YA WANNA KNOW WHAT IT'S LIKE TO BE REALLY BENT?

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While reading the last issues of both UWS and the NACD Journal, it dawned on me that I could remember only once reading anything on the subject of DCS. Why? Is it a dirty word? Are we ashamed of it? I don't think so. I'm certainly not, and we all are aware of it. So, perhaps this is as good a time as any to share my personal experience with you. Unfortunately, I can condense it only so much.

May 26, 1997. My wife, Polly, and I were at our home on Bonaire. We usually spent about 60% of our time there and 40% at our home in Florida. I had taught some open water courses to houseguests doing 16 dives in 13 days. The last two dives were less than 1 hour and less than 30 fsw. After our guests' departure, we took two full days to rest and to out-gas. After 54 hours of surface interval, we took an afternoon "cool-off " dive, one we've done hundreds of times from our back steps: 42 ft for 40 min, surface to surface, with a time of about 8 minutes to ascend from 3I ft. When we left 31 ft to swim (drift) home from our favorite vase sponge, my Aladin Pro indicated 99 minutes ANDL, as did Polly's. I used less than 32 ft of air. We both felt great cooled off and relaxed.

Within seconds after I stood up in shallow water, I knew something was wrong. I felt slightly weak as if going into a mild shock; I detected a slight loss of strength in my left arm and leg, and I had a mild "sensation" in my chest but no pain. As I walked up our steps (Polly had me stop for the photo), my brain processed all the related data in an instant. I knew it could not be dive related: 42 fsw for 40 min surface-to-surface with an 8 minute ascent from 31 ft and 54 hours of surface interval? No way, Jose! It could not be a "hit!" Polly felt fine. Therefore, I assumed it was a coronary as the symptoms were identical to those my Dad described before he died. When we reached our patio, I told Polly, "I think I am having a heart attack." Before I could peel my wet suit, I had lost all capability in my left arm and leg, and my right leg was in a spasm. Immediately Polly had me on 100% 02 from a SCUBA regulator on one of my 02 tanks. I was on the way to the hospital within a few more minutes breathing pure 02 all the way.

No more than 20 to 25 minutes could have elapsed from the time I surfaced until I arrived at the E/R where the Dr. was waiting. We had radioed ahead. I felt much better then. By the time the films were developed and the physician (personal friend) finished examining me, I felt great! All my neuro checks, and EKG and pulmonary X-rays were OK, and I felt like going to happy hour! The Dr. assured me it was not a heart attack; however, he felt it possibly could have been a TIA (Tangent Ischemic Attack- mini stroke) cleared by the 02 or there was a remote possibility it could have been dive related in spite of my contrary convictions. He ordered me to stay in the hospital overnight for observation. (20/20 hindsight: should have gone into the chamber immediately - VERY SERIOUS mistake!). Neither the Dr. nor I knew Pam Teitel (chamber supervisor, good friend and former cave dive student) had gotten the chamber ready and had lined up a crew who are all volunteers on Bonaire.

About two hours later, I began having uncontrollable shivers and spasms at intervals like labor pains. As soon as I could get word to the Dr., he ordered me to the chamber in another building. In reply to my query, he told me he would probably give me a Table VI with one or two extensions depending upon my reactions. My response was "Hey I better pee!" That could be 6 to 7 hours!" You guessed it. When they tried to get me off the gurney, I was completely paralyzed from waist down, bilaterally. They dragged me to the toilet, dropped my shorts and said, "Pee, man, pee!" No luck. I had no feeling and no control, and I was losing my upper body strength rapidly. They called for a nurse and a Foley catheter, STAT, and transferred me to the board to slide me into the chamber. The nurse arrived and catheterized me with a Foley (one with a balloon in the bladder to keep it in), and they shoved me into the chamber with another nurse diving friend of

mine as my tender tossing my shorts in as an afterthought. Modesty was the least of my worries. By the time they got me in that cozy little chamber, catching my Foley bag on the lock-out door in the process (an experience to remember), I was virtually quadriplegic! I could move nothing from my neck down just barely able to move my hands and that capability was going fast! Bad hair day!

