

**“MAGIC CARPET”**  
***By Erin Brady Worsham***

March 21, 2007-----I’m sitting in an adaptive bi-ski at the top of Crawford’s Blaze run at the Bretton Woods Mountain Resort in New Hampshire. Across the valley I have a beautiful view of the Presidential Range of the White Mountains, including the renowned Mt. Washington. What’s a girl from Nashville, Tennessee, who’s almost completely paralyzed from ALS and breathes with a ventilator and who’s never skied before in her life, doing here? Got a minute? It’s a long story ...

TORINO, 2006

February 10-26, 2006-----I have always loved the Olympics. Watching finely tuned athletes at work is mesmerizing, especially since I have little or no muscle myself. As usual, the commentators were spending too much time talking about the athletes’ personal lives. Speed skating was a favorite event for me, but I was bored silly by the Chad Hedrick and Shani Davis feud off the track. The snowboard cross was exciting, but I wasn’t interested in why Lindsey Jacobellis threw in a hot dog move that cost her the gold. It only drove home the fact that the race wasn’t over until it was over, and nothing is a foregone conclusion when you’re racing on snow and ice. And who was this Bode Miller everyone was crucifying both on and off the slopes? I wasn’t particularly curious about what he did on his own time, but their comments made me take a closer look at alpine ski racing. What I discovered was an excitingly unpredictable sport, where .01 of a second could win the day. By the end of the Olympics, when my formerly favorite commentator, Bob Kostas, delivered his personal diatribe against Bode Miller, I was hooked on alpine ski racing.

**BRETTON WOODS ADAPTIVE PROGRAM**

I was ashamed of how little I knew about the U.S. Alpine Ski Team. These men and women spend the bulk of the World Cup season on the road competing in Europe and they deserve to have their country’s attention and support. I set to googling to educate myself on the sport and the athletes. That’s when I discovered that Bode Miller supported the Bretton Woods Adaptive Program. The word “adaptive” caught my eye, because it was from my world, the world of disability. Again I googled and read about this incredible program that allowed people with a wide range of disabilities to ski, using specially trained instructors and adaptive equipment. I had no idea such programs existed. Though I felt myself beyond the abilities of this program, because of my spaghetti body and ventilator, I was still inspired to create a piece called “Go Fast.” In it Bode Miller was guiding me down an impossibly steep slope. I was sitting snugly wrapped in blankets on a sort of sit-up sled. In the distance were the beautiful White Mountains. I had no experience with skiing, but

this picture expressed the freedom I felt when I watched the alpine ski racing. I e-mailed my picture to the [Bretton Woods Adaptive Program office](#) on April 28, 2006.

## CRIS

Cris Criswell, the Director of the Bretton Woods Adaptive Program, e-mailed me the next day. It was just a short note and he included a picture of himself on his monoski. (Cris, a retired business executive, took up monoskiing ten years ago as therapy for his post-polio.) Also in the picture was Tom Wade, a history teacher from Milford, Conn., sitting on an adaptive bi-ski. Tom also happens to be a quadriplegic. Cris told me he is tethered down the mountain by another skier from behind. That blew me away! It was my first inkling that someone like me could ski. Cris cleverly planted the seed and then sat back and let it grow. He called the house one day and mysteriously asked my nurse how I handled the cold. When she told me, I thought, "My God, he thinks I can do this!" The possibility was becoming more real in my mind.

## "ARE YOU GAME?"

On June 13, 2006, Cris first directly broached the subject of our coming to Bretton Woods. "What do you think?" he asked. What did I think? "I think I think about it every day," I replied. "I think God is telling me to get my butt up there." The adaptive program had never dealt with someone quite like me. I think I was a challenge! But New Hampshire is a long way from Tennessee, and the logistics of such a trip were a nightmare. It would take two long days of driving to get there. My husband, Curry, would be hard-pressed to do that and take care of our son, Daniel, 11, and me. In a perfect world, we would have a nurse with us who could help with the driving. Finding a nurse, who was willing to travel and was adept at communicating with me, was almost impossible. And so it was. I couldn't even consider a trip of that length without another adult along. In stepped our good friend, Iva Webster McGavock. She agreed to go and learned how to deep suction my trach in a pinch. On February 4, 2007, I gave Cris the green light. We were going to New Hampshire ...

## THE VENT

Plans were falling into place for us to travel during Daniel's Spring Break (Cris surprised us by extending Pat Corso's, President and CEO of the Bretton Woods Mountain Resort and the Mt. Washington Hotel, invitation to come as the resort's guests.) We would stop for a couple of days in Richmond, Virginia, to visit with Curry's brother and family. As the day of our departure, March 16, drew near, my respiratory people at Apria started to panic. They had been in touch with their office in Littleton, NH, who reported a temperature of 9 degrees. According to the maker of the ventilator, Pulmonetics, the optimum operating temperatures were 41-104

degrees. I had been totally unaware of this range and had been out in much lower temperatures many times. They warned that if my ventilator circuits seized up, I would have to go to the hospital until they could get another special-order ventilator like mine. This was, of course, assuming I would be irresponsible enough to let the same thing happen to the back-up ventilator I always travel with. The weather forecast for the time we would be in New Hampshire was for the low 30's and 40's. We went ahead with our plans.

