My name is Mahlon Frankhauser and the name of my talk is "Never give up ~ persevere!" I was a securities attorney for 40 years and during that time worked for the SEC and The New York Stock Exchange. For the last 28 years I had been a partner of a large International nationwide law firm from which I am now retired due to my injury and inability to practice law.

I am here to share my story of <u>my recovery</u> from a <u>severe traumatic brain</u> <u>injury</u> that I sustained when I fell from a ladder onto a <u>concrete driveway</u> while hanging Christmas wreaths on the windows of our home in December, 1997. (almost 9 years ago) My life changed totally and completely in the blink of an eye.

I had <u>several brain operations the first two days in order to save my life.</u>
During the surgeries a large portion of <u>both</u> of my frontal lobes were removed. The frontal lobes are the organizational and executive functioning part of the brain, they control impulses, balance and mine were severely damaged in the accident. There has also been damage to <u>each area</u> of my brain. You can imagine what this has done to my chances of ever returning to the practice of law, which I have dearly loved <u>all</u> these years!

I was on a ventilator, had a feeding tube, a superpubic catheter and slept on an <u>ice mattress</u> to keep my temperature down. When I awoke from my coma <u>after two months</u>, which is <u>nothing</u> like the movies or TV I might add, I had a long journey ahead. I was then transferred to Mt. Vernon Rehab Hospital for 7 <u>weeks</u>, but was unable to keep up with the pace of the therapy so was transferred to an <u>acute care facility for  $7\frac{1}{2}$  months while receiving therapy and regaining strength and some memory.</u>

My wife, Joan decided to take me home where she believed I would have a better chance of regaining my memory and further recovery in the warmth of our loving home. Encouraged by <u>Dr. French</u>, and with the help of Susan Rudolph of Brain Injury Services, but against the advice of a number of my doctors and therapists, Joan had an elevator installed and redid the master bathroom to make it handicapped accessible.

Once the decision was made, all my therapists supported us in everyway possible. So on Halloween, 1998, I went home! When I first came home, I was in bed 22 hours a day, couldn't sit up or turn over, was tube fed, still had the superpubic catheter and wore diapers.

My first goal was to get out of bed and into that wheelchair fulltime. It was hard work, but the therapists worked with me 3-4 days a week, and I kept getting stronger. My aides would help me exercise when the therapists were not there, and before long, I was downstairs most of the day. After two years, I got out of the wheelchair and I felt overjoyed! My first steps gave me my freedom back! Now I use a rollator walker and a cane. I have just started

walking short distances around the house on my own, and I'm thrilled! I still have a way to go, but I'll do it. You can believe that!

<u>In 1999</u>, following two back to back surgeries, I developed a very rare neurological syndrome called <u>Capgras</u> (<u>Capgrah</u>) <u>Syndrome</u>. This can occur to a person, generally <u>after</u> a brain injury, who is <u>lucid</u> but suffers from a <u>misidentification</u> of someone who is usually a close relative or loved one.

In my case, my delusion happened to be <u>my wife, Joan.</u> I thought she was a former co-worker, whom I really <u>did not admire or respect.</u> The feeling was mutual, I might add, so it was bizarre that I had this delusion between the two women. None of my doctors could figure out this delusion, as Joan would be my wife for a few minutes and then switch to this other woman. I even made her sleep in another room, because I thought that "my wife, Joan Callahan", as I called her, would be very hurt and upset to find "her" (I also called her "Joan".) in my room. I became very fond of this woman "Joan" because she was very kind and good to me, but I was always in love with "my wife, Joan Callahan" and told everyone that she was probably in Philadelphia going to law school.

My neurologist, with the help of his partners, found a reference in a psychiatric textbook to Capgras (Capgrah) Syndrome and that was how I received the diagnosis. But none of my doctors knew anything about this bizarre delusion from which I was suffering.

Our daughter, <u>Victoria</u>, went on the Internet to see what she could learn and found a doctor in Australia, who is a specialist doing a study on just this subject. Victoria e-mailed her and told her about my problem, and she set up a phone interview for a few days later with "my wife, Joan Callahan". The doctor spoke to the department heads at the hospital in Sydney and plans were set for her to come to the U. S. to meet, interview and work with me for a week. There has never been documentation of anyone suffering from a delusion like mine where a person would switch from one person to the other hundreds of time in a day. It has only been documented with people suffering from this type of delusion to see the person as an imposter.