After seven back-to-back, double extended Table Six's (over 40 hrs total in that hot little chamber lying on a slab of plywood), I had recovered some upper body strength with all kinds of sensory deficits and an ability to stand only if held up. Consultation with DAN, which had been on-going, concluded it was time to get other specialty capabilities such as imaging, neuro, pulmonary, cardiac, etc., none of which was available on Bonaire. At 7:00pm the 28th, I agreed with DAN that I would go to Mercy hospital in Miami for a number of reasons, which I will not enumerate for the sake of brevity. DAN told me to be on the tarmac at 9:00 am the next morning. Waiting for me there was a Citation 5 into which I was loaded on a stretcher and wired for sound, with an E/R physician, an E/R surgical nurse, my wife, and Pam. We flew to Miami pressurized to sea level. There we were met by a waiting ambulance that took us to the E/R at Mercy hospital where Dr. Ivan Montoya was waiting for me (one helluva fantastic physician). It took no more than 10 minutes to sterilize me and change my catheter, clean a little salt off me, ask a few questions, and wheel me off to another chamber. Dick had sent a hand-written discharge report with me for the Miami doctors and had talked by telephone with Ivan. I had already been assigned a team of specialists. During the next two + weeks, I had another twenty-odd chamber treatments of different schedules and every test known to mankind except a mammogram and a Pap smear! The Trans-esophagus echocardiogram was the worst. They stick about an 18" wand down your throat to view your heart chambers. You have to be awake to swallow the wand. I gag easily, so it was hell for me! I retched for 30 minutes while that wand was down my throat as they looked for any opening between chambers. Also I had six + hours of physical and occupational therapy every day. It was 13 days before they induced my first bowel movement. I won't describe it. It was horrible! I have never felt so helpless and so humiliated in my life. I cried and sobbed like a baby. I really wanted to die. You can't imagine what it's like to be unable to pee or poop.

Approaching 30 chamber treatments, I reached pulmonary 02 toxicity. My lungs simply couldn't take any more oxygen at any pressure. I had to terminate the HBOT so I was discharged. We flew home pressurized to sea level. Discharge diagnosis: DCS type 11, Multiple ischemic demyelination injuries to the spinal cord (Damage to the myelin tissues by oxygen starvation allegedly due to N 2 "bubbles" in the spinal cord) lesions too small to be detected by MRI and an ischemic demyelination lesion deep in the lower right frontal lobe white matter clearly detected by MRI. Cause: Unknown. Prognosis: Fair to Good. The Doctors at Duke (DAN) referred to it as "Hit and Run DCS II in the form of a shower of microscopic bubbles." They did a lengthy article in "Alert Diver" magazine (Nov.'97) using no names. At that point, I was an expert in self-catheterization (not so great a sport; masturbation would have been more fun). However, with great effort and concentration, I could start urination at times, but I had no bladder sensations whatsoever. I had to discipline myself to drain my tank every few hours to preclude a bladder overfill which could be quite dangerous. I could stand-alone and even take a few steps unaided, but I had to use a walker to ambulate. Bowel functions still had to be induced, and I had virtually no feelings in my upper body though I had regained most of the functions above my waist such as arm movement, hand movement, etc. still with major sensory deficits and significant weakness.

I arrived home where a couple of my kids had put together a complete rehab gym in a large room next to my office. One of my daughters has a masters in OT. That very same day I dove into my rehab program with every ounce of energy, intensity and determination I could muster 7 days/wk. My daughter had already arranged for me to get under the care of a physiatrist (rehab specialist) at the Florida Spinal Rehab Institute and a neurologist as well as my personal physician, of

