## The Story of a Nasogastric Tube Gone Wrong

Deahna Visscher, Patient Advocate

When I was 18 weeks pregnant, I went in for an ultrasound. I remember the room getting quiet when they were looking at my baby's anatomy. We learned two things that day. One, we were having a boy. Two, he was going to be born with a heart defect. From that day forward my routine obstetrics exams included follow-up with a cardiologist to monitor my sons' heart development. It was amazing to see on the monitor his little heart through my body and his. At every cardiology appointment we watched his heart grow. Each time I would leave with a new fear of what might have caused his heart defect. I would go home and immediately search the new terms and potential syndromes my cardiologist would tell me might to explain the abnormality with my sons' heart. With the ones I especially disliked I would call my cardiologist and tell her "I don't like this one, it says he will die shortly after birth". She would in turn tell me how much she hated Google since it always seemed to give the worst case scenario.

During one of my obstetrics appointments we learned that my amniotic fluid was lower than it should be. I was sent to a specialist for that problem. They took lots of pictures and measurements. I was then sent home with instructions to drink as much water as I could, to sit submerged in a bath full of water for as long as I could stand, and to come back the next day. That follow up appointment would determine when my son would be born. His original due date was April 26. Since I would have a C-section we had planned to schedule it for April 24 to share my mother-in-law's birthday. That date was moved up to April 10 due to low amniotic fluid. I was ok with that since it was my grandmother's birthday. If my amniotic fluid didn't improve then my delivery would be earlier. When I went in for my next appointment, the fluid was lower and I learned that my son would be born the next day.

Grant Lars Visscher was born on April 8, 2008 at 5:58pm. He was beautiful and perfect despite the known heart defect. He was 6lbs 5oz and 18 inches long. He also shared my step-grandfathers birthday. Less than 24 hours after he was delivered he was taken by ambulance to the hospital where he would later have surgery. Although I had just had major abdominal surgery, I medically discharged myself so that I could be with him every step of the way. Together we rode with the ambulance team to the referral hospital. We almost didn't make it. A car was traveling the wrong way on a one way snowy street and almost collided with us!

Upon arrival at the new hospital the staff began evaluating Grant and scheduling CT scans and blood work. After review of his scans it was determined that Grant had coarctation of the aorta. The surgery would correct the coarctation by replacing his malformed valve with a gortex valve. Surgery was scheduled for 10:00am on Saturday, April 12, 2008. The surgery would be about 5 hours long.

On Saturday, April 12 Grant went into surgery around 9:00am and came out a little after 3:00pm. The surgery went well. The doctors were able to sever the coarctaction and tie the valve off on both sides. The gortex valve was inserted to replace the coarctation and put the replacement valve correctly in front of his esophagus and trachea. [They also tied off the left superior vena cava valve that led to his small mitral valve to see if it would help the mitral valve grow to normal size.] While inside his tiny little chest the doctors did find a small hole inside the top section of his heart so they corrected it with a couple of sutures. That was

the only surprise they had and they said it was a minor surprise. He was doing so well post-op that he only needed one chest tube for drainage, 6 medications, a catheter and he was intubated. By Tuesday, April 15 Grant was weaned from his medications, with only oral Tylenol remaining. He also had his catheter, breathing tubes, pacer lines, and chest tube removed. He was doing so well that he was moved from the PICU to the Cardiac Progressive Care Unit.

By Wednesday Grant was having trouble with his feedings so the staff wanted place a feeding tube. They first tried a nasal feeding tube, but he struggled, so they moved to an oral feeding tube which he later coughed out. They ended up postponing milk feedings and put him back on intravenous fluids. He also started having trouble with low oxygen saturations in the low 80s. A chest x-ray was ordered to find out why he was suddenly having trouble getting oxygen. They discovered that his lower left lung had collapsed, a common side effect of open heart surgery in infants. They put him on a CPAP machine to re-open his lower left lung. He looked so cute snorkeling in bed. The next day he had improved and they took him off of the CPAP machine and put him back on a nasal cannula for oxygen. The staff also ordered an upper GI test to find out why the nurses were struggling to insert the feeding tube. He did not have any blockage in his esophagus, but he did have severe reflux. They then inserted the feeding tube under x-ray and he started feeds on milk again.

