# I Want to Try

## A Biographical Account of a Trail Blazer

As told by J. Fred Stack – husband, friend, advocate and supporter.

Those are the words, “I want to try!” Glory expressed regarding actions to take for the biggest struggle of her life. Those words came easy for her, as I am sure she felt them many times throughout her life. This is the story of that enormous struggle and some of those events that helped prepare her for it. It is hoped her story will inspire others to overcome the obstacles they face with determination, assertiveness and kindness as exampled by Glory.

Born December 18, 1953, Glory Ellen Sumka, was destined for struggles as she would have to compete with her Savior Jesus Christ for attention at each of her birthdays. This was one competition she was happy to take second place.

When Glory was two she was caught up in a local pediatrician/pediatric surgeon scam. The pediatrician would diagnose “cardiac issues” in what later was found out to be hundreds of children. They would all be sent to this same pediatric surgeon, who upon subsequent investigation, would open the chest, do nothing, then suture them closed. Her dad took her to the surgeon, but something at the time did not sit right with him and he refused to subject Glory to that surgery. Years later, the Cook County DA indicted both on fraud. Unfortunately, the medical reports were incorporated into every child’s permanent record. Why do I tell you this?

Glory always wanted to be an astronaut. She applied to a NASA Junior Space Camp and was rejected…due to a non-existent heart condition. She was extremely dejected but eventually moved on.

Her adolescent years were not well recorded, so we do not know what events helped to give her high degree of confidence in accomplishing whatever she set her mind upon. But we have a few indications. Glory is left-handed, but when she went to school the teachers demanded she only write with her right hand. This requirement lasted until partially through her third grade. She is now ambidextrous. For most sports she was right-handed, but she wrote with her left.

We also know Glory entered two science fairs while in middle school. She came in second place with a project demonstrating the controllability of electricity. The next year she was determined to try again. Her presentation was on rocket propulsion — a new liquid fuel. This science fair was a big deal with city aldermen in attendance. Her presentation included a live launch out in the parking lot as well as a Q&A at her booth indoors. She won 1st place as well as referrals to NASA Space Camp. Glory was ecstatic as she had a desire to be an astronaut someday. Attendance at the Space Camp would open doors for her. NASA wanted her, but later withdrew the invitation when they learned Glory had heart issues.

(false info)  Appeals of this rejection were never accepted. Glory was devastated, but eventually moved on.

In the mid 60's there were few opportunities for girls in sports, but Glory was a star softball pitcher, and her bat was impressive.

On a more challenging event, she transferred high schools from Illinois to New Jersey after her sophomore year.  A difficult prospect, especially for a girl.  She did not let the change slow her down as she obtained a summer job via Kelly Girl Services during her Sophomore, Junior and Senior year summer breaks at Johnson & Johnson, Supermarkets General, AT&T and Sears.

She started her freshman year at college, at Bowling Green State University majoring in Pharmacy.  While she did well during her first semester, her year was cut short when her father had a heart attack.  Glory transferred to Middlesex County College with a major in Engineering Science for two years.  I can only imagine her saying "I want to try!"  as people advised her she would be better off with a different major.  It was then off to Rutgers University with a major in Mechanical Engineering.  She was the only female engineer in her graduating class. During her senior year at Rutgers, she was selected to join a National Student Competition Team.  They designed and flew a small plane utilizing a VW engine they modified to handle the requirements and g-forces of flight. One member of the team was a certified pilot. They took 1st place in the competition beating MIT.

On 7/7/77 Glory joined the Technical Marketing Program of General Electric. She always felt her start date was a lucky day. She started in an inside sales job for the Industrial Sales Department in Millburn, NJ. She focused half her time helping the turbine sales team to prepare their presentations and presenting data for Exxon's coal gasification study. After three months she requested a transfer to the Gas Turbine Marketing group in Schenectady, NY. She was told this was not really a career for a woman. She said "I want to try" in many ways and with such determination they gave her a position first with the domestic sales group and then promoted her to the International group. She won the SELL, SELL, SELL Award from the Gas Turbine Division. The award was a set of cuff links made to resemble Gas Turbine blades. They had nothing more befitting a female. I, (her husband) wear them proudly often.

In 1980, Glory got married to a luck guy — me. At our wedding I heard her say "I do!", but some have told me she said "I Want to Try!" We were married for 40 wonderful years. That also resulted in a move to Houston as a Turbine Sales Engineer covering nationwide and International customers. She was recognized as being instrumental in a large Aramco project that included her escorting an Aramco team to England to tour and become technically comfortable with an aircraft derivative turbine project. She was the only technical expert assigned. She thrived on a challenge. Yes, they got the order.

I recently found an old letter from her boss in Houston. He was trying to convince her not to resign. She was apparently very upset. She had found a new potential customer for GE turbines. She worked with this customer for over a year, but when she put in her monthly report information about the $65 million job she felt she would close within the month, the boss assigned a more experienced salesman to the account. They got the order two weeks later. Her boss committed to spread the word that she was the one responsible for the order.

Glory's career continued to grow and expand into new, very diverse opportunities. She worked for GE's VP of Industrial Sales as a strategic planner including efforts to develop a Strategic Account Management System, a sales forecasting system and automating sales planning and reporting. She enjoyed the challenge of taking on something new.

We then moved to Wisconsin, near Milwaukee, where Glory started as a Product Manager for a large industrial corporation specializing in hydraulics. Glory tackled the different technology with ease, the bigger challenge continued to be working in a man's only world. One of the product lines she was assigned was the Dicky Nut Splitter. I thought it was a joke, but Glory took it in stride, focused on how to succeed. Today, that product is still the standard in the construction industry for replacing old roadside guardrails.

