HEALING HEARTS

Families' experiences with Down syndrome and heart surgery

A unique, parent-driven resource featuring first-hand stories of nurturing a child with Down syndrome through open heart surgery and recovery.

Including answers to common questions, guidelines for choosing a cardiac care center, glossary of terms, helpful resources, and information curated with input from pediatric cardiologists.

NWDSA

northwest down syndrome association

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HEALING HEARTS: FAMILIES' EXPERIENCES WITH DOWN SYNDROME AND HEART SURGERY

The information in this book has been reviewed by Dr. Mark Reller, OHSU Pediatric Cardiology. The purpose of this book to connect families and share personal stories to help parents and families prepare for their child's upcoming heart surgery. This book is not intended for use as medical or therapeutic services and should not be used in lieu of professional medical advice. In all instances, families are encouraged to seek the input of a qualified pediatric cardiologist when discussing their own child's care.

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MESSAGE FROM JAMIE

When my younger daughter Karley was just a few minutes old it was clear that her heart was not working at full capacity, and within weeks it was determined that she would need open heart surgery before she was four months old. This news was far more terrifying than her diagnosis of Down syndrome (Ds), in part because, while there were many resources to be found about Ds, there are relatively few personal accounts about Ds and heart surgery. The doctors provided us with medical information, but what we really missed was a connection with another family who had survived what we were about to go through. We needed to hear from other parents who had faced our deepest fears and come out the other side, and we needed to meet children who had been tiny and vulnerable like Karley, and made it through surgery successfully and grew to be active, healthy children.

When I started NWDSA's Open Arms Playgroup with Sydney Shook in 2004, I always made it a point to check in with new parents about their children's heart condition, and to introduce them to Karley so they could see a kid who survived open-heart surgery. I came up with the idea of this book as a way to create a resource that could be put in the hands of parents faced with a surgery date. It is my hope that with the help of NWDSA and area cardiologists and pediatricians, we can share this book with families and help them see that they are not the first to go through this and are not alone. I want to send my sincere thanks to each and every family who contributed a story to this booklet. In sharing your darkest and