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Grant did well with his feedings through the NG tube both Thursday and Friday that we were told that by Monday or Tuesday he would be going home. On Saturday, the morning nurse told me that she wasn't comfortable with his feeding tube as they had placed it trans-pyloric to help with his reflux. She requested and was approved to insert a new feeding tube that would not go past his stomach for feeds. I watched as she struggled to insert the new tube. I told her how the staff that inserted his current tube



had struggled to get it in so they did it under x-ray. She struggled a bit and then got it in. She asked me if I wanted to learn how to do a feeding with an NG tube since Grant would probably be going home with it. She then proceeded to show me how to insert a burst of air into the NG tube and listen for the sounds in his body through the stethoscope. At this time I asked her how you would know if the burst of air was in his stomach or not. I stated, "Wouldn't there be a burst sound regardless of where it is in the body?" The nurse said that she supposed that would be true. She then told me that is why they take a sample of fluid out of the tube to verify that it is taking fluid out of the stomach. She then did that and showed me the fluid in the tube. I asked her how she knew that was fluid from the stomach. She told me that she was confident it was there as she had been doing this for 20 years. The nurse then started Grant's feeding of milk. We then discussed how to get Grant back onto the regular feeding schedule since the insertion of the NG tube delayed his feedings and we needed to coordinate the NG feeding with my breast feedings.

After his feeding I took Grant out of his bed and held him in the rocking chair. While holding him he was very fussy and his pulse ox started to fluctuate. The nurse checked things and said it could because of them weaning him down on his oxygen. She also took this time to switch out Grant's bed to a crib. A couple of hours later I paged the nurse because Grant was sounding raspy and was blowing whitish bubbles out of his mouth. A different nurse came in because our regular day nurse was at lunch. I explained what was happening to Grant and the nurse had me put him in the crib. She then began to suction out his mouth with a long tube. Grant seemed to do a little better after that.

Later that day we had several visitors come see Grant, including his 15 month old brother Mason. We took a family picture with Grant since it was the first time we could all be together. My parents came by and gave my husband and me a little break. I hadn't left the hospital in days. We ran a few errands and then came back to the hospital. When we returned to the hospital around 7:00pm my parents told us that Grant seemed to be distressed. They told us that when they called the evening nurse in she told him that the sounds from his monitors were going off probably because he was moving down in his crib and needed to be moved back up. They told us that the nurse then asked them if they would like to hold Grant and of course they did. They said that Grant seemed to do better when they held him upright. Shortly after that my parents left.

My husband hadn't held Grant in a while so he picked him up and held him in the rocking chair. Around 8:00pm, while my husband was holding Grant, I noticed his color seemed off. He was ashen, and he was blowing whitish bubbles again. We paged the nurse and when she came in we told her that when Grant did this earlier in the day that the nurse suctioned him out. She then got a big suction tube to suction out his nose; we told her that the earlier nurse used the suction tube in his mouth, not his nose. She then got the other suction tube and started to suction him. This nurse seemed a bit distracted to us. We felt like we had to tell her what to do.

After she suctioned him she started a feeding for Grant. Just afterwards his color got worse. The nurse was doing something with

the feeding tube or monitor when I told her that Grant was turning blue around his mouth. She then hit the call light and told the person that answered that we needed a nurse in there. The lady told her that she would send my nurse in. Our nurse told the lady that she was the nurse and needed a charge nurse in there right away. No one came in at that second so the nurse told me to go into the hall and call for a charge nurse. I ran into the hall and hollered that we needed a charge nurse now that Grant was turning blue. A few nurses ran into the room then and within in seconds an over head page was made requesting code blue to room 902. Immediately thereafter about 20 people charged into the room to help revive Grant.

We had Mason, Grant's 15 month old brother, with us so Rich took Mason out into the hall while I stayed in the room watching them work on Grant. One of the doctors in the room started to ask me questions and I answered them. A nurse took Mason from Rich so that he could come back in the room to be with Grant while the team worked on him. While Rich and I watched them work on Grant we heard the doctor who was putting a breathing tube into Grant's airway state that the NG tube had gone through Grant's trachea. Sometime during this a nurse started describing what the team was doing to try to save Grant. Later another doctor turned to us to start to tell us that they had done all that they could for Grant. I cut her off and begged her to keep working on him and to not give up. She gave us sad eyes and said that they would try for 10 more minutes. The nurse that was describing things to us then asked us if we would like to hold Grant's feet while they continued to work on him so we did, each of us taking one of Grant's tiny feet into our hands. Shortly after that the doctor said that they had done all that they could for Grant. Rich and I both collapsed to the ground in sobs. Our beautiful baby boy was pronounced dead at 9:10pm on Saturday, April 19, 2008.