course. I spent virtually every waking minute for 3 months working at my rehabilitation, taking time out only for meals and a little rest when I reached near exhaustion. By the latter part of August, I had regained proprioception such that I could stand on one foot with my eyes closed; I could walk on my own, and I could drive. I could ride my mountain bike 10 miles, and my bodily functions had improved considerably. You just cannot imagine the pure pleasure of peeing if you have never been married to a Foley catheter or had to self-catheterize! Many sensory deficits remained throughout my body. I had slight feeling in my hands but none in my fingertips. I could stick a needle + inch into my thigh and feel nothing. Ever thought about using a keyboard without feeling in your fingers?
August 29th I had to attend a board of directors meeting in Atlanta for a large corporation in the process of a merger. I had attended all prior meetings by teleconference, but this particular meeting was critical and required my personal presence. I flew there pressurized at sea level. I had our pilots do this just to be on the safe side. Only one of the five HBO docs I conferred with said it would be safe to fly commercially pressurized at 8K ft which is roughly a 25% drop in ambient pressure and therefore PPO. The other four flatly stated there was either an "unknown" or a "definite" element of substantial risk due to the nature of my injury. Shortly after arriving in Atlanta, I received notification of an emergency and needed to return immediately. The company plane had departed. The big question: Should I fly home commercially pressurized to 8K ft? I pondered all the questions. With great reluctance, I took the commercial flight home to be at my mother's bedside who was not expected to live through the night. My gut said, "big mistake." My presence could not save her life, but it was expected of me, and I did it.

When I got to the hospital about 1:30 am that night, my wife said I looked like a ghost, and I felt as if I were in shock cold sweat and exhausted. I felt as if I had been shot at and missed and shit on and hit. My mother lived another three years and not because I was there. Two days later, I could not walk at all and had a number of other serious neurological symptoms. I went to the E/R and was checked into the hospital under my neurologist. One more time for nearly two weeks... Test after test after test and, of course, daily therapy. Diagnosis: Possible re-injury of some of the myelin tissue sheaths in my spinal cord; cause unknown. Could a one-hour 25% drop in ambient pressure have caused this? Could stress have caused it? Would it have happened anyway? No one knows. My neurologist and I conferred with all the "biggies" in the country: Barnes, Johns Hopkins, Linda Loma, Bethesda, National Health Institute; I won't name them all, but we went the full gamut. Conclusion: Refer to a psychiatrist who would help me get adjusted to living as a paraplegic. My response: "Unacceptable."

I concluded that if none of the doctors at all the major medical centers in this country could not help me recover, then I would re- sort back to the HBO Docs with whom I had made friends during the past several months. Two of them suggested I consider an experimental HEOT treatment regimen of a pressure of 1.5 ATA on 100% 02 for 1 hr/day, and both referred me to a couple of other HBO docs who were “on the leading” edge of HBO technology research. However, there was no experimental grant pro- gram being formed at that time. I checked with Baptist Hospital here. IF they treated me, it would cost a minimum of $550 per treatment for the standard 2X2 problem wound treatment with other patients. They would not treat my regimen. Their risk management people refused treatment of any kind. To add complications, I was turning 65 and going on Medicare. I decided to get my own chamber one way or another. “It’s your body, and you can do what you damn well please,” to quote one of the HBO doctors with whom I was working. All of my HBO consulting doctors agreed and gave me over whelming encouragement and still do.

Again, making a long story short, it's not easy to get a chamber! After extensive efforts to get one, I finally had a portable, collapsible 2 ATA chamber made for me by a company in New York. While my chamber was being fabricated, the president of this company stopped his reliability test program and sent me his only prototype chamber the same day I talked with him. It arrived the next day. A neighbor carried it upstairs, and I put that chamber together by myself scooting

around on my belly. That took two days. Fortunately, I had two 02 analyzers and all the necessary hoses and adapters among my gas mixing apparatus as well as a SCUBA compressor with more than 20 tanks I had for cave driving perfect for chamber pressurization. I also had a source for unlimited ABO (Aviation Breathing Oxygen) for which I needed no Rx. A couple of USN chamber operators moon-lighted a few treatments to give Polly confidence in operating it, though I could give her verbal instructions as well as operate some of the controls from inside. I developed some log forms and wrote a detailed operating manual for her and others I trained as operators. We were in business. That was December 1997. I had lost four precious months.

I have now had between 400 and 500 HBO treatments. I have my therapist, Donna, who has been coming to my home, and still is, three days/wk for 4-hour therapy sessions. She also learned how to operate my chamber to relieve Polly when I am in a treatment cycle. I have a 20 X 45 ft room devoted solely to my chamber and recovery therapy with all kinds of Physical and Occupational therapy gadgets with pulleys and harnesses (typical cave diver jury rigs) to get the heavy 02 cylinders safely up and down the stairs in my home. Less than a year after the neuro team told me I would never walk again, I was walking even without a cane. I now once more drive wherever and whenever I want to within reason; I go out to dinner, shopping, etc with a cane; I danced two dances with my wife at my 50th HS reunion, and all my bodily functions have finally returned to nearly normal. (Hurray!! I actually take great pleasure in peeing!) I am still left with some significant difficulties; however, which I am still battling.

