

**Brooke and Colin Queen**  
**Remembrances on their 4<sup>th</sup> birthday**  
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By Gretchen Queen

**Getting Pregnant:** My husband and I thought getting pregnant was going to be the hardest part of parenthood. Little did we know that God had a couple of surprises for us. After six years of infertility, we finally got pregnant through a fresh IVF cycle where we had 2 good embryos to implant. Dr. Meldrum, an incredible fertility specialist, said he only needed 1 good embryo and we had that. We were elated to learn that we were pregnant with twins! Our treatment process of surgery, numerous invasive procedures, and intense and lengthy drug therapies had finally paid off. We were finally beginning to realize our dream of becoming parents.

**In Utero Diagnosis:** Colin was diagnosed at 24 weeks in utero with a serious heart condition. His left ventricle function was severely compromised. The doctors said that they would not be able to determine the course of repair for his condition until after he was born. Fetal surgery was out of the question due to his twin's good health. Colin initially was diagnosed with Shone's syndrome, which turned into Hypoplastic Left Heart Syndrome, HLHS. Rob and I weren't concerned about the gender of the twins until we learned that baby B had this poor prognosis. We asked to know the gender of the twins so we could begin building a more personal bond. We began envisioning a life with our sick little boy.

**Finding the Best Treatment Site:** It was a challenging journey finding the right institution to treat our son's condition. After many words of doom and gloom, tears, phone calls and marathon sessions on the Internet, we found The Heart Institute at Children's Hospital Los Angeles. Thankfully, we didn't need to travel to Philly, Boston or Cleveland for the delivery and subsequent heart surgeries. We were prepared to do what ever it took to get Colin to the most capable doctors and hospital. We had not learned much about CHLA until a nurse from an out-of-state institution said to look in our own backyard - wise words from a complete stranger.

**Beginning the Process:** It is terrifying to hear that your baby may not make it, once delivered. The staff at CHLA remarkably walked us through the terrifying process of preparation and decision-making. Dr. Mark Sklansky, Colin's cardiologist, sympathetically guided us through a fetal heart echo using his gentle hands and genuine concern. This was not our first fetal heart echo; however it was our first positive experience. Dr. Sklansky took as much time as we needed to confirm the initial findings and discuss our options. Later we met with our son's future cardiothoracic surgeon, Dr. Vaughn Starnes. Then we toured the Heart Institute facilities. The facility is quite impressive and, at the same time overwhelming. We felt like we were in an

alternative universe. Finally, our tour took us across the street to Hollywood Presbyterian where I needed to deliver. I remember saying to the nurse manager, "What if I can't hold off until the scheduled delivery date?" I remember her being positive and saying, "You will". My task was clear. I was to keep the babies in my belly for as long as I could. Little did I know at the time that in only 3 weeks we would be spending weeks and months on that same medical campus with our preemie twins. The twins and my body had another schedule in mind.

**The Challenge of Getting to Los Angeles in Time to Deliver:** After having intense contractions at 31 weeks, my husband Rob drove me to Mission Hospital in Orange County. Twice before their large doses of Terbutaline allowed me to return home for more bed rest. I was admitted to labor and delivery and was stunned to learn I was 4cm dilated. This was not welcome news. We knew that we needed to get to Hollywood Presbyterian to deliver the twins, so Colin could be quickly transported directly to CHLA. It was too early to deliver and we were in the wrong place. Dr. Posner, my incredible perinatologist, knew we needed to get up North in order for Colin to have a fighting chance. He worked his magic with the magnesium sulfate (not my favorite drug) and got me stabilized so I could be transported via ambulance to Hollywood Presbyterian the next day. It was the most challenging trip I've ever had on the 405, 110 and 101. The paramedics made me promise them I would not deliver on the way up to LA. Thankfully, I kept my end of the bargain, as did they.

**The Holding Pattern Ends:** After four days of fighting eminent delivery, with copious quantities of the dreaded magnesium administered by Hollywood Presbyterian Hospital, Colin's placenta abrupted. I started bleeding and Colin started having rapid heart decelerations. The call went out to proceed with delivery. Literally 2 minutes later an anesthesiologist inserted the spinal anesthetic and I was whisked into the OR. The twins were delivered via stat C-section 12 seconds apart, 8-1/2 weeks early. Brooke appeared healthy, weighing in at 3-1/2lbs. Colin weighed 3 lbs and was intubated quickly. Both children were shown to me for seconds and then promptly worked on by the 14 neonatal staff members. The only thing I really remember was hearing both kids cry. I knew that was good. The rest of what happened is only a blur.

**Moving Colin to CHLA.** Just hours later, Colin, accompanied by his father Rob, was transported via ambulance 100 yards to CHLA. They nearly lost him on the ride. At only 3 lbs a very sick Colin had a most challenging road ahead of him. While he was moved next door, his twin spent the next month gaining weight in the NICU at Hollywood Presbyterian. A decision was made to keep Colin in the CNICC (NICU) to give him time to gain weight, thus increasing his chances of having a successful surgery. Typically, HLHS kids go to surgery hours or days after they are born. Due to the pre-term delivery, Colin was too small and had little or no reserves to recover from such an intense, open-heart surgery. So we waited and watched our

little man in the NICU for 7-1/2 weeks awaiting his first surgery. Over that time, he fought several almost fatal infections and gained very little weight. Colin continued losing ground on all fronts, necessitating scheduling the life-saving *Norwood* procedure. Colin would have been lost had the surgeon not moved forward quickly.