#### AN UNEXPECTED ALMOST

We got our usual late start, actually leaving at 2 a.m. on March 17. We ran into sporadic snow flurries in Virginia and arrived in the late afternoon. Curry did the bulk of the driving and was wiped out. When he put me to bed, he hooked me up to my Liberator communication device so I could call and fell into a deep sleep. Some time later I woke up needing a suction. I operate my Liberator with a sensor taped between my eyebrows, but this time when I moved my brow, nothing happened. I knew I was in trouble because the ventilator alarm was not waking Curry. The congestion slowly moved up my lungs over the next half-hour or so. I can't be sure how long. I do know my ventilator was working very hard to keep me alive, but it couldn't push past the congestion. I was getting maybe one out of four breaths when it reached the top of my lungs and those breaths were very shallow. My thinking was becoming confused from the lack of oxygen. For the first time in 12 years of ALS, I accepted I was going to die. I knew my body could not fight for breath and I mentally told it to stand down. My parents' picture is taped to the front of my Liberator. I focused on my mother's face and asked for her help. My mother, the artist, who now lives in a nursing home and is entering the advanced stages of Alzheimer's. All the while I prayed for peace. Then for absolutely no reason, Curry came out of a deep sleep and was standing over me. He suctioned me and fixed my sensor. When Curry realized how long I had been in distress, he said he had been surprised to find me looking so peaceful. After that brush with the hereafter, the thought of skiing down a mountain didn't seem daunting at all ...

[BRETTON WOODS, NEW HAMPSHIRE](#) We left for Bretton Woods at 2 p.m. on March 19. We couldn't see the beauty of New England in the dark, but we were excited by the piles of snow we began to see on the side of the road. Daniel's cousin, Stephen, 12, had joined our party. They jumped out of the van at a stop in Vermont and threw snowballs, a rare treat for two Southern boys. We pulled into the [Bretton Arms Country Inn](#), on the grounds of the famous Mt. Washington Hotel, at 4:47 a.m. on March 20. I had just enough energy to take in the white clapboard charm of the old inn, which was built in 1896, before falling asleep in our spacious, wheelchair accessible room. The morning sun revealed the startling beauty of the White Mountains roundabout. The boys had gotten

plenty of sleep in the van and were raring to go. Cris joined Iva, Daniel and Stephen for breakfast in the inn's cozy dining room and then whisked the boys off to go tubing at the Nordic Center, followed by swimming in the heated outdoor pool at the Mt. Washington Hotel and, finally, ski lessons at the ski area. They were going to sleep tonight! Curry and I met up with Iva and the boys at the base lodge later in the afternoon.

#### DRY RUN

Cris suggested we have a dry run the day before the actual run to work out any kinks. We met Cris and Sandy Olney, the new Director of the program, at the Adaptive Skiing Program Office in the base lodge, along with other volunteers. We were shown two different models of bi-ski, one with a more upright back than the other. Neither had any head support, which my spaghetti neck has to have. Curry suggested bolting the headrest from my wheelchair to the back of the bi-ski. Enter Cordele Bushey from the Repair Shop. A template was taken, a plate was made and attached, and we were ready for the transfer. Sandy, who I dubbed "Earth Mother" because of her kind eyes and long, golden braid, held my head while they moved my headrest. We worked out where to place the bi-ski and the ventilator to facilitate Curry moving me with the gatebelt. Iva transferred the back cushion from my wheelchair to the bi-ski as Curry lifted me. I was tightly belted into the seat and the headrest was adjusted. It was determined that the best place for the ventilator was on my shins. Every detail was addressed. These people are about safety; they don't want any surprises. The person who would be taking me down the hill had the option of either holding on to the bar above my head or they could tether me several feet from them. If they chose the latter, outriggers would be extended on either side of the bi-ski to keep me from falling over. Transitioning onto those outriggers would not be gentle, so we practiced rocking me back and forth hard. It felt wonderful! We were ready.

#### PREPARING TO LAUNCH

Run Day, March 21<sup>st</sup>, dawned clear and sunny with brilliant "bluebird" skies. It was supposed to get up to 32 degrees. I knew that between the sun and a warm blanket over the ventilator, we could reach that 41 degrees benchmark. For the second straight day, Curry wrestled me into my ski clothes. After years of wearing only the loosest garments, the constricting clothes were torture. We arrived at the base lodge around 1 p.m. and then began two hours of preparing the "astronaut" to launch. Curry and I were introduced to George Hollingsworth and Dave Blenkhorn, the master tethers on loan from the White Mountain Adaptive Ski School at Loon Mountain, who were going to take us down the mountain. (Curry would be riding on another bi-ski to be near me if there was a problem.) Tall, lanky George and shorter, sturdy Dave made quite a team with George's direct, dry wit and Dave's reassuring manner. They inspired confidence.

At some point in the process, I noticed that people had gathered to watch. Bode Miller's sister, Kyla Miller White, dropped by to say hello with two of her three beautiful children, Iris and Satchel. My mind was racing with last-minute details. We had decided to leave one external battery for the ventilator with the chairlift operator at the bottom and one with the operator at the top. I would be going down the mountain on the ventilator's internal battery, which was supposed to have 60-80 minutes of power. Out came the duct tape in the final preparations. Everything was taped down. The ventilator was taped down over my shins, the tubing was taped to the ventilator, and a blanket was taped over it all. My hands, which won't go into gloves, were taped into warm caps and then onto my lap. We were ready to roll, literally. They lifted the bi-ski onto a bar supported by two large wheels and rolled me outside into the blinding sunshine ...

#### CRAWFORD'S BLAZE

Dave lifted me off the bar and I slid smoothly across the snow for the first time. Sandy perched sunglasses on my nose and Dave skied me over to the chairlift. Without stopping the lift, Dave and George hauled the bi-ski onto the seat between them. Curry rode with us. He would get in his bi-ski at the top. Just before we boarded, I asked Curry to inflate my cuff. The cuff is a small balloon at the bottom of the trach that, when inflated, prevents air from escaping out of my mouth and nose. I didn't want to risk losing my air every time we hit a bump, but it also meant I would not be able to make any sound. The chairlift ride was a thrill in itself. I felt no fear, only wonder at finding myself soaring over the heads of skiers and snowboarders flying down the hill. Without missing a beat, Dave and George skied me off the lift at the top. The view of the White Mountains was stunning from up here. We stopped to take pictures. Cris had thought of everything. George Mitchell, a local professional photographer, was documenting the day in pictures, complete with skiing down the mountain with me. Harry Newell was covering the day with video. Daniel joined us for a family picture and then was taken back down on a snowmobile. He hadn't graduated from the lower slopes yet. From the time I left the base lodge I was on my internal battery. We pushed the reset button twice to keep the alarm from going off every minute. Now, if the alarm went off, we would know it was something other than the ventilator warning us it was on the internal battery. Curry got in his bi-ski, which was being navigated by George, and we were off. I was amazed by how fast and smoothly the bi-ski rode under Dave's direction. We headed down Crawford's Blaze, a tree-lined, winding run with breathtaking views of the mountains. My paralyzed body moved forward naturally into the turns. It felt exhilarating and strangely familiar. As the grade got steeper, Dave criss-crossed the slope with shallower sweeps. At the end of each sweep was a jarring bump that threatened to dislodge my head. We rendezvoused with Curry and George, and Curry adjusted my head strap.

About halfway down the run my ventilator alarm started sounding. Again we met up with Curry. Looking under the blanket, he saw the “battery low” warning. That didn’t make any sense. I couldn’t have been using the internal battery for more than 25 or 30 minutes. I had never tested the ventilator battery past that warning. Curry was concerned and said we had to move. Dave took a more direct line down the hill, which was fine by me, but it resulted in a few more bumps. Out popped my head! Within seconds three people converged on me, and within 30 seconds they had fashioned a chinstrap out of duct tape that attached to my headband. Thank God for duct tape! Sandy, my “Earth Mother,” was looking very worried. If she only knew how many close calls Curry and I had weathered with God’s help over the years, she would not worry. So I smiled, and she looked relieved. Dave took a very direct line at the end that gave me an incredible rush. The only problem with our plan to have batteries at the top and bottom of the mountain was that the cable to attach it to the ventilator was left on the battery at the top! A very nice volunteer rode the chairlift up to get it. In the meantime, Dave and Sandy got me inside the base lodge and Curry ran to the car for the power cord to plug the ventilator into the wall. As he plugged the ventilator in, I saw a warning I had never seen before: battery empty.

#### EPILOGUE

We were later told by the respiratory people at Apria that the ventilator had to work harder at the top and bottom of those ranges and therefore ran through its internal battery more quickly. Well, why didn’t they say so before?! Next time, I’m taking the external battery on board with me! I want to enjoy the silence of the mountains without the frantic beeping of my alarm. We were prepared for any eventuality, since I had my ambu bag and suction machine with me. The people of the Bretton Woods Adaptive Program took my vision in “Go Fast” and made it a reality. I can never truly thank them for that. So, why did a girl from Nashville, Tennessee., who’s almost completely paralyzed from ALS and breathes with a ventilator, and who had never skied before in her life, feel the need to make a pilgrimage to the White Mountains to go skiing? Cris, who is also a minister, put it best in an excerpt from his invocation at the annual [Hartford Ski Spectacular](#) in Breckenridge, Colo., which is the country’s largest winter sports festival for people with disabilities. “So whether by birth, by disease, by accident or by war, whether you ski or whether you ride, one board or two, two legs or one, sit-down, stand-up, with or without sight it is our magic carpet ride, -----we all glide over frozen, sparkling crystals for the same reason, to be transported into another world, a Place where the crippled dance, the lame walk and the blind see, where we may all, each and everyone, no one left behind, all together, mount up with wings like eagles and join the Dance which has no end.” Amen to that!