This delusional thinking lasted for <u>nine</u> months, and <u>nothing</u> my children, physicians or anyone said to me could change my mind. It was a very painful time for my wife, Joan and our children. Shortly after the doctor went back to Australia, my delusion cleared, and that helped me come back to reality and my normal thinking.

The daily activities of <u>personal care</u> I used to take for granted have taken a great deal of effort to relearn. I still need help with showering and dressing, and I am unable to drive due to seizures, which is the result of my brain injury. I am now able to use my credit cards and can figure out tipping (I use a tip card.) for when we eat out so that I again feel I am "in charge". I have also learned to use currency so that I am able to make cash purchases. I have had to relearn simple

addition and subtraction, and am in the process of tackling multiplication and division.

I have had <u>16 major</u> surgeries <u>and</u> continue to keep moving forward. God isn't finished with me yet! Joan calls me 'Miracle Man"!

I work with a therapist in an adapted aquatics program twice a week and also exercise with my caregiver, Edna, twice a week. With the help of Michelle Thyen, the Volunteer Coordinator at Brain Injury Services, we identified volunteer opportunities I would enjoy.

- I read books to 22 four year-olds at the local YWCA every Friday morning and I LOVE IT!!
- Every month, I take a brain injury survivor to his Community Center for activities and lunch.
- Joan and I do volunteer work for Hospice from home. We prepare packets
  of information for prospective clients, stuff envelopes and label letters and
  pamphlets for mailing.
- We also do the same type of volunteering at the Dominican Retreat Center.
- And lastly, I help Joan make sandwiches for the homeless.

This plus 3 children, their spouses and seven grandchildren, and Joan's 94 year old mother, Nana, keep Joan and me very busy. I've lost 90% of my hearing due to the accident, and now wear digital hearing aids and use an additional transmitter with microphone to enhance my hearing and am hopeful in being able to learn to read lips.

I had surgery last October to reconstruct my frontal skull as it had collapsed. The surgery was successful and my brain is once again protected, but I ended up deaf in my left ear, so I am feeling very isolated and frustrated because I am virtually unable to hear anything even with the special hearing device and fancy hearing aids.

I also have <u>Parkinsonian</u> Syndrome caused by the brain injury which causes my right hand to shake so much that I am unable to write and it makes eating quite difficult. It takes courage to eat out in public at times, but I will never give up! I am now using my left hand in eating and am doing pretty well, if I might say so myself! When I hold a book or paper, it shakes so badly that I have difficulty reading. I usually prop it on a lap desk pillow, or use this small stand or rest it on a table. (Today is the first time I've tried to give my talk without Joan's sitting next to me and helping me with my cards.) I am unable to write with my left hand, however. I have optic nerve damage to both eyes that affects my vision, also caused by the injury.

My family was told that the window of recovery for a man my age, I was 66 at the time of my accident, is 6 months to one year.....wrong! I continue to make progress and amaze all of my doctors. It is our belief that many people are left in nursing facilities and are given little or no hope of recovery. All of us here today

are proof that though our lives have changed dramatically, we can have good quality to our lives and be an asset to our families and communities.

It has been a long journey, and the most difficult part of this journey is not being able to practice law. As I said previously, I was a practicing attorney for over forty years, and it has not been easy to walk away from a career I loved. I thoroughly enjoyed every aspect of the law! The other thing that I really miss is my inability to drive due to a seizure disorder, which I mentioned previously. I REALLY miss driving!

A residual problem I have is not being able to control my <u>temper</u>. I go from calm to rage in seconds with absolutely no warning. It saddens me to tell you that only Joan bears the brunt of my anger. I am trying to control this, but have not been very successful.

Because of the tremendous need for the guidance, knowledge and help provided by Brain Injury Services due to the huge number of brain injury survivors needing their services, they are sorely overworked, understaffed and run on a very tight budget. Their financing is made up of funding by the state government, fundraisers and private donations. I ask you to consider making a donation to Brain Injury Services, which in turn helps so many survivors lead productive lives.

The message I would like to leave with you today is "Never give up....persevere!" Things are never as bad as they seem. Ask God for help, but remember, He expects you to do the leg work! Thank you for your attention and for allowing me to share my story with you today.

Questions ~