After several years, Glory was ready for something new. She set her sights on starting her own business. She bought a franchise whose business was home decorating. Yes, Glory had an artistic side as well as her engineering. There were a dozen new franchises that year nationwide. Of that dozen who attended a training session in DC, Glory's was the only one still in business a year later and her profitability ranked in the top half nationwide. For her success she found a new market niche in addition to the typical family home market — serving large corporations in fully furnishing apartments for visiting expatriate families.

Glory sold her franchise and moved back into the industrial market becoming the manager for training at the world leader in programable controllers for the factory. Can you hear her say "I want to try something new." I do not know the specifics of her successes in this new endeavor, but I am certain they were many. Sadly, this was also the time that Glory's dad died of a heart attack. Glory's mom moved in with us and Glory took on the role of caretaker. We moved to St. Louis and Glory filled her time outside of caretaker in several different ways. She started a group to train other house wives on how to invest with intelligence in the stock market. They met weekly and she learned and then shared how to investigate and evaluate various companies for investment. There were about a dozen in the group. Glory was very successful. I was an executive in a Fortune 500 company, but she made more money than I did.

When we moved to Dublin, OH (near Columbus) Glory's time became more and more consumed with her greatest challenge. Her mom was coming down with Alzheimer's. Glory struggled in this support role with her mom in our home for nine years. Eventually her mom had to go to a nursing home where she passed a short 9 months later. Even with this extra burden of duties, Glory also had various volunteer efforts, most in the church, but the one that captured her attention and inspiration most was the local city arts council. Not as an artist, but as one to assist in raising funds. Eventually she became the Director. The artists (about 12) all worked for her and she helped in motivating them and coordinated several art exhibits to raise money for the artists as well as projects for the city. Glory then took up the game of bridge and became an expert, almost reaching Life Master in record time. I should also mention her dedication to God as this was the foundation for much of her success. She loved her bible study group and made sure we visited many religious sites around the world — Fatima, Jerusalem, Medjugorje, Lourdes and Rome.

The year 2019 was a challenge for Glory. Glory had struggled with neuropathy in her right foot for over ten years. This is the year the neuropathy spread to her right hand. She could no longer hold her bridge cards in that hand. Thus began an aggressive investigation with doctors and other specialists as to the cause. Just before Thanksgiving she learned she had a protein in her blood that was spiking at ten times the proper level. This protein is normal. The body uses it to attack your nerve ends near an injury. It deadens the nerves and helps to minimize the pain. The problem was, at ten times the concentration, it was attacking her nervous system with great force. The Doctor believed the cause of the protein spike was Waldenstrom's Macrobulinemia. This is a non-Hodgkin's lymphoma cancer that resides within the bone marrow. The decision was to do a bone marrow biopsy after Thanksgiving to help determine the proper chemotherapy to control the protein. At the same time, they would do a full body scan to check on all her lymph nodes to see if the cancer had spread. Glory got the results on her birthday, December 18. Her bone marrow was normal and all her lymph nodes were clear. She did not have cancer! We went out that night and had a big celebration. The radiologist did see something abnormal at the top of her spinal column and advised an MRI asap. The results of this was the discovery of a tumor at the top of her spinal column, draping around her brain stem. It is called meningioma. It is common in people over 60 and often is just left alone. Only if there are symptoms like headaches - or like Glory - the location is in a bad place, they elect to remove it.

Glory elected to proceed forward with the operation on January 7, 2020 as recommended by her doctor. It was reported to normally be very routine lasting only 3 - 4 hours. For Glory it was 12. The good news is the tumor was not malignant. The rest of the news was not as good as hoped.

The tumor started in the spinal column and grew out toward the brain vs the reverse. This means it is very compacted in the spinal column. It also did not have a separating membrane around it to keep it separate from the spinal cord. Thus the doctor could not get it all out. Like an ice cream cone. He got the top but not all that is in the cone. Too dangerous to go deeper. Normally this type of tumor is like a bowl of over cooked spaghetti swimming in butter. Grab a strand and pull and it slowly comes with no negative effects. With Glory the spaghetti had hardened. They tried to scrape it out piece by piece.

Glory lapsed into a coma. Significant swelling on her brain required them to tap a 1/2 inch hole into her scull to relieve the pressure.

Today, Jan 11, was a great day. At 7:00 am Glory was up and bright eyed. She was eager to communicate with yes/no blinks. Latter this morning she had a surprise visitor from her bridge group and you could see her try and smile around all those tubes in her mouth. She was overwhelmed with joy. Later when another friend called I put the phone to her ear for 10 seconds or so and again joy burst onto her face. This afternoon a third visitor arrived and although you could tell she was getting tired she repeated her happy welcome. She still can not breathe on her own or move anything else below the neck. But her brain is definitely healing. We are communicating with yes/no blinks of her happy eyes. Only need time and help from God for a full recovery. Glory is anxious to try!

One of the nurses gave me a book called "The Diving Bell and the Butterfly" by Jean-Dominique Bauby. It is about a journalist in France who suffered a stroke that injured his brain stem. He was paralyzed from the neck down, like Glory, but he wrote this autobiography by using blinks and a white board. A friend would read the alphabet to him and he would select the letters he wanted and she would write them on the board. The book explained what he was thinking and feeling while trapped in his body. He spoke of how this new life of his changed over time. First craving visitors, but later understanding why they never came around anymore. Today is one week from the operation. Glory's mind is 100%. We are now communicating via the "white board". Getting full conversations, although it is slow and tiring. Glory says I am not allowed to get tired as she wants to keep trying.

