dedicated a column to the "dozen or so" hospital workers and therapists who helped her recover.)

But "the equipment and support are not always available for homeless people even if a clinic suspects someone has TBI," says Dr. Barb Wismer, board member of the National Healthcare for the Homeless Council.

"It's trial and error," says Dr. Phil Shapiro, a psychiatrist at the 12th Avenue Recovery Center who has many homeless patients. "We try different things depending on symptoms." Shapiro is not convinced TBI can be separated from PTSD or fetal alcohol syndrome, and he adds, "Neuropsych testing is difficult to get these days, and a much deeper assessment can take hours. Many of the clients I have couldn't sit for that."

## What other cities know

Cities that have done studies on how many homeless suffer from TBI report numbers that are scattered but all statistically significant: 98 percent (Hamilton, Ontario 2008-2010), 53 percent (Toronto, Ontario 2008), 67 percent (Boston, Mass. 2006-2007), 48 percent (Milwaukie, Wis. 2004), 24 percent (Fort Lauderdale, Fla. 2003) and at least 50 percent (National Healthcare for the Homeless Council). Of those, 70 percent occurred prior to becoming homeless in (Toronto), more than half occurred prior to age 20 (Boston), and the average age for the first TBI was 17 (Hamilton).

Compared to an estimated 2 percent of the general population that gets TBIs, "we're seeing an enormous medical crisis," says Dr. Theresa Petrenchik, who helped lead both the Hamilton and Fort Lauderdale studies. Petrenchik's research leads her to conclude that homeless people with TBI use more services, are homeless more often for longer periods of time, are more frequently incarcerated and have greater co-morbid risks than homeless people without TBI.

TBI among the homeless often overlaps, masquerades and partners with a laundry list of other ugly problems. Sexual abuse, neglect, domestic violence, substance use, family breakdown — often occurring in childhood — are just a few. When Petrenchik