After we collected ourselves the staff let us be with Grant alone. Sometime after, while we were holding him together on the couch in the room, the doctor came in to tell us how sorry she was that they could not save him. I asked her how come this happened, that I didn't understand since he was doing so well and was supposed to go home later that week. She told us that they think the NG tube had something to do with his death. I responded with, "So you're telling us the nurse killed our baby?" The doctor just repeated how sorry she was.

# "She told us that they think the NG tube had something to do with his death."

The nursing staff came in later and told us they could take pictures of Grant for us. I asked if there was a professional that could do it and she said they would page the 'Now I Lay Me Down To Sleep' on call person to see if someone could come in for us. We then started making the calls to our family to let them know that Grant had passed away and asked them to come to the hospital to say goodbye to him. It was at this time that a nurse brought Mason back to us. He had no idea what was going on and why his par-

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ents were so sad and distraught.

Two doctors came back to see if we had any questions and to let us know again how sorry they were. I was so angry that I told them that they couldn't give me the things I wanted, which was to have my baby back and to have the two nurses that day fired. One of the doctors then told us that she was the doctor that gave the nurse the authorization to change the NG tube. She said that it is quite normal for the nurses to place them. They went on to say that they even teach parents how to do it. They apologized again for our loss and told us they didn't know what else to say. Then they left us when we told them we didn't have any questions.

Our family started arriving to say their "good-byes" to Grant. The coroner came and looked at Grant and then the photographer came and took pictures of Grant with us and our family. I have more pictures of Grant deceased then I do of him alive. The nurses then made a mold of Grant's hand and foot for us. Once the mold was ready we said our final goodbyes to Grant and handed him over to one of the nurses around 2:00am. That was the last time we saw Grant at the hospital.

We held his funeral on April 26, 2008. We were surrounded by family and friends as we said goodbye to our 11 day old son. My father did the eulogy. We asked people to come up and share with us their brief memories of Grant. My step-mom spoke and asked that from now on that every year, from April 8-April 19, she would like for us to do something kind in memory of Grant. We now call that anniversary Grant's Pay It Forward days.

In the days following Grant's death we were told by 3 separate medical professionals that Grant's death was a medical error and that we should think about suing the hospital to prevent this tragedy from happening to anyone else. During my post-op c-section care my OBGYN heard our story and referred me to a lawyer. My husband and I could not stand to be in our home that was prepared and waiting for our baby son to come home. It hurt every time that someone who had known we were expecting asked after the baby. So, we ran away with our son Mason to Puerto Rico. While at a pediatrician visit to see if Mason needed anything for travel to Puerto Rico, his doctor heard our story and referred us to the same lawyer as had my OBGYN. My sister is an operating room nurse and told her co-workers our sad story. One of the anesthesiologists recommended the same lawyer as the other two doctors had. We took that as a sign and made the call.

We worked with our lawyer and the risk manager at the hospital to come to terms on a settlement. We had done some research and learned that if the nurse had used a pH strip to test the fluid she had removed from Grant that he might still be alive. We made it part of our settlement that the hospital had to change their policy and procedure for feeding tube placement and verification so that no one else would have to suffer a death and loss like ours. We also invited the hospital to use our story to explain why they were making changes.

A few years after Grant died; we had another son, Liam. It was during his first few months of life that I started wondering if the hospital ever put in place the changes we requested on behalf of Grant. I decided to inquire and find out. I met with several staff members who reviewed Grant's case file with me. They told me that they had changed their policy and procedure at the hospital. In fact, they knew that at least 4 babies' lives had been saved because of this change. They told me that they were using a pH strip to verify placement and if any distress occurred they used x-ray to perform the procedure.