There is no sensory feeling or control below the upper neck. She is on a ventilator. Also her eyesight is very poor. She has Nystagmus, or dancing eyes. This means they vibrate left to right making it hard to focus. She also has a severe case of Strabismus. The opposite of cross-eyed. This means she has double vision. I bought her an eye patch that we move back and forth to try and eliminate the double vision. She looks like a pirate. I don't think she likes it. The belief is the remaining tumor is still swollen and is pinching off her spinal cord. Once the swelling subsides, we hope for a full recovery. For now she remains in the ICU at Mission Hospital in Asheville. This is a waiting game.

Ten days from the operation we learned from an MRI the swelling is still significant around Glory's medulla a part of the brain stem. There are also signs of damage to her pons. The Pons is the brain area that controls eye function, mouth and sleep functions.

Doc says they can make her more comfortable by putting the ventilator tubing through her trach and feed her with a tube to her stomach, not thru her nose. But he does not believe she will ever have motor function. Have to decide with Glory what she wants.

Glory made the decision that she wants to continue this fight even though all the doctors have stated there is no chance for a return of her mobility skills. Glory decided she is not ready to give up. The words she had me write on the "white board" were "If Charles can do it, I want to try" She is referring to Charles Krauthammer. He was a brilliant young man in medical school when he suffered a broken neck in a swimming accident. He went on to write books and become a news commentator. He obviously inspired her. Tomorrow they will preform an operation to move the ventilator from her mouth to a more permanent location on her throat. They will also move the feeding tube from her nose directly to her stomach.

They have already begun the process of weaning her from the drain they placed in her brain.

Once she has fully recovered from these surgical efforts, we will transport Glory to a nursing home. This will probably be next week or the week after.

It is true that Glory has not shown signs of improvement, and she is essentially trapped in her head with very poor sight, but excellent hearing and a very sharp brain, she has fought off despair and will continue to fight for that miracle.

Today Glory had 15 visitors including Fr Cook who gave her the Sacrament of the Sick and prayed several prayers with her.  She was tired with all the attention, but I believe she loved it.

Glory's operations today to move the ventilator tubes and the feeding tube were very successful.  You can now see her whole face.  Except somehow they managed  to have her bite her tongue as they transported her from the gurney to the bed.  Her tongue is swollen so large it will not go back into her mouth.  The good news is her eyes are big and bright again.  You can see her smile when you crack a joke and when we told her the Packers lost she pushed out her lower lip even though her tongue is so badly swollen and protruding from her mouth.  It is truly a joy to see her smile.  Other progress continues to be a waiting game.  I am hoping she can get her diaphragm working soon so she can cough and clear her lungs.

The respiratory therapist had some good news for us. She had just tested Glory without the ventilator, Glory failed.  But then she put the ventilator into assist mode. Glory had to generate enough suction (14 psi) to cause the ventilator to turn on and provide the required volume to fill her lungs.  In other words Glory was breathing on her own and the ventilator was helping her.  Her diaphragm is working !!!  It just needs to build its strength.  After 20 days it was beginning to atrophy.  She had interesting conversations with several visitors, although yes/no makes it one sided, you would be amazed how much info can be shared.

She is communicating full words and sentences with me using the "white board". She told us where she was uncomfortable and even asked for an ice-pack on her neck. This communication is tiring for her, but it gets better every time. They also moved her to a lounge chair for two hours today. She looked like a queen just sitting there looking around.

Tomorrow I get the report from the full medical team. I anticipate great optimism.

They tried to move her to her chair this morning, but had to abandon the effort due to low blood pressure. Medicine has corrected that. They have finally inserted a hard plastic "cigar" in her mouth to protect her tongue. She has severely cut her tongue with her teeth, both top and bottom. Now it can heal. I expect significant improvement tomorrow.

Today I spent significant time researching augmented communication products. Getting bids from three companies. Eyegaze, Talkd to me technology and Tobii. Should have responses and a decision by the end of the week. The first vendor arrives tomorrow. (e.g. Computer reciting the words she types with her eyesight.)

Today was a very busy day.  Glory stayed awake for 90% of the day.  Glory's tongue has fully receded back into her mouth.  She is now mouthing words, It is my challenge to understand them.  She mouths "Hello Mary or Hi Steve" with the correct name to all who came to visit.  I even recorded a video of Glory saying "Hi Mom" and sent it home.  She does not want any pictures posted, so you have to visit her to see her say Hi.  To learn how she says various words I have had her practice saying numerous colors and numbers.  I have a lot to learn.  I use the white board to spell out words I can not understand.  One time she said and spelled out "Can I have a special dinner for Super Bowl?"  Still has a great sense of humor.  She also asked a lot about her condition.  Once she said or spelled "My brain is dried out?"  asking about the swelling she had experienced and wanting to know if it was gone.  I'm sure she expects when the swelling is gone she will start to recover.  I lied and said I did not know.  Many fun discussions, but also tiring for her.

Also, one company came today with their "eye gaze" technology.  Sadly Glory's eyes flutter too much and do not show sufficient up/down movement for the system to work.  Several nurses tried it and it is remarkable.  People have been able to type 40 words per minute just with eye movements.  And then the machine just speaks what you type.  Play games, do email, surf the web.  Amazing.  So I am now looking at the "old" technology that requires sensors on the skin to measure eyebrow or jaw movement.

These are called switch technology.  Slower but still effective.  Only one company still doing the old technology as the eye movement technology put the rest out of business.

Today is February 2.  Glory has been sleeping constantly for days.  She did wake up once today and asked for the white board.  She then spelled out "Heart worm Challis".  She was reminding me to give Challis, our dog, her heart worm pill.  We always do that on the 1st and I had forgotten.  She knows me well.  And always thinking.  She also would wake up for about 5 minutes each time someone stopped in to visit.  You can see her lips say hello and your name. as well as Thank-you when you tell her how good she looks.

