

My Friend Fran

I will never forget the day I was introduced to Amyotrophic Lateral Sclerosis (ALS) in a very personal way. My knowledge of the disease was almost non-existent because like most folks it had not affected me personally or anyone I knew. As an avid Boston Red Sox fan and a lover of baseball, I knew that Lou Gehrig at a very young age had died of this disease that now bears his name. But I knew very little of the way he succumbed to the ravages of this terrible affliction. That all changed on the Sunday, October 22, 2000.

The day was a typical fall day in New Hampshire with the sun shining brightly amidst the incredible color that only New England can bring to the landscape during that time of year. I had just finished a rather unspectacular round of golf at Sky Meadow Country Club with my dear friends Jim Malanson, Rodney Thomas and Fran Delaney. We were a very close group of four golfers who tried to play every Saturday and Sunday from opening day in the spring until the course closed in the fall usually around November 1st. Playing every weekend was not always possible as work and family demands had an impact but never the weather. We had a rule that we called the "Jim Malanson Rule". It stated that if there was any question about the weather, always show up at the course and as long as you are there you might as well play. Sometimes we were the only folks on the course and the pro Rich Ingraham would only shake his head.

After finishing our 18 holes of ready golf, Jim always played ready golf and at times seemed more interested in finishing in record time than scoring well; we went to the grill room and ordered lunch. While drinking our beers, we reviewed our day of golf peppered with the casual embellishment of a great shot that was sure to bring us back the next weekend. Little did we know that this would be the last time we were to play a round of golf with Fran.

As we left the grill room and walked to the parking lot, Fran stopped just before we reached Jim's car and quietly said that he needed to share something with us. We all looked at Fran with a bit of worry and anticipation of bad news. It had become evident over the course of the year that Fran's golf game had slipped dramatically. No longer could he hit his 5 wood 235 yards down the middle of the 12th fairway or hit his irons with a crispness that we had been accustomed to. In fact his 7 iron only carried about 120 yards instead of 160 yards. This was not the Fran we had played with over the years and we were all puzzled as to what had happened to his ability to hit the ball long distances, although not always straight. We knew that something was wrong but did not have a clue as to what it might be.

In a very quiet manner Fran shared with us that he had been diagnosed with a form of ALS, Lou Gehrig's disease. Our world stood still for what seemed like days as each digested the news. I was very quiet, Rodney grew emotional and Jim asked all the questions that we wanted to hear. Fran's answers were stunning.

"No known cause, no cure and no effective treatment"

Over the course of the next few months I scoured the internet and publications for anything about the disease or for something that could help save my friend's life. I learned that this disease was more insidious than I could have imagined.

"Amyotrophic lateral sclerosis (ALS), often referred to as "Lou Gehrig's disease," is a progressive neurodegenerative disease that attacks nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With all voluntary muscle action affected, patients in the later stages of the disease become totally paralyzed. Yet, through it all, for the vast majority of people, their minds remain unaffected.

A-myo-trophic comes from the Greek language. "A" means no or negative. "Myo" refers to muscle, and "Trophic" means nourishment---"No muscle nourishment." When a muscle has no nourishment, it "atrophies" or wastes away. "Lateral" identifies the areas in a person's spinal cord where portions of the nerve cells that nourish the muscles are located. As this area degenerates, it leads to scarring or hardening ("sclerosis") in the region.

As motor neurons degenerate, they can no longer send impulses to the muscle fibers that normally result in muscle movement. Early symptoms of ALS often include increasing muscle weakness, especially involving the arms and legs, speech, swallowing and breathing. When muscles no longer receive the messages from the motor neurons that they require to function, the muscles begin to atrophy (waste away). Limbs begin to look "thinner" as muscle tissue atrophies."

In summary, Amyotrophic Lateral Sclerosis (ALS) has no cure and no effective treatment. The disease is marked by a rapid loss of voluntary muscle contraction due to the death of motor neurons in the brain and the spinal cord. The result is complete muscle paralysis, communication impairment, aggravated swallowing and breathing, and eventual death. More than 5,000 people are diagnosed with ALS each year, but the speed of progression and fatality means that only 30,000 people are alive with ALS at any given time. Following diagnosis, the average ALS patient survives 2-5 years.

The above was a simplified explanation of ALS excerpted from the "ALS Therapy Development Foundation Fact Sheet" as well as the "Living with ALS, Manual 1: What's It All About?" by the ALS Association.

It was now January, 2001, the weather had turned typically cold and snowy and with out golf, I had a lot of time to think about Fran, his family and what to do. For most of my life, I have been able to fix things whether it were a particularly stubborn technical problem with the Digital Equipment Corporation medium or high end computers I repaired or with the customer services operations I was tasked to manage for the New England Customer Business District. Fixing a technical problem really only required that you know to the smallest detail how the computer was designed to operate. When it malfunctioned, I would just figure out what part had failed and replace it. I know that I am oversimplifying this but the reality is that we know more about computers than we know about the human body or ever will. At least in my life time this will be true.

The same also could be said about operational problems with a service organization. Training, process control, problem management and people management were all keys to delivering exceptional service to a customer. Fran used to tell me "The Customer may not always be right but they are always the customer. Do what ever you can to fix the customer". Understanding this part of the job was made easier by the guidance of my friends, Tim Hines, Jim Malanson, Bob Zepf, and Rodney Thomas and all of us had the luxury of having Fran as our mentor.

I kept asking myself "What would Fran do to fight ALS?" but in my heart I knew with our even asking Fran. He would fight and fight until he ate the bear or the bear ate him. Shortly there after with 15 close friends and family, Fran guided us in the formation of The Fran Delaney Foundation with the expressed goal of raising funds to find a cure for ALS. When you make a decision to fight a disease like ALS, there are only 2 things you can do. Find a medical cure or raise money and give it to someone who can. We would raise money...

The Annual Fran Delaney Foundation Sky Meadow Golf Tournament was conceived in my dining room a few weeks after that initial foundation meeting. Charlie Meeker, Walter Whelan, Jim Malanson and I decided that we would run a golf tournament at Sky Meadow Country Club, where we were all members. It is a wonderful venue for a golf tournament and besides everyone knew Fran. We had a modest goal of raising \$30,000 and thought if we could do that we would be successful. The problem was that none of us had ever conceived of or ran a charity golf event in our lives, but we were determined to do it anyway. We were all connected to the hi-tech industry and knew how to get things done, so we just moved forward.

I searched the internet for golf tournament plans and examples on how to put on our event. Jim, Charlie and Walter did the same thing and we talked, bounced ideas off of our friends, brainstormed with cohorts and ask so many questions that in a matter of 3 weeks we had a plan.

Six months later, Fran delivered the key note address to over 160 gofers and dinners guest at the 1st annual Fran Delaney Foundation Sky Meadow Golf Tournament. We raised over \$100,000 before expenses. To say this was a success is an understatement. It was a testimonial to Fran and all the supporters who came forward from his business life, his family and network of friends to lend a hand in our fight.

September, 2006 will mark the 6th anniversary of our Sky Meadow Event and the 2nd since Fran succumbed to the complications of ALS. This single event will have raised over \$550,000 in six years and the Fran Delaney Foundation over \$1.7 Million.