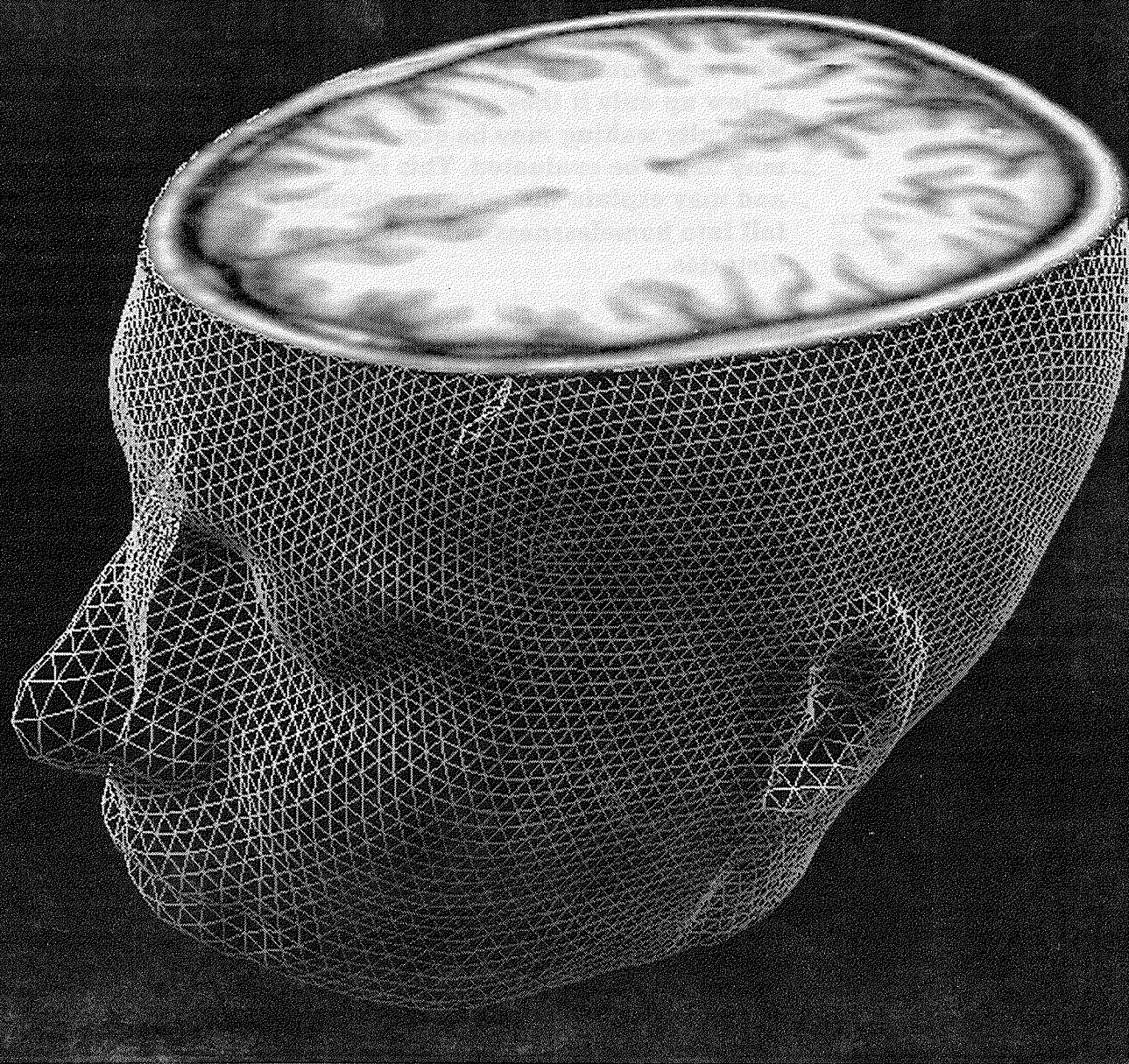


PHOTO ILLUSTRATION BY REUTERS/HO NEWS

**BRAIN INJURY, from page 3**

tallied the average number of "adverse experiences" in the case notes of the original 176 homeless men in Hamilton, she came up with 14 per person. "We find them in spades in this population," says Petrenchik.

Just four adverse childhood experiences, according to the CDC, put someone at risk for a multitude of health and social problems. Having six or more adverse childhood experiences decreases your life expectancy by 20 years.

Dr. Stephen Hwang, leader of the Toronto study, is teaming up with Wismer and other researchers around the country to try to get funding for a national study on TBI and homelessness. San Francisco, Calif., Baltimore, Md, Albuquerque, N.M., Boston, Mass, Cincinnati, Ohio, Houston, Texas, Orlando, Fla, Los Angeles, Calif., Hyannis, Mass. and Manchester, N.H. are the 10 cities they hope to survey.

"We think TBI is under-identified among the homeless," says Wismer, "and we think a lot of health care workers don't know about it."

**What a disability attorney knows**

Cheryl Coon, board member of the Brain Injury Association of Oregon and the Social Security disability attorney who represented Smith, says she has many homeless clients with TBI. She describes a common pattern with her TBI clients: first, they stop being able to focus in the workplace. Then, they lose their jobs. Their physicians may not recognize TBI. And then many become homeless.

Chart notes follow Coon's clients whenever they come in contact with the system and sometimes these files "come back to haunt folks," says Coon. If a past doctor noted that a client was inebriated or high, even if that client was also diagnosed with TBI, that can be enough reason to deny them, she says. In fact, Coon thinks of TBI as a "Catch-22 for getting disability benefits" because the symptoms of a TBI can be associated with so many other causes.

"The Social Security Administration is not eager to take these people on," she says, "but disability benefits have become one of the few safety nets this country has."

Winning Smith's hearing was a personal victory for Coon, who says that around two-thirds of cases are initially denied in Oregon. "The number one piece of advice I give for any client is 'you've got to hang in there and file for appeal,' because the process is set up to weed out those who don't have the perseverance to pursue it," says Coon, who estimates that well over half of cases in Oregon are won when people keep appealing.

**What a domestic violence shelter knows**

Molli Mitchell, residential services director at Bradley Angle House says she

**Many emergency departments have yet to implement screening and referral for (TBIs). As a result, many patients who are treated and released from ERs with instructions to follow up only if they experience dizziness, vomiting or difficulty waking may be experiencing cognitive changes that may never be evaluated. This is a widespread phenomenon and may explain the poor functioning of some persons who fall into homelessness without clear abuse or neglect histories.**

"definitely" sees women coming to the shelter with TBI. In a study of 53 battered women, Dr. Helene Jackson found that nearly all reported suffering blows to the head while being battered; 40 percent reported loss of consciousness.

Mitchell and her staff are trained to recognize symptoms of TBI, but she says referring women to clinics doesn't often work. Battered women who are candidates for TBI may have trust issues with counselors and doctors, lack of transportation to clinics, not to mention a host of competing problems. Mitchell says the link between PTSD and TBI is a complex and often a fine line.

**What the military knows**

"TBI has become the signature injury of the current wars in Iraq and Afghanistan," according to the Brain Trauma Foundation. About 320,000 American troops have suffered TBIs since 2001, with 7 percent reporting both TBI and concurring PTSD or major depression, according to a 2008 report by nonprofit research group RAND Corporation. Blasts are the leading cause.

With its massive budget, the Department of Defense provides arguably the most cutting-edge research around TBI treatment. Eye-tracking goggles, neuroprotectants, biomarkers and hyperbaric oxygen chambers are just a few of the superhuman technologies being funded by the Pentagon to explore TBI, to varying success.

