

This Holiday Season, Consider Donating To Paralysis Research

It is virtually impossible to participate in any high risk sport, be it horses, skiing, auto racing, or anything else, without knowing someone who has suffered a devastating injury. It is the nature, the risk, of our world, one that we accept every time we sit on a horse. Therefore, for us, the equestrian community, spinal cord research is not an abstract idea, a distant concept. It is a very real, very immediate need.

With the death of Christopher Reeve, the equestrian world lost high profile voice for research for a cure for paralysis. Nevertheless, many in our community are continuing to soldier the message on, including Irv Naylor. Irv has been a risk taker his entire life, both in business and in sports. He founded his first business in 1963, and turned one of his two sporting passions, skiing, into a business in 1964 when he founded Ski Roundtop (Pennsylvania). Over time his company, Snow Time, Inc. acquired Ski Liberty, Windham, and Whitetail.

When he wasn't skiing, Irv was foxhunting or steeplechase racing, and was a regular rider in some of the world's most prestigious timber races, including the Grand National (MD) and the Maryland Hunt Cup (biggest timber fences in the world), and he still oversees his active Maryland breeding farm and training stable.

One Rider's Story & The Case for Stem Cell Research *by Irv Naylor*

On April 17, 1999, about 3:30 PM, my life changed forever while riding my good Irish horse, Emerald Action, in the Grand National timber steeplechase at Butler, Maryland. He ran and jumped brilliantly, and was leading as we approached the 16th of 18 fences, when the horse I knew we had to beat, Welterweight, came along side.

I can only assume that Action was distracted by the presence of Welterweight, because Action apparently arose to the unbreakable stake-and-bound fence only at the last moment—and then a half ton of horse, traveling at 25 or so miles an hour, came down heavily, throwing me to the right side of my face, and breaking the C5 vertebrae in my neck.

I remember little after the fall—just that I was paralyzed and could move neither my feet/legs nor my arms/hands. It seemed hours before I was transported, first by an ambulance and then a helicopter, to the final destination at the shock trauma medical unit of the University of Maryland Hospital. You cannot predict life's vicissitudes; you can only prepare; but nothing could have prepared me for what I saw on being turned face down on a revolving gurney. Lying directly in front of me were both my organ donor commitment card and my living will.

I do not recall much of that first week, as I was heavily sedated, and still in the mental mode of refusing to accept my paralysis. I was originally diagnosed as a "C3 complete" as the doctors thought I was completely paralyzed from my neck down with no use of my arms. Within a day or two after the accident, however,



Irv Naylor aboard Emerald Action winning the 1996 Alda Clark Plate at the Howard County Iron Bridge Hounds Race Meet.

Cappy Jackson, courtesy of Maryland Horse Breeders Association

I began moving my arms, which, thankfully, changed my status from "complete" to "incomplete"—the latter meaning that I had experienced some "return" and could probably anticipate more. My category of injury was also changed from C3 to C5/6. On July 1, ironically our 25th wedding anniversary, I wiggled my left big toe, and I suddenly realized that I had some "return" in my left foot. I can now swing my left lower leg in a 12-inch or so arch and recently I moved my right big toe a tiny bit; otherwise, the paralysis in my feet/legs and hands remains as it was immediately after the original injury.

Right after I was hurt, my mantra became "to have just one day

with neither frustration nor tears." Regretfully, that day has not yet arrived.

The commercial side of my rehab was quite active. For liquidity's sake, I sold my corrugated box company, Cor-Box, Inc., which I founded in 1966. That was in September 1999—almost exactly the same time the Whitetail Ski Area in Pennsylvania came on the market. Both the sale of Cor-Box and the purchase of Whitetail were challenging and complex, and it was gratifying for me to see us complete both before year-end.

By September I was able to travel to my ski operations and farms in my wheelchair and a specially outfitted van. And I have a full plate of board seats and real estate responsibilities.

Still, five-and-a-half years after the accident, and after several surgical procedures—including a laminoplasty of my neck, after which I had a "near death" experience from infection and the Levoquin antibiotic used to fight it, and several microsurgeries to both hands which left both completely useless except for the thumb "pinch" of my right hand—I am constantly reminded how helpless I remain. That is a very tough acknowledgment for a previously active man who played tennis weekly; who skied five weeks or more every year, including heli-skiing in Canada; who was active as a scuba diver from the Caribbean to Truk Lagoon; who fly-fished from Alaska to Russia; who fox hunted annually in Ireland, England and the US; who traveled more than half of each year; and who genuinely loved his commerce and home. Prior to my accident, I was in charge of my life; now I am dependent on someone for almost everything.

We never accept an invitation or make restaurant reservations or travel plans until we have confirmed "accessibility." I eat with the aid of a Velcro strap on my right hand which positions a fork or spoon; I rely on a benign dinner partner for drinks and cutting chores; and I hope that my collar napkin catches my inevitable drop. I can't bathe or dress myself; "tetraplegics" live with little dignity. I'm desperately trying to write, but the effort is seldom legible. I can hold a piece of paper, but I cannot file it or retrieve another. The utter frustration can never be appreciated by anyone unless they have experienced a similar handicap.

Sleep is a benefit seldom enjoyed throughout the night. Like Christopher Reeve, when I dream, I am always able-bodied. Medication seems endless and leaves me in a stupor most mornings till noon or so. My body is constantly in a high state of "tone," which means that I tend to spasm often.

Our home is not a dwelling of doom. It, however, is far from the atmosphere of joy it once was. I may have been the one to receive the blunt trauma from my injury, but my wife, Diane, has suffered with me. It is she who does all the driving, who organizes the pills and the personnel and sees to the schedules. Her fingers have become mine. Her devotion to me has raised my spirits and made me appreciate how meaningful it is to care for someone "for better or for worse." Her encouragement is my touchstone; her focus, my north star.

After over five years, what can I realistically do to regain my dignity and independence? I ask myself that every day; its solution my epiphany. I now spend half of my waking hours in boring physical and aqua therapy. I am preparing my body as best I can to again walk; to be able to sustain my weight on strong bones and only modestly atrophied muscles. Today, there is no cure for paralysis—but the great hope is in stem cell research.

Stem cells are the master cells that have the ability to differentiate into other cell types including those in the brain, heart, bones, muscles and skin. If taken from the patient, they will be DNA specific, thus eliminating the real hazard of rejection.

Nearly half of all Americans could benefit from stem cell research, including one million children with juvenile diabetes, 8.2 million people with cancer, 60 million people struggling with heart disease, 4 million Alzheimer's sufferers, 10 million people fighting osteoporosis, 43 million arthritic sufferers, 250,000 people with spinal cord injuries (with a net increase of about 12,000 per year, mostly young men injured in motorcycle accidents), and 30,000 Lou Gehrig's disease (ALS) patients. Unfortunately, some politicians (including the current Bush administration) still put their philosophy and/or their religious persuasion ahead of the health of the nation; therefore, research dollars are scarce (total funding by the U.S. government, through the National Institute of Health, for stem cell research for 2003 is only \$11 million) and the industry is too young for serious venture capital.

"We must not let the misplaced fears of today deny patients the cures of tomorrow." I never thought I would quote Ted Kennedy, but I just did, and, in this case, he's absolutely right.



Irv Naylor accepting the Maryland Governor's Cup Steeplechase Horse of the Year, given in recognition of Make Me A Champ's outstanding race season.

I have become an advocate for stem cell research. In November, 2002, I arranged to have a one-inch diameter skin plug removed from my right inner thigh. That piece of skin was used to create a line of skin stem cells specifically to my DNA. In August, 2003, I had the fat from my girth liposuctioned (my "six-pack" stomach at April, 1999, had, in spite of my best efforts at calorie control, "matured" to a small keg!); that fat material was then converted to adult stem cells. Both stem cell lines will be frozen until techniques are developed to transform them into embryonic cells (which may be more useful than other stem cells) and/or until the second part of the dilemma has been clinically proven—how and where to return them to my body and how to direct their neurons to repair my spinal cord injury. A two-year horizon is optimistic.

Between now and then, I must practice patience; I must try to control my frustrations; I must find joy in what I can do, and not become depressed by remembering what I cannot do; I must continue to have faith in both prayer and the scientific community; and I must never forget how precious today is, for none of us know what tomorrow may bring.

I encourage anyone wishing to contribute to stem cell research to do so. The most effective 501(c)(3) group I have found is:

*Bedford Research Foundation, Inc., 53 Concord Road
Bedford MA 01730, Attn: Dr. Ann Kiessling, Phone: 617-623-5670, Fax: 617-275-5970, www.bedford-research.org*