Today, Glory woke up as visitors arrived and said Hello as well as some other simple statements, but mostly slept.  They did tell me she has a bacterial infection in her lungs and is on an antibiotic and other meds to combat this.  She also has a slight fever.  All this is why her body wants to sleep.

About 3:00, after her PT exercises and transfer to a chair, the respiratory specialist and speech therapist arrived and wanted me to stay while they performed some tests.  First they set up the ventilator to oversupply air to force it out her mouth.  They told Glory to speak.  It started slow and they are very quiet whispers, but she spoke.  On command she said Yes and No,  And then "Hi

Fred"  All great first steps in getting her to exercise her vocal cords.  Then they turned the machine to assist mode.  If she did not breath it would kick in.  First there was one breath,  then a long wait for the second.  Then a third, then every other breath was her.  Then she was 100% on her own for 8 minutes.  They put her back on the machine so as to not wear her out.  They will do this more tomorrow as they try and strengthen her diaphragm muscles.

One month in and Glory had a good day.  She was up most of the day with over 5 hours in the chair.  Looks like a queen.  They were not able to try and let her breath on her own as she was having difficulty breathing with all the mucus in her lungs.  She was also in a lot of discomfort today, complaining of being too hot.  Her actual body temp is a degree below normal and I have ice packs on several parts of her body.  Her brain stem is just confused.

On the good news side of the equation, Glory has learned how to make smacking noises with her mouth to get my attention if I try to read a book, or my phone. This gets me up doing the white board drill. Always interesting conversations.  She now tells me to rub her legs. Not bad for someone who can not feel.  She also has developed a reflex twitch in her left leg and foot.  Signs of progress???

Had a second vendor in with an eye gaze technology. We were failing again with the ability to calibrate when Glory asked for the White Board.  She typed "My

Glasses." as she could not see well, I explained I did not bring her glasses so she tried mine. Trifocals but with a 2.5 for reading (the rating of her reading cheaters). This was not working so she again asked for the White Board and said "Glasses in the Truck." Dummy me forgot we always kept a pair in the truck. With the cheaters Glory was able to calibrate the left side of the screen. The vendor promised to customize a screen to the left half only and give me a 30 day free trial. It is on order and due in before the end of February. Miracles are coming. With exercise the muscles in her eyes will get stronger and she will have the full screen available (per Doctor Fred). Even the angels are crying now!!!!!!!!

Recovery is a rollercoaster. Even Glory can fall into a state of despair. She is struggling with another bought of pneumonia. This caused the pulmonologist to refuse to let the nurses try and wean her from the ventilator. Also no practice speaking with her vocal cords. She was up most of the day, but complaining of wanting to through up. Her blood pressure also continues the up and down chase. Communication was also difficult as she no longer likes the White Board and wants me to get better at reading her lips. She can be persistent. She is also having difficulty maintaining her CO2 and PH levels in her blood. This is caused by difficulty with breathing even with the machine doing all the work (The infection in her lungs is creating the problem.) Her temperature is often above 102.

After only two days of depression, Glory was up, bright and cheerful most of the day. She enjoyed lip talking to all visitors. She was feeling very good today, no fever, white blood cell count dropping (infection is getting under control). The biggest thing though was her smile. She was happy! It was infectious. She had her spunk and assertiveness back.

Yes Glory actually got angry with me as I could not understand what she was lip saying. I just could not understand. She was saying "I want a Pen" Once I understood, I asked what she would do with a pen. She said I want to write with it. I mentioned this exchange to the doctors and nurses when we had the morning group meeting. They immediately said we need to get her a pen to see if she can use her mouth to write. When I told her what they said she smiled and said "Yeh! Yeh! Yeh! Yeh!" She was so happy!

Sadly, with only tongue motion to move the pen, the pen idea did not work. But she really is trying. I will close with Glory's instruction for me as I left this evening. "Bring my Computer tomorrow." I think we will try and go through her email some how.

Two days latter was another setback. The Neurologist told Glory it has been too long with no progress. She will never have any mobility again and she will never be off the ventilator. Although he was surprised and pleased with her control of her facial muscles and mouth. He pulled no punches. Needless she was disappointed, but demanded they test her again without the ventilator. She failed. Three hours later she demanded they try again, again nothing, Then at about 5:00 she wanted another try. She got one breath. She then asked me not to leave her that night, so I stayed. Yes she is scared.

In the morning she did not wake until about 8:30. After Hello, her first words were "When do I get to try and breathe again?" That happened about 10:15. She got 4 breathes over about 3 minutes. She then got to see several great friends and was all smiles. At about 2:15 she demanded another test. She then breathed on her own for 10 minutes. After that she was very tired and complained about pains in her chest. And then asked we delay the next test til tomorrow. The next day tried again, twice, but failed. She complained about "lung pain". I am sure from yesterday's workout. I should clarify yesterday's success. The machine normally is set to provide 40 psi at a rate of 15 breathes per minute. When I say she breathed on her own, the machine monitors when she decides to take a breath and then assisted with 16 psi to help her overcome the resistance of the machine. She only did 9 breaths per minute, but kept her "total volume" near 600 where the machine would hold it when it was in control.

She is craving companionship to stay out of despair and asked me to stay until at least 9:00 tonight,  I will.

As the days progress, Glory continues to fail at her breathing tests.  She keeps asking for Lucy the night shift "lung doc".  Glory believes Lucy is her last hope to breathe.  On a positive note, the speech therapist coached Glory to actually say some words on her own as well as clear her throat.  Her most memorable words were "Fred, I love you"  numerous times.  This talking lasted for over 5 minutes, It wore her out.  But also cause her blood pressure to drop to 52/34.  Glory maintains her hope.  Always wanting to try something.

