



By Allene Creacy

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## Special Feature: Bill's Journey



May 1, 1997 was a joyous day. It was our anniversary of 32 years. We planned to celebrate the next day, which was Friday. Friday came and brought with it the worst nightmare of my life. Our lives as we knew it were gone and would never be the same.

Bill collapsed on the job with a massive brain aneurysm. He was taken to a local hospital and lay there in the emergency room, comatose for almost 6 hours with little treatment, before we could get him care-flighted out and back to Dallas. Even though we had the top neurosurgeon with Bill at a major trauma hospital, they gave him no chance for survival. We were told he had bled too long, the clot was too deep in the brain and that he could not make it through surgery. I was asked to donate his organs. But, I had to give him this one last chance.

He had brain surgery and they still told us he would not survive. Then, they told us he would never wake up, and that if he did, he would be a vegetable the rest of his life. Bill stayed in a deep coma for almost 6 months.

He did eventually wake up, but was away from the house for another 6 months in 5 different re-hab hospitals. We were told he would be in a wheelchair all his life and never talk or be able to be fed without a tube. Every doctor we came into contact with screamed, "nursing home." I replied, "Not in this lifetime!"

I took Bill to acupuncture and he walked. I started him back in the gym. I gave him nutritional supplements. I took him for chiropractic treatments. I found ozone therapy for him. I gave him massage. You name it, and if there was any chance it might help him, somehow,

we got it for him. Bill was only 55 years old, and we felt that if God had wanted Bill, He'd had that first 6 hours to take him, when Bill had gotten so little treatment. And yet, God didn't.

Bill has literally defied all odds. His intracranial bleed could not have been in a worse area—deep in the brain—left frontal lobe basil ganglia area. He had no short or long term memory and virtually no retention. He was totally incontinent, drooled constantly, dragged his right leg, and his posture was very bent forward. He had developed a massive deep vein thrombosis in the right leg while in the coma. We had to place a Greenfield filter in the stomach area to stop a clot from killing him, should it break off and move. He developed high blood pressure (which he never had before) and arterial fibrillation. He had to have a pacemaker implanted. You name it, we survived it.

All these things helped. But, the one thing that we had been desperately trying to get for him from the moment he came out of surgery, was hyperbaric oxygen therapy (HBOT). We did our research and the one therapy that kept coming up to possibly help with stroke and traumatic brain injury was hyperbaric oxygen therapy. And, it just made sense. A brain deprived of oxygen, especially for as long as Bill's had been, needs oxygen to help it in the healing process—and, much more than he could get from just normal breathing.

We talked to doctors in the United States and in several different countries. Dr. Neubauer was the first person I called, and he wanted me to fly Bill to him immediately. But, Bill was so critical for so long, I never got to do that. Three more long years went by, and I

still felt hyperbarics could help, since Bill had now reached a plateau and was stale and stagnant in his progress.

Three years post stroke, in August, 2000, Bill had his first set of hyperbaric oxygen treatments. He literally woke up in the chamber after the 8th dive. He became conversational. He stopped dragging his right foot and leg almost completely. He stood more erect. The drooling ceased—now only a little when he is extremely tired. To date, he rarely has a bathroom problem, unless he just can't get there in time. No more adult depends.

He got 25 treatments, and I knew we could not stop. In February, 2001, Bill had 40 HBOT treatments. In March, 2001, he had 10 more. This time we noticed much improvement in short term memory retention. Everyone was amazed at his further improvement—especially his primary care doctor. In fact, his doctor is now an avid believer in hyperbaric oxygen therapy.

What I am trying to say, is that out of all the things we have done for Bill, hyperbaric oxygen therapy is the one thing that pushed him over the hump and gave us a reason for real hope for further significant recovery for him. If I had listened to mainstream medicine, I could be visiting him in a nursing home or in the cemetery. Instead, he is standing behind me as I type Bill's story and humming the *Aggie War Hymn*.

The journey has been long and hard, but definitely one worth taking. We have entered into a whole new arena—the arena of children and adults we have met who have been helped by hyperbaric oxygen therapy. And on the flipside, an arena of those who are desperately seeking treatments and who

## Bill (continued)



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cannot afford them.

