



**Brain Injury
Alliance**
ARIZONA

Seeking Alternatives: How One Brain Injury Survivor Responded to HBOT Therapy

By JOEL GOLDSTEIN

The views and opinions in this article are those of the author alone, who is not a medical professional. This is neither an endorsement of nor recommendation for Hyperbaric Oxygen Therapy (HBOT) or any other form of alternative therapy by the Brain Injury Alliance of Arizona or any of its agents. It is not, and should not be construed as medical advice. Always consult a trusted medical source prior to pursuing any medical or therapeutic treatment for brain injury or any related conditions.

On Christmas of 2001, my wife and I were plunged into a parent's worst nightmare — a car accident resulting in our teenager's traumatic brain injury. After a month-long coma, he gradually emerged with disabling cognitive, emotional, and physical deficits. After eight months of grueling hospital therapies, the school district agreed with the hospital — he was not ready to return to class, and would be better served by placement in an institution.

My wife Dayle and I railed against warehousing our 17-year-old son Bart in a nursing home, and fought to win him a chance to heal and make progress. We were determined to raise the bar, to set difficult but attainable goals, and then raise the bar even higher, again and again. We hunkered down to explore whether alternative therapies might push Bart's recovery further along.

Faced with the sprawling chaos of alternative therapies and the awareness that a false step might risk further injury to Bart, we were stumped. How could we determine which approaches were safe and held real promise?

We eventually cobbled together an informal "medical board" of trusted physicians. When someone discovered a promising alternative therapy, we'd talk to each other about whether it might



Joel Goldstein's son, Bart, is a traumatic brain injury survivor who has responded well to Hyperbolic Oxygen Therapy, or HBOT. Pictured above is Bart, in the New York Yankees jersey, with his Dad and sister Cassidy.

potentially be harmful. The options that received a clean bill of health were then considered for further investigation. Some of the most promising and exciting therapies failed this simple litmus test.

Doctors sometimes offered an editorial opinion too, suggesting that a therapy, though safe, was a waste of time and money, certain that all alternative therapies were bogus. But here was where we had an advantage — at least we knew we were ignorant. It seems a truism, but even the best-trained, skilled, and well-intentioned professionals in the world often suffer a kind of tunnel vision, sticking to familiar, well-trod paths that pioneers once blazed. Before eventually winning universal acceptance, performing open-heart surgery and treating peptic ulcers as infectious, were doggedly opposed and bitterly denounced by the medical establishment. To be clear, we don't wish to demonize physicians; Bart's remarkable recovery resulted from best practices of conventional medicine, plus some forays outside of the box.

Eventually, we tried several alternative therapies, which are defined as practices falling outside standard medical practice and not usually covered by health insurance. Some were useless. Others, like Hyperbaric Oxygen Therapy (HBOT), were remarkably successful and gradually helped transform Bart's life.

Some successes were breathtaking. Bart had only been allowed to return to school provisionally for half-days in special education classes while accompanied by a dedicated aid. Every half hour or so, he'd fall asleep, nodding off mid-sentence. We jokingly referred to these as "power naps." But sleeping the day away was no laughing matter. If he failed to keep up in his classes, Bart would be removed from high school. An extrovert, he desperately needed to be around familiar faces, among people who loved him, in order to have even a fighting chance at recovery. Imagine our excitement and relief when, after only four sessions of HBOT, he was able to make it through an entire school day without a nap. He then went on to make steady intellectual and physical gains, eventually becoming mainstreamed and graduating high school.



Bart and Joel's certified therapy dog, Nico

How HBOT works is only partially understood. The patient is placed in a diving bell, (an open-bottomed chamber containing compressed air that can be submerged in water), which is gradually pressurized to 1.5 atmospheric pressures, the equivalent of being under 16 feet of water. The cabin is flooded with pure oxygen, which the patient breathes for an hour or more. Normally, oxygen, which constitutes 21% of the air we breathe, only enters the bloodstream one way- picked up in the lungs and carried via red blood cells to the body's tissues. But breathing pure oxygen under pressure overwhelms the carrying capacity of red blood cells, so blood plasma and other bodily fluids become saturated with oxygen -- up to 15 times the amount normally available. Excess oxygen helps injured sites heal by allowing them to re-vascularize, that is, to re-grow the network of tiny arterioles and



capillaries supplying blood to the injured tissue. The new blood supply does the serious work of healing by removing toxins and bringing in needed oxygen and other healing building blocks. That HBOT improves blood profusion and promotes healing is well-established. Burn centers use HBOT to speed recovery and the Federal Drug Administration has approved 15 additional applications. Though not an FDA-approved application, HBOT is part of the standard of treatment for acquired brain injuries (ABIs) in Israel and parts of Europe and Asia.

No matter how encouraging, Bart's successes were purely anecdotal. Yet a neuropsychological exam conducted several years after the accident reported that the examiner had hardly ever seen such improvement in a person so severely injured as Bart.

Conventional wisdom holds that good progress after a traumatic brain injury (TBI) only lasts a year or two, though this is changing in light of recent work in the study of brain plasticity. In our case, we found that the window of opportunity remains open indefinitely, although we acknowledge the therapies that worked for Bart may not be safe or effective for every survivor. Using our "medical board's" oversight, we set out to make marginal gains and came up with several useful approaches, and since TBI is a life-long condition, we still rely on this method to this day. In addition to HBOT, Bart has made notable gains recently using neurofeedback and Dr. Michel Lewis' Omega-3 protocol.

We are not cheerleaders for any particular therapy, but we are advocates of a persistent search for alternatives. 15 years later and counting, Bart still struggles with diminished short-term memory, visual field, and fine motor control. Psychologically, our bags are always packed. Today, with high school, a semester of college, and a couple years of cognitive therapy under his belt, Bart is a lively, charming young man, living nearly independently in his own apartment near Albany, New York. How different his outcome might have been had we heeded the advice of well-meaning, busy bureaucrats. If there is one universal truth about TBI, it is that survivors need strong advocates in order to navigate mind-boggling and difficult challenges.

To ignore safe alternative therapies is to make a fateful decision fraught with risk, since TBI survivors are already more susceptible to a number of other conditions, including Alzheimer's, Parkinson's, and subsequent TBIs. Faced with this existential dilemma, we chose to try for a better outcome. Conventional medicine often only takes survivors of severe TBI so far, with many ending up in nursing homes, or being heavily medicated at home, facing long empty hours, and overwhelming their family's resources. Alternative and unconventional therapies are not merely a reasonable option, they may be a necessity.

After retiring from our day jobs last year, my wife and I moved to the Albany, New York area to be closer to Bart. We're four miles away — not too close for comfort, but a huge improvement over the 160-mile roundtrip we made every Sunday for the last 11 years. Proximity to our son has also made it easier to help him pursue new therapies. He recently completed 15 sessions of LENS therapy (Low-Energy Neurofeedback), which seems to have lowered his anxiety and shored-up executive functions, especially initiation. We are considering additional safe alternative therapies, including hypnosis, which may help improve working memory in ABI survivors, according to some recent studies. Nowadays, Bart joins me whenever I speak on the radio or at brain injury conferences, even testifying at New York State legislative hearings on TBI. The whole family is involved in the Brain Alternative Rehabilitation Therapies Foundation (the BART Foundation). Being a survivor-advocate is very meaningful to Bart. Giving back helps all of us make sense of what has happened. Our kids grew up with a dog in the house, and we've recently fulfilled a long-time dream of training a certified therapy dog. Nico, our Sheepadoodle, works at the local elementary schools and is an enchanting member of our family. And so it goes.

Joel Goldstein is father of a TBI survivor, writer and advocate. Author of *No Stone Unturned: A Father's Memoir of his Son's Encounter with Traumatic Brain Injury* (University of Nebraska Press, 2012), he has written for Brainline.org., Exceptional Parent, Caregiver Space, and Adoption Today. Recently, the Goldsteins formed the BART Foundation, a 501(c)(3) public charity, to explore and promote the use of safe alternative therapies for brain injuries. To learn more about his family's journey, visit www.thebartfoundation.org, or email him at jgoldstein@thebartfoundation.org.