**The First Open-Heart Surgery:** The day Colin had his first open-heart procedure, *The Norwood*, was the actual due date for the twins. We called it Colin's rebirth. Dr. Starnes had all of the odds stacked against his success that day. Colin was a very sick baby with few reserves for recovery. If it weren't for Dr. Starnes' impeccable surgical skills, Colin wouldn't have made it past surgery. He just squeaked out of the OR without being hooked up to ECMO. The next 72 hours were touch and go for our champ. Colin's vitals continued to nose-dive. The doctors told us going back on the heart-lung machine wasn't an option for Colin because it would just be prolonging the inevitable. Tough news for any parent to hear but we knew it was up to Colin to fight and he did just that! He began turning the corner and making an upward climb when he started collecting fluid around his lungs and the chest tubes that had just come out. The tubes had to be reinserted. The first tube went in smoothly, but the second tube created a problem. Colin started bleeding out after the insertion of the second tube. In fact, he bled out twice his blood volume. The CTICU staff were performing chest compressions and pushing blood into Colin just as fast as it was coming out. He was rushed into the OR for a thoracotomy. The doctors were able to find the tear in his lung and repair it. Thanks be to God, Colin recovered from the mishap. However, MRSA, a hospital super bug then attacked him. The strongest of antibiotics were administered. Colin survived it all and one month later he was reunited at home with Brooke, his twin sister. We finally made it home as a complete family after 3 months. Colin's oxygen level was in the 70's and he was alive.

**Awaiting *The Glenn* Procedure:** The next six months were spent at home getting reacquainted with his sister. During the wait there were several emergency runs, ambulance rides and hospitalizations due to illness. When his oxygen level began to dip into the 60's it was time for his next open-heart surgery (*The Glenn*). It was harder for us than we imagined when we gave Colin to the doctors for the second surgery, even though we knew his heart needed fixing. He made it through the surgery with flying colors. We only spent a week at the hospital. It was a breeze compared to the first 3-month ordeal in the NICU and CTICU. Colin did have some difficulty adjusting to his new physiology. He also looked much better than he did before the procedure. With more stress taken off of his heart, he showed increased energy. His oxygen increased to the low 80's and he was not as blue (cyanotic) as before the surgery.

**Brooke's Surprise:** After Colin's *Glenn* procedure, we had a bit of a surprise with our little "cookie monster", one-year old Brooke. One day she was unusually fussy and inconsolable. I instinctively put my hand to her chest and felt her heart racing beyond what I could count. Because of Colin's heart condition, we had a pulse oximeter at home. I put it on her finger and could not believe the reading, heart rate - 300, so I did it again, with the same result. I immediately called her pediatrician and he thought it might be WPW (*Wolfe-Parkinson-White Syndrome*), another rare heart condition. He told me to get her to the ER immediately. The docs there were unable to get her heart rate down by using conventional methods so they tapped a line and pushed a special drug to slow her heart. The medication didn't work the first time so they tried again, this time with success. When I asked the doctor if it was WPW he replied, "no". My instincts told me to the contrary, so we scheduled an appointment at CHLA with Dr. Bar-Cohen for follow-up. During Brooke's first cardiology appointment, Dr. Bar-Cohen confirmed our suspicion that Brooke had WPW. It is a life-threatening condition where patients have an extra nerve near their internal pacemaker that causes them to have SVT's (supra ventricular tachycardia) – rapid heartbeats. When having an SVT, WPW patients can go into cardiac arrest. Since the first incident, Brooke has had several episodes that involved calling the rescue squad and taking trips to the ER for treatment. The cardiac ablation procedure to correct her condition will be scheduled when the doctors feel she is big enough to minimize the risk of damage to her heart. Brooke's condition can be corrected. She takes a BETA-blocker three times a day to control her SVTs. She is now on a dose that has prevented subsequent episodes.

**Colin's Third Open-Heart Surgery:** Colin had his third open-heart surgery, *The Fontan*, when he was 2-1/2 years of age, September 2007. This completed his 3-stage palliation. It was a very difficult surgery and recovery. Colin's oxygen level bumped up to the 90's. He now has the energy to run around and keep up with his sister, without turning blue! His full energy personality has emerged and he is determined and humorous. Colin was on Coumidin, a blood thinner, for almost 1 year after *The Fontan*. The frequent blood draws; diet changes and high risk of bumps and bruises are now a thing of the past. Now he takes a baby aspirin, a diuretic and an ACE inhibitor. He still has therapy - OT, PT and ST - and he is catching up rapidly. People seeing him on the street would see a normal 4 year-old, not a miracle of medical science.

**Four Years and Celebrating:** The twins turned 4 in December. They've started their first full year of preschool and they love it! Considering their 3-1/2 years in protective isolation, it is amazing they socialize with such ease. They are as happy and healthy as they can be. Colin just LOVES trucks, trains and dinosaurs. Brooke is CRAZY for sea creatures, horses and unicorns. They have a blast riding their big boy/girl bikes, swimming and playing in the park down the street. We thank God every day that Brooke and Colin are in our lives. We are truly blessed to be caring for such amazing little human beings.

**Gratitude and Thanks:** We have our family due to an accomplished team of caring people. We are grateful to so many: the healing hands of our fertility specialists at Reproductive Partners, my incredible perinatologist Dr. Posner, our always available pediatrician Dr. Carruth and his staff at TLC Pediatrics, the labor/delivery and NICU teams at Hollywood Presbyterian, CHLA's CNICC and CTICU staffs, and the support of family, friends and our network of prayer warriors throughout the country. Without their collective sense of urgency, skills and watchful eyes, our children would not be here today to celebrate their 4<sup>th</sup> birthday. With great sadness we have mourned some of our little heart patient friends we've met during our journey. Rob and I understand the gifts we've been given of these two little miracles. Living life to it's fullest is an important thing for us to do, realizing that your whole world can change in a minute. Life is wonderful right now and we're basking in the warmth of each and every day.