Ours was a very similar case: Financial hardship because of his long illness. I had applied for Medicaid payment for these treatments, and been turned down. Then, I devised a plan of action, and to our knowledge, on October 13, 2000, Bill was the first adult in the United States to have a Medicaid program approve and pay for our requested 40 treatments for an off-label treatment (stroke).

Bill is on a Medicaid program called Community Based Alternative. This is a program for adults. You must qualify medically, and be re-certified each year. Depending on your needs, each certification determines the amount you are allowed yearly for medical devices, home adaptation, in-home aides—whatever you need medically. They also pay for daycare and respite, which are separate from medical necessities for therapies. The range is broad. I applied for and received approval for 40 hyperbaric oxygen treatments for Bill from the Texas Department of Human Services.

I got Bill's primary care physician to write a prescription for hyperbaric therapy. This doctor also wrote a letter describing Bill, his intracranial hemorrhage in 1997 and his significant cognitive and physical impairment. He described all the different therapies we had tried to improve his cognitive function, with minimal success. He stated he had become stagnant from a neurological standpoint. **He requested Hyperbaric Oxygen Therapy to possibly help his cognitive function and to prevent any further deterioration.** He requested this therapy for central nervous system disease.

I got an invoice from a hyperbaric center stating the price for 40 treatments at \$100.00 each (that is what they charge) to total \$4000.00. I asked Bill's case worker to request 40

treatments at \$4000.00 to Medicaid. The last piece of authentication needed was to get the nurse from the home health care agency to come and request these 40 treatments to help his cognitive function and to prevent any further deterioration. All these documents were submitted by Agapy Home Health Care Agency in Dallas to the regional nurse for Medicaid in Denton, Texas. Agapy also submitted articles I had faxed to them on the benefits of hyperbaric oxygen in stroke patients and the effects it has on the brain.

These precisely written letters, documented articles and requests paid off. We received the approval letter, and everyone involved was jumping up and down. I have kept the Medicaid office informed regularly of Bill's improvements with HBOT while he was taking the 40 treatments and after they were finished.

I asked if I could bring Bill in to meet them and they were very much in favor of this. So much in fact, that the regional nurse who had approved the treatments called and asked if she could come to my home with her supervisor to meet Bill. This, they did and were absolutely astonished.

I spent 3 hours telling them everything I knew about hyperbaric oxygen. I gave them copies of studies of research on cerebral palsy, stroke, traumatic brain injury, you name it. I gave them copies of *Hyperbaric Medicine Today*.

I showed them Bill's medical records when he first collapsed and neurological work-ups stating he would be a vegetable the rest of his life. I told them of his condition before the first set of HBOT and how he literally started waking up in the chamber—how the drooling stopped, how he stopped dragging his right leg, how he no longer needed adult depends, and how for the first time in 3

years post-bleed he was initiating conversation. Bill talked to them and stole the show. They laughed, they cried. They simply could not believe it. The nurse told me I had to apply for more treatments and I told her I had already started that process as soon as we came home. This time, we requested 100 treatments.

There is a procedure to follow and certain wording to use. I asked her if other patients had ever requested hyperbaric oxygen therapy and she responded yes, but that she had turned them down. When I asked why, she stated that she really knew nothing about this therapy. My next question was would she have a different approach to these requests after seeing Bill and knowing of his improvement from these treatments, and they both responded **ABSOLUTELY**. Education is the key.

I have been very involved with House Bill 1676 which was presented to the Texas Legislature. I have testified before the insurance commission about the desperate need of brain injured children and adults for treatments that might offer a better quality of life for so many, but that are out of reach because insurance won't pay, and these debilitating illnesses have financially destroyed so many.

As many of you already know, our sheer determination and unwillingness to give up has paid off. House Bill 1676 became a mandated law in Texas on June 14, 2001. It is now official. Texas leads the way.

I hope Bill can be of help to those who are constantly struggling daily to find their own way. I truly know what it is like to feel helpless and hopeless. There is light. Ours came inside a steel chamber when Bill looked, scared, through a clear plastic hood, and was told to BREATHE.