1) I have a condition termed hyperpathia from my waist down (extreme sensitivity to very light touch), and 2) 1 have muscle lock- ups (far worse than a cramp or Charlie horse) of all muscle groups below my waist after walking or standing for 10 or 15 minutes. This also limits my bike riding to about one mile. Both these conditions are extremely painful which makes pain management my biggest challenge at the moment. Rather than become a "dope head," I am working with a Comprehensive Pain Management medical team to get the best pain management I can without going into narcotics of any type. I had one Dr. recommend an implanted morphine pump, which I rejected, of course. However, It "ain't easy" by any means. A couple months ago I finished a 38 treatment HBOT series in which I picked up some additional sensory capability in my right hand. Improvement comes quite slowly, a little bit at a time, but it is still coming. Patience is not my long suit, but I am learning it the hard way. I am on break between treatment cycles now which is TBD but probably will be several months. No one can explain the science of what I have been doing, but one can't argue with results and the myelin cellular healing theory of two of the docs I'm working with.

So far, this little episode of being "bent" on a simple, shallow dive has taken over four years from my life, and I still have much more hard work in front of me. I began diving at age 13. I will be 69 next week, 11 Sept. 2001. I have logged nearly 3500 legitimate dives (many teaching), nearly 900 of which were cave dives. **I did not do anything stupid or careless during my last dive to cause my "hit."** My wife and my computer dive log substantiate that. I have never had even the slightest symptom of any kind of DCS in my entire life. So why did I get a DCS II hit, and why did I "crash" after a one-hour commercial flight when I was recovering so well? No one knows, and no one will ever know. However, I have a theory, which goes as follows.

Over a number of years, I think I accumulated minuscule amounts of N2 in my myelin tissues which you might think of as the insulation around the nerve "wires" in the central nervous system & critical to proper nerve function. You might also consider your spinal cord as a twisted bundle of myelin insulated wires integral to your CNS. I accumulated more of my technical diving (deep, long, multi-gas, multi-stage deco dives) in my later years the 20 years after I was 45 yrs old. I did more and more teaching then as I had more time for diving, which increased the frequency and accumulation of my dives. Normally, doing 16 O/W teaching dives in 13 days, none extreme, is well within the generally accepted safety envelope with plenty of margin. Hundreds of instructors do it. 54 hrs of out-gassing is certainly considered conservative, especially following the last two dives in two days of less than 60 minutes and less than 30 fsw. And I had gone a few weeks

without diving at all prior to this trip. So what happened? DAN called it *"hit and run" DCS* with no explanation. Personally, I think I accumulated residual N2 over a very long period of time (years) and never absolutely, totally "out-gassed" my myelin tissues. Then, on a virtual "non dive" for me, I absorbed just a teeny bit more N2 enough to cause the residual N2 in those tissues to create a "shower of microscopic bubbles" in my spinal cord inspite of an 8-minute ascent. That one, simple shallow dive put me over the top.

With 20/20 hindsight, what have I learned that I can pass on to you for your safety?
This is the purpose of my sharing this experience with you even the personal stuff, and I'm not ashamed of it if it will help you. For those of you putting more and more candles on your birthday cake, you cannot be too conservative. When I first began mixing my own Nitrox, eons ago, Nitrox was a dirty word in the O/W community but it was common, and pure 02 was a standard in the deco procedures of our cave diving community. Frank Howard and I even went up to Terrytown, New York to Dr. Bill Hamilton's home and engaged him to work with us in developing a "conservative" breathing mix catalog & philosophy for our ages which we incorporated into all our diving primarily for cave diving but for open water as well. It is well known that some folks on Bonaire would not dive with me. I was a "pain in the ass on conservatism" and went overboard on "being prepared." Thank God I was. Also, looking back 20/20, Polly and I were prepared at our home, and we did everything right under the circumstances first aide wise. We had a full '80's of 02 on hand, and Polly did exactly the right thing. However, I should have insisted the physician put me in the chamber immediately rather "observe" me for recurring neurological symptoms. I think he (and I) erred seriously. The immediate 02 at my home gave me temporary and very misleading recovery symptoms. With my experience, I should have known better and insisted on immediate chamber treatment rather than "observation." Who knows how many myelin cells were damaged beyond repair in that time? No one. My gut tells me that immediate chamber treatment would have changed my life. Point: If you have a "hit" and 02 relieves the symptoms, don't think you are cured: stay on the 02 get to a chamber!!