Today had some challenges for the doctors as Glory's blood pressure had a low of 42/31 in the morning to a high of 207/98 two hours later.  They are trying different meds to try and find out how to stabilize it.  Obviously these up/down pressures make Glory very tired.

The good news was by early afternoon it was running steady at 135/80 and they gave me permission to go get Challis, our dog, as Glory had been asking for her for the past few days.  I got her and both Challis and Glory loved it.  Both smiling as happy as you can imagine.  All the nurses on the floor also loved Challis.  They also reversed the ventilator and closed the cuff to allow Glory to speak to Challis.  Very raspy voice, scared Challis at first, but then she just listened attentively.  Challis stayed with Glory for a little over 2 hours.  FYI they have also decided that one of Glory's vocal cords is paralyzed, thus the raspy voice.

February 23  was a remarkable day.  Glory was so happy to see so many good friends visit.  She was beaming a broad smile for so long her cheeks had to be sore.  She also breathed alone today with the machine only providing a little extra pressure after she initiated a breath. The nurse then cranked up the volume to try and force the air out Glory's mouth and across her one working vocal cord.  She did this for 31 minutes.  She ran out of things to say (Cant just say "Love you Fred "all the time) so she started to sing.  First it was Glory Glory Hallelujah, then 99 bottles of beer, then Brown Cow… and on and on she went.  What a show.  During all this her blood pressure and pulse remained very good.

She was so happy today.  Thanks to all that visited. You made the difference.

Tomorrow we will start a new month. Glory's roller coaster continues. Her heart is having many difficulties. Very low blood pressure 46/38 that did not respond well with the medicine.  This and a pulse rate in the 40's wore her out.  She was only able to stay awake for 10 minutes while with Challis over 3.5 hours.  Challis still enjoyed seeing Glory and laying on the bed with her.

As we enter March we started an investigation on a new treatment opportunity suggested by a good friend

Attila Poka. Thanks to all who kept forwarding messages until they reached him.

Tomorrow, Glory goes back to Mission Hospital for tests on her phrenic nerves to see if she qualifies for a Diaphragm Pacing stimulation device. They apparently had discussed this option early on, but then Glory got pneumonia. This approach is specifically for patients with upper cervical spine injury. Those with injuries above C2. Glory's is above C1. If Glory's diaphragm is strong enough this would allow her to get rid of the ventilator. Breath and eat on her own. Obviously after much rehab.

The answer from Mission regarding the tests on her phrenic nerves to see if she qualifies for a Diaphragm Pacing device was "given Glory's complications they do not have the proper experience. They have made referrals to Duke and UNC Charlotte." I hope to hear their answers tomorrow or Thursday.

Thursday, Glory gave a real scare to the staff at ASH. Her BP went from 170/85 to 40/??. They were calling for this stat and that stat. Lowered her head below her feet — quickly administering fluids. They got her pressure up to 135/65 very quickly, but it took almost an hour for her to wake up, even with shaking and yelling at her to wake up. They said her brain was not perfusing. She was fine this afternoon, except very tired. We also heard today from Duke, Wake Forest, UNCC, Emory and Sargent (in Atlanta). None accepted Glory for Diaphragm Pacing stimulation. Many stated they no longer initiated that function although they did have patients that began the procedure elsewhere.  Others stated Glory did not qualify because she has not been infection free for 3 months or concern about her BP instability.  We have a few more Universities / Hospitals under consideration.

I was waiting for some good news.  AND WE GOT IT TODAY! March 11.  University Hospital Cleveland has agreed to accept Glory as a candidate for the diaphragm stimulation pacemaker.  No guarantee it will work since it has been over two months, but they agreed to try.  Got bids today for an air flight ambulance to fly Glory to Cleveland, Ohio on Monday.  Provided we have no complications with Glory's blood pressure we are all systems go.  Glory is smiling again.

Well Glory and I are currently in Cleveland, OH.  She is at University Hospital and I am finally in a hotel.  It started with a call after midnight Saturday stating University Hospital had a room opening up.  We scrambled and got an Air Medic Taxi out of upstate New York that was heading back to their home base in Arizona.  The flight was less than an hour, but when we got to the hospital at 7:00 am, they did not have Glory on their list to be received.  Apparently the invite was withdrawn due to the desire to reserve ICU beds for COVID 19 patients.  But ASH did not get the word until after we left the building. They ignored this with the excuse they did not know how to contact me or the ambulance. Yes Glory got admitted and this place is truly amazing. The facility, the equipment, the people. Truly amazing talent. I spoke with the doctor who will perform the operation tomorrow at noon. He is the inventor of this procedure. It was exciting to hear him talk of his hopes and expectations for Glory. We should know within 48 hours of her long term prognosis to eliminate the ventilator and stomach tube.

Glory did the plane ride perfectly. Her BP was stable the whole way. She anxiously awaits tomorrow.

BTW all restaurants have been closed here and hotel guests are being restricted to 50% of capacity. The two LTACH hospitals that Glory would go to in 2-3 days are being allocated to the COVID-19. This means a longer stay at UH and then a return to ASH for rehab. Another Air Medical Taxi.

I sure am glad we got here today. Our luck was certainly great that time.

Today was a good and productive day. Glory's BP was stable all day. never dropped below 90 and never above 150. She was also very talkative, challenging all the nurses on their ability to read lips. They are all falling in love with her.