But despite funding such gadgets, the Department of Defense has been notoriously resistant towards paying for cognitive rehabilitation therapy for the tens of thousands of service members who have suffered TBIs. A 2010 NPR and ProPublica investigation found studies by the military's health care program, Tricare, "deeply flawed" and at odds with many medical groups. They cite the cost of cognitive rehabilitation to be as much as \$50,000 per soldier—a daunting number even for the Pentagon's budget.

How many end up homeless? The Department of Veterans Affairs conservatively estimates that 107,000 veterans are homeless on any given night, and that nearly one-fifth of the homeless population is veterans. PTSD, closely linked to TBI, is cited as a leading cause.

**What the NFL knows**

Just last year, former NFL doctor Ira

Casson told Congress, "there is not enough ... scientific evidence at present to determine whether or not repeat head impacts in professional football result in long-term brain damage." The resulting outrage from players, doctors and sports reporters led to heightened investigations of TBI cases in pro-football.

Mike Webster was one former NFL player held in the spotlight. Doctors estimated that the former Pittsburgh Steelers star's brain had been through the equivalent of 25,000 car crashes in his 25 years of playing football. The depression and profound dementia that followed contributed to Webster becoming homeless and dying at age 50.

As TBI-affected ex-players come forward, the \$33 billion NFL is changing its position on TBI, albeit reluctantly. In cooperation with Boston University, the NFL opened a brain bank in 2010 to conduct post-mortem analyses of players' brains. They donated \$1 million to help fund Boston University's TBI research, started by a former wrestler. They announced harsher fines (tens of thousands of dollars) for players who tackle above the neck. They explored advanced helmet technology.

High school sports (and the PTAs behind them) seem to be making the true groundbreaking steps on TBI. Oregon enacted "Max's Law" in 2009 — legislation that protects young athletes from damaging multiple concussions by requiring that all high school athletic coaches in the state receive concussion recognition training. It also prohibits any athlete showing concussion symptoms from playing until the next day.

**The silent disease**

All of the above candidates for TBI — homeless people, domestic violence victims, soldiers and pro-football players — are also conditioned to be silent about TBI.

Thirty of 160 NFL players surveyed by The Associate Press in 2009 said they have hidden or played down the effects of a concussion. "By the time a guy reaches pro-sports, he will not complain," says Jane Arnett, wife of ex-player John Arnett in Lake Oswego. Together, the couple founded a nonprofit to help disabled ex-NFL players get health benefits.

A similar hush factor pervades the military. The 2010 NPR/ProPublica investigation found that, to remain with their unit, soldiers will often ignore

symptoms of a blast and commanders might ignore such symptoms in order to keep soldiers on the field. Medics, forced to prioritize life-threatening injuries, may lack the time to recognize a concussion, the study adds.

Homeless people and domestic violence victims know silence better than anyone — lack of trust, resources and support prevent many from seeking help. Stigma certainly plays a role. And a 2007 study of homeless people in Denver found that homeless individuals are less than half as likely to be admitted to a hospital as non-homeless with similar conditions.

A 2008 report by The National Health Care for the Homeless Council said the following:

Many emergency departments have yet to implement screening and referral for (TBIs). As a result, many patients who are treated and released from ERs with instructions to follow up only if they experience dizziness, vomiting or difficulty waking may be experiencing cognitive changes that may never be evaluated. This is a widespread phenomenon and may explain the poor functioning of some persons who fall into homelessness without clear abuse or neglect histories.

**What Portland knows**

Dr. Paul Lewis is partnering with Street Roots to start a pilot project to track vital records and cause of death among homeless Portlanders. The deputy health officer for Clackamas, Multnomah and Washington counties says that as far as he knows, it's never been done before, and he wouldn't be surprised if accident injury was a major cause of death. "(Addressing TBI) is really an upstream problem," says Lewis.

Diane Malbin of the Portland nonprofit FASCETS leads training sessions for parents and professionals on rethinking cognitive disabilities. Malbin believes that teaching people who work with the homeless to recognize the link between brain function and behavior is crucial, and you don't need a PhD to do it. "Addressing neurological issues will give us the foothold we need to tackle so many other social problems," says Malbin.

**... And doesn't know**

"Some cities don't want to survey for TBI because then you might uncover a real service need," says Petrenchik. "When we talk about the intersection of social services and health services, no one wants to hear about the need for long-term support ... but we pay for it one way or the other."

"Being able to recognize that there is a true disability as opposed to willful noncooperation is helpful," says Hwang. "It's worth investigating."

"Who's keeping track of TBIs?" says Coon. "Nobody."

Read "All in their heads," our first report on traumatic brain injury on the streets, at [www.streetroots.wordpress.com](http://www.streetroots.wordpress.com)