Concerning my "crash" after three months of substantial recovery? I should not have taken that commercial flight. My gut told me not to. I knew better, and I took the perceived risk only because I was expected to be at the bedside of my mother. I certainly could not have made the difference whether she lived or died. However, with 20/20 hindsight, I would have waited for the company plane to fly back pressurized at sea level. I do believe that flight did a lot of damage. Physicians can argue the science of it forever, and still do. The point is I believe it. I am living through it. That is why I am sharing it with you. Had I not made those two mistakes, I believe I would be fully, 100% recovered today.

Another thing I learned is that determination and tenacity pays off when it comes to taking charge of your own medical care. It was shear determination and help from a few visionary physicians, my family, my therapist, and my cave dive buddies, Jeff Bozanic in particular, that paid off. I took the initiative to seek out those visionary HBO physicians who have been helping guide me through this experimental treatment regimen. I also took the initiative to make contact with the president of the company that made my experimental chamber (NOT FDA approved). Otherwise I would surely be confined to a wheel chair today. I also learned that DAN is essential for any diver. They helped me get through the air evacuations and initial medical bills even though I had excellent insurance. DAN's reaction times were unbelievable. However, that insurance runs out in a year, and all the other stuff such as chamber, a therapist 3 days/wk for years, all the 02 I use, a substantial portion of the costs of all my medications, etc., are out of pocket and will continue so, probably for years. No telling how long this fight for more recovery will end if ever.

Fortunately, we have been able to afford it. Many less fortunate could not. It has been extremely expensive, and that is a gross understatement. Those of you who know me personally, and many of you who don't, will ask the $64 question. The answer is absolutely YES! I intend to dive again, and I intend do that same dive again on Bonaire. However, it will NOT be on air. It will be

on either EAN 65 or 100% 02 and I will hold the depth so the PPN2will not exceed 0.8 ATA, and the PPO2 will not exceed 1.5 ATA to which I am well adapted. Also, I will either charter a corporate jet and fly to Bonaire pressurized to sea level or get there by surface transportation depending on the cost/time trade-offs. We sold our home there.

I have reluctantly accepted the fact that my in-water dive instruction days are over both open water and cave diving. My first love, underwater cave surveying is no more. Even at nearly age 70, Polly and I will still be able to enjoy shallow, underwater photography, God willing. I hope my sharing this experience gives you a real sense of *what it's like to be really bent!* You don't want to try it! It can radically change the rest of your life. It necessitated my closing my practice and resigning from all my boards, which stopped all working income. I became unemployed and unemployable overnight! You don't want to try that either! This has been quite a journey. There lies still a long road ahead, and I hope I can continue to travel that road with the same level of determination and optimism and continued recovery. If anyone would like more specifics, I would be happy to respond. My contact information is:

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About the author: *John Burge is a lifetime member of the NSS and NSSICDS as well as the NACD. He is a NSSICDS cave diver instructor and PADI Master SCUBA Diver Trainer Educated in engineering and business, he is the retired CEO of a major aerospace corporation and the founder and principal of an elite international consulting firm. He began diving at age 13 and has dived in the Gulf of Mexico, Atlantic and Pacific Oceans, and the Mediterranean and Caribbean Seas accumulating nearly 3,500 dives, nearly 900 of which were in underwater caves many of which were extended duration and penetration doing pioneering survey work.*

He is the developer of the Underwater Cave Survey course, the sole author of "Basic Underwater Cave Surveying," a co-author of the "NSSICDS Cave Diving Manual, " a co-author of "the Art of safe Cave Diving, " and the author of numerous published articles and papers as well as a prolifically published underwater photographer.

His story in this publication is meant to be educational and helpful to his fellow divers all over the world.