Yes she had the diaphragm pacer installed. Her diaphragm is twitching, but is very weak. Tomorrow starts the exercises that will determine if she will get strong enough to wean off the ventilator. First estimates is it will take months. She will stay here in the ICU at University Hospital for at least 4 days while they determine an estimated progression. Then on to an LTACH. Either here in Cleveland or back to ASH. They are expecting ASH as the beds here in Cleveland are being locked down due to the Virus. Note all restaurants are closed (except the drive-thru's) as well as some de-populating of hotels. I have reserved an Airbnb room for $30 per night for a month.

One other test they did for me today was an electrical test to determine the continuity of the nerves between Glory's brain and her extremities. This will define the possibility of any improvement in Glory's motor skills. They will share the results tomorrow.

The electrical test done yesterday to see if the nerves between brain and extremities were still intact came back negative confirming our fears that no mobility improvement will be possible. The nerves were severed in the operation. The good news is the diaphragm pacer is working and Glory's diaphragm is stronger than they thought. This first baseline measurement is very encouraging. The pacer is now on 100% of the time giving her diaphragm much needed exercise.

She also got to try a voice box. This is an easier way to exercise her vocal cords. She should be doing these vocal exercises at least twice a day.

Yesterday I made a terrible mistake. I agreed to transfer Glory to a local LTACH (Long term acute care hospital) called Grace Hospital after ASH refused to take her as a transfer. ASH were fearful of a patient with a device with which they were not familiar, even though I explained that I was fully trained on it. And it is very simple. Anyway the new place is nice enough, except starting tomorrow they are implementing a new policy of no visitors, no exceptions. I am trying to get permission to take her home and wean her off the ventilator myself. UH trained me how it is done in a home setting. Now the challenge is to convince the doctor at "Grace Hospital" to agree to discharge her. That fight starts on Monday as he left at noon today prior to the policy change.

One other problem is another LTACH here in Cleveland was closed to all but COVID-19 patients on Thursday. All other patients were transferred to Grace, as well as the RN's'. Problem is the nurses did not show up today. They are on strike. Thus very understaffed. Some that were there were very upset when I helped turning Glory or suctioning her or other "nurse duties" This is a Union shop.

So I was escorted out. In my Airbnb, wondering what to do this weekend. Or next week for that matter. Glory is scared and I am pissed.

Other news on Glory is the Diagram Pacer is doing wonderful. She is now on it 100%. They will just slowly wean her from the current support level of 15 psi down to 5, which is as low as you go. After that the next step will be turning it off. They did run it at 10 psi for 7 hours to see how Glory tolerated the extra work. She did great. Questioning her BP? I do not know this place does not monitor it. Not even with a manual hand pump version. Pray they let me take her home soon.

Well today was the third day of not being able to see Glory. The room only has a land line. I tried to get the nurse to let me call her personal cell. She said no; so I could not talk to Glory. Only got a report that she was doing fine, but not very talkative. They did not seem to understand that she can not talk. Also they had not yet started weaning her from the ventilator. Waiting for the pulmonologist to arrive, he was out all weekend and they did not know when he was coming in. The nurse that understood the pacer was transferred to another hospital where their were COVID patients that needed her help.

After many days of struggle, never seeing Glory and seldom getting to talk to her, I got her transferred to Regency Hospital in Greenville, SC. She was so happy to see me as she exited the hospital on the gurney going to her ambulance ride to the airport.  Steve, my best man from our wedding 40 years ago, helped me by driving me, first from my rental car return to the hospital and then to the airport following the ambulance.  The nurse in the ambulance said Glory could see me in the car following them and was blowing kisses the whole way.  The flight was smooth and uneventful.  I got to ride in the ambulance to the hospital and snuck my way in with the ambulance crew to Glory's room #424.  Once there, I was overwhelmed.  Every one kept coming to see Glory and asking all kinds of very good questions.  It was obvious they had read the info faxed down by Grace Hospital and UHC.  It was wonderful to have so many people stop in to discuss the why's and how's of Glory's treatment so far.  There were two respiratory specialists that were very familiar with the diaphragm pacer and were studying and analyzing the detailed data sent by Grace. The Pulmonologist came in from his day off to see Glory and talk to me!  The head doctor spent 30 minutes with me discussing everything.  He already knew most of the details, dates procedures, prior treatment ups and downs,  He was just looking for clarification on some missing links.  The discharge case worker stopped in to go over the details on what our hoped plans were for as things progress.  A Medicare benefit specialist stopped in to explain in detail what was happening with Medicare and my supplemental insurance coverage.  Good news we have 66 days to work toward the next step.  A deadline that we will surely beat by a mile.

What a thorough and organized experience.  I finally got Glory to where she needs to be.

April 1, not much to report today, except I am truly enjoying being home with Challis.

Glory has had a more difficult time as they found she had pneumonia upon arrival.  Yesterday it was as if she put herself in a coma to heal herself.  Today she was more alert, but not lipping.  I have not seen her lipping since she moved to Grace Hospital.  This COVID lockdown has really negatively impacted her.  She is also 100% on the ventilator to assist her recovery.

Glory took four days to beat the pneumonia this time.  On the video she is always smiling and tries hard to communicate.  I admit I have gotten worse at reading her lips due to less practice, but she keeps trying.  Also the video quality on FaceTime of Zoom is far to jumpy to read lips.  I miss the white board to fill in the blanks on the words I miss.

They also started weaning Glory off the ventilator on Friday.  I do not know how aggressive this restart has been, but will find out more details on Monday.