I left that meeting feeling empowered. Grant's death was not in vain. I asked myself how I could prevent more deaths and make feeding tube placement and verification safer. I reached out to the

Chief Safety Medical Officer at the hospital where Grant died and he invited me to sit on one of the hospital committees. I chose the Patient Safety Committee. The hospital was implementing a new program called Target Zero. That stands for zero harm. The Patient Safety Committee split up into small groups to tour the hospital to talk to the staff about Target Zero. Of course, I looked at every single child while we were talking to the nurses. I saw one child who had a feeding tube. I started asking the nurse some very leading questions regarding placement and verification. She answered my questions and then explained to me: "Well, about five years ago we had an infant who had a feeding tube placed incorrectly and so that's why we do it here differently now." I looked at her, and I said thank you. You have just told my sons story back to me and validated that his death was not in vain. People have learned from it, they understand why it was important to change the procedures, and they remember him.

Through my work with the hospital I got involved with another committee called the NOVEL (seeking New Opportunities for Verification of Enteral tube Location) that is a sub-committee of the American Society of Parenteral and Enteral Nutrition (ASPEN). With the NOVEL project we have been seeking a gold standard for feeding tube placement and verification. Through our work we did a study in 2016 with 63 participating hospitals and found that there are probably at least 25% of children that are at risk of a misplaced feeding tube. We also learned there was wide variation in how placement of these tubes was verified. We found the prevalent method was to use aspiration and auscultation for verification. This is a direct contradiction to the 2012 safety alert that was distributed by the Child Heath Patient Safety Organization that recommended the immediate discontinuation of the auscultation method for the assessment and verification of nasogastric tube placement. This study only fueled my desire to find a solution in which all hospitals use a unified gold standard.

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A colleague told me about the work that the Patient Safety Movement Foundation does to get to zero harm by 2020. He, the nurse who reviewed Grant's case, and I went to their conference July 13-14, 2017. I proposed the idea that they help find a gold standard for feeding tube placement and verification. I shared my story and the NOVEL project research findings to illustrate why it is important to find the best practice for all hospitals nationwide and worldwide. The nurse also shared what her hospital had done to make changes there after Grant's death. Of all of the medical safety ideas proposed, ours was voted as the number one issue to be championed and solved by the next conference.

An international team was formed by the Patient Safety Movement Foundation to find the gold standard for feeding tube placement and verification. Team members were from England, Mexico, and the United States of America. We all came together with research, literature, and personal experiences that supported definition of the gold standard. The Actionable Patient Safety Solution (APSS) #15 was formulated: pH testing should be used as the first-line

#### **About The Patient Safety Movement Foundation**

More than 200,000 people die every year in U.S. hospitals and 4.8 million worldwide in ways that could have been prevented. The Patient Safety Movement Foundation is a global non-profit which creates free tools for patients and hospitals. The Patient Safety Movement Foundation was established through the support of the Masimo Foundation for Ethics, Innovation, and Competition in Healthcare to reduce that number of preventable deaths to ZERO by 2020 (0X2020™). Improving patient safety will require a collaborative effort from all stakeholders, including patients, healthcare providers, medical technology companies, government, employers, and private payers. The Patient Safety Movement Foundation works with all stakeholders to address the problems with actionable solutions for patient safety. The Foundation also convenes the World Patient Safety, Science & Technology Summit. The Summit brings together some of the world's best minds for thought-provoking discussions and new ideas to challenge the status quo. By presenting specific, high-impact solutions to meet patient safety challenges, called Actionable Patient Safety Solutions, encouraging medical technology companies to share the data their products are purchased for, and asking hospitals to make commitments to implement Actionable Patient Safety Solutions, the Patient Safety Movement Foundation is working toward ZERO preventable deaths by 2020.

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method for checking bedside NG tube placement. If there are issues with placement or the pH is not at the correct value, then x-ray should be used to confirm placement. On February 24, 2018 we shared our APSS at the conference held in London, England in front of an international audience.

I was naïve to think my work was done with the creation of the APSS that defines the gold standard for feeding tube placement and verification. I thought if we created the gold standard then it would be used. I was wrong. People and organizations need to be informed that the gold standard exists, that there are valid reasons for using it, and that it needs to be followed. It's been 10 years since Grant died and I am still blown away when I encounter a hospital that is still using auscultation as their method for verifi-

cation. How many more people need to die before action is taken at those organizations? Does it have to be a death or a near miss that makes them embody change?

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Deahna Visscher Patient Safety Advocate. Michael J. Skolnik Award for Patient Safety (2015) American Hospital Association-McKesson Quest for Quality Prize (2015)

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