Sunday the nurse forgot her iPhone so I tried talking to Glory on a regular land line with the nurse trying to translate Glory's lips. That was tough. Yesterday was tougher as I never got a call from her room. Only the liaison who is off site and tries to read the reports from the nurses. Today we got to try a FaceTime. Glory looked beautiful and peaceful, but they could not wake her. The pneumonia was never cured, they never took her off the antibiotic, but her temperature was up to 101 and her WBC is now 19. They have had to stop weaning her from the ventilator as she is too weak to get a full breath even at the very high support levels. She needs to sleep to fight this on her own.

Happy Easter to all of you. I do not have much news today as Glory has continued to sleep all day. I think she is preparing for a big day tomorrow. Our 40th Anniversary! I plan to go to the hospital bearing thank you gifts for all the medical staff as well as some decorative balloons for Glory's room. I am secretly hoping they let me sneak in to see her. I know the odds are not good for that, but I am hoping.

They would not let me in the hospital today, but they did get her on FaceTime for a long time and they moved the bed around in the room so she could see me in the parking lot. She could hear me yelling and screaming, and yes even singing through the phone while I waved and jumped up and down out side. John Fair went with me. I think I embarrassed both him and Glory with my singing. They said she really enjoyed it and was blowing kisses.

The other good news is yesterday was a great day for her weaning from the ventilator. She went 7 hours.

Since my last update I have had two long (45 min +) FaceTime sessions with Glory. The first had Glory very frustrated with me. She never spoke and kept her eyes closed. If I stopped talking to her for about 3 minutes she would open her eyes, but when she saw me she would quickly slam her eyes closed. Like playing peak-a-boo. The second session (yesterday) was better as Glory did try to speak. The speech therapist was there, she deflated the trach cuff so we could try and hear her voice. This failed. A month ago she was singing during this phase, but yesterday she could not force the air across her vocal cords. One other issue surfaced yesterday. Glory is having great difficulty opening her mouth. The nurse could not get the "younker" tube into her mouth to suction the phlegm. This is probably due to the lack of practice trying to talk. I also learned the two respiratory therapists that knew the diaphragm pacer, were transferred to a different hospital where they were needed by Covid-19 patience.

Now for the good news. Glory has a discharge date of April 27. That is a week from Monday! The only thing that could delay this is if she still has pneumonia. Her temp is normal, but her WBC count is still a little high, but greatly below the peak of a week ago.

I know it has been a long time since my last update. To be honest I was very concerned about Glory. She has come down with a condition similar to Lock Jaw. She could not separate her teeth. She would move her lips, but with no jaw movement and no visible tongue movement, reading lips was impossible especially on FaceTime. The good news is I just spent two full days and a full night with Glory. She is still her spunky self. With a speech therapist and a handful of tongue depressors and many hours massaging her cheeks and jaw muscles we got significant results. Not perfect yet, but enough to know when I get her home, I will get her back to where she was three weeks ago.

My training on the ventilator went very well. Including three critical alarming situations that worked out just fine. They definitely built my confidence that I can handle any issue that comes up. She now comes home on Monday with an estimated arrival of 12:30 to 1:00. I know Elaine (thanks Elaine) has started to organize a welcome home celebration, with every one invited to line the street with well wishers waving the American Flag as our OLD Glory comes home. She will love it.

April 28, As you know Glory came home yesterday. We had over 80 people line the street to welcome Glory home. Many of you shared photos and videos. They are all wonderful and will be cherished.

Glory is enjoying being home well as seeing her favorite — Challis. The road back to proper lip reading will take time. I am out of practice and Glory's jaws currently do not allow proper movement for anyone to read her lips. She is also very frustrated at this reversal in capability. This causes her to refuse using blinks to communicate yes and no. She will get over this soon and we will be back on the road to recovery.

Two weeks since Glory got home. Things are going well. I currently have nurses 24/7, but will change to 16/7 on Monday. Just a cost saving move. If I can't handle it I will go back to 24/7. Things are always busy now, with so many meds and turning and cleaning. Strange having so many people in and out. They have kind of taken over the kitchen area.

Glory is happy to be home. She smiles and says "good morning" every morning. I have managed to massage her jaw and cheeks enough that she can open her mouth now. But she does not like to talk much. Not like back in February when she was constantly moving her lips and using the "white board" when I could not understand. Now the white board does not work as she will not blink to select a letter.

Glory's health is adjusting to being home. She has pneumonia again. Runs a fever. It was as high as 102.5, but now is mostly around 100. She is getting good attention. Her general practitioner has had three telehealth videos with her and did a house call for over an hour one day last week on only 15 minutes notice. The respiratory therapist has been here twice and we had two tele-health video's with her Pulmonologist. I have also hired a OT to help strengthen her eye muscles. Only two sessions so far, but this should help.

We get Glory into her wheelchair almost every day for 3 - 5 hours. Usually you will find her in our four season deck. This was her favorite room with a view. We even gave her a shower last Thursday. That was work. Will only do that every 2 weeks.

It was four weeks yesterday that Glory came home. Her prior 6 weeks of isolation were very tough on her. She cam home with what they call ICU delirium. Many people on a ventilator in the ICU get this after 3 - 4 weeks. For Glory it was 4 months with the last 6 weeks with very little ability to communicate with the ones she loves. Thus her brain shut down. Being home has not yet brought her back. In fact she has gotten worse. She no longer communicates via lip reading, eye blinks or facial expressions. She will on occasion give a subtle smile when I kiss her good morning. The Doctors say give it time. Most patients recover in 3 weeks after getting home, but Glory was in this condition much longer than the average patient.

On the good side Glory has shaken off her latest bought with pneumonia last Friday. This means she is not sleeping all the time, but will open her eyes. All visitors are welcome to provide her entertainment. She does enjoy hearing people battering around her (come in pairs so you can talk)  I have a specialist coming tomorrow to help me work out her lock jaw, and one was hear today helping with her eyesight.  Also today we finally got the key to the ability to program her ventilator to wean her from it.  We did one session today for 5 minutes.  At first Glory did not respond for 20 - 30 seconds, but then she started to breathe with the ventilator providing some assistance.  She did great given how long it had been since her diaphragm did any work.  Taking it slow each day now so she does not get too sore.  Should start seeing real progress in about 2 weeks.  That may also help her snap out of her delirium.

You should know Glory is improving every day.  She defeated her last bought with pneumonia about 10 days ago.  And on Monday this week she began her exercise process to wean her from the ventilator.  Her exercise routine has gone from 5 minutes per day to two 30 minute sessions per day.  And she is doing them exceptionally well.  Her diaphragm is definitely getting stronger. She still sleeps a lot and she is not very communicative when awake.  But that will come with more time.  She did break out of her delirium about 7 days ago, so again things are getting better.

I have an OT (occupational therapist) coming three days a week trying to break her lock jaw.  It is starting to loosen and on occasion she will mouth a few words, especially in the morning.  I also have an OT coming twice a week to try and strengthen her eye muscles.  She currently can not move her eyes much, but with proper exercise this should come back as well.

Glory's favorite holiday is tomorrow, July 4. There continues to have been many ups and downs, return of pneumonia, sleep 95% of the time, very little communication, but I can tell you things are improving. On Wednesday the Pulmonologist authorized a new more difficult weaning procedure on the ventilator. He also authorize me to be able to extent the test time as I see fit. That started yesterday and Glory is doing fantastic. Today she went for 20 minutes and could have done more. Glory's "lock jaw" was getting much better, until the trip to the hospital via taxi for some tests. The bouncing caused her to bite her young again. Very bad. But it is healing now and she is starting to loosen up again. Hope she starts mouthing words again.

Glory has had many visitors. Some come to pray the rosary with her (she enjoys that) Some come and sing to her (wonderful) others just come to talk and share what is happening. These stories often result in a tremendous smile and sometimes a tear. It is very enjoyable to see her emotions and joy. She loved the family events.

July 17 Time for an update. It is hard for me to see the changes as I am here every day, but I recently had a visit from a nurse practitioner from a local palliative care organization. She visits once a month to check on Glory, and to check on me as well. Her observation of Glory was one of astonishment on the degree of improvement since the last visit one month ago. Last month

1. Glory was struggling to exercise on the ventilator for over 5 minutes. Today she is in weaning mode 2.5 hours per day and the level of effort required has been increased to level 2. Next week we hope to go to level 3.
2. The swelling in Glory's hands and face is gone
3. GLORY'S "Lock Jaw" is significantly gone. She opens her mouth on command for the nurses to clean her tongue. Still not mouthing words or opening mouth more than 3/4 inch. But definite improvement
4. Glory has no infection.
5. Glory's medications have been greatly reduced or eliminated.
6. Glory has great color in her face, no longer ghostly
7. Glory shows significant emotions with her eyes and facial expressions.

These changes have been so gradual that I hardly noticed, but the monthly overview has been very encouraging.

Glory's days are filled with doctors and nurses and therapists. They have become some of her best friends. The good news is their efforts are working. Glory has returned to me. While her mouth only opens a little, it gets better every day. I can now read her lips most of the time. Her eyes, although they have very little motion are lit up with happiness every time she gets a visit from Shana or Allison her therapists. She knows they are helping her and is so grateful. She also loves when members of her old bible study group come to visit every Thursday. They say the rosary with her, yes she prays along, and then sing to her. She absolutely loves it.

Today Allison asked Glory a question. She said "Glory, Shana tells me you said your favorite color is purple." Glory replied "I say that a lot, but I really like Blue." Then gave a big smile. Always a jokester.

The weaning of Glory off the ventilator is going very well. She is now having two one hour sessions a day with the ventilator at only 10 psi assist.

I know most of you have now heard the news, Glory passed on to a wonderful spot in heaven yesterday August 5, at 12:14 pm. Yes it was a surprise, she was doing so well weaning off the ventilator. We were all convinced she would be able to shed it completely during the daytime by the end of September. But she fell victim to a stroke, and the recognition that the hard fought battle was over.

She was a fighter. From being the only female engineer in her class at Rutgers, to her early fights with corporate America not believing a woman should be an engineer, to starting her own franchise business and ending profitably. Helping her mom battle Alzheimer's was probably her hardest fight and her biggest disappointment was not getting her Life Masters at ACBL bridge (She was close.  Only 60 points to go).  She almost beat this latest challenge to try and emulate Charles Krauthammer. I should  also remind you about Glory's dedication to God, which was the foundation of her success. She loved her bible study group and made sure we visited many religious sites around the world — Fatima, Jerusalem, Medjugorje, Lourdes.

One of the final things Glory said to a neighbor was "Tell Fred I love him and thank him.  I had a wonderful life."

I remember, from some where, a story that the difference between humans and all other animals is we are rational animals.  What that means is we have the capacity to think, we have free will and the ability to love. These attributes constitute our soul.  I have also heard that our soul is like a snowflake - every one is unique. It is your soul that helps define your happiness for it is within these attributes of the soul that you learn the meaning and purpose of your life.  It is our soul that lives forever in heaven.  Glory's soul is defined by her determination, kindness and love of family.  What defines your soul.

I started this story with the hope her story will inspire others to overcome the obstacles they face with determination, assertiveness and kindness as exampled by Glory.  Remember her smile, but also her commitment to family, friends and faith.  Her love of a challenge and willingness to be a pioneer.  Remember her determination to always strive for what was right and her commitment to God.  The importance of prayer and the belief of how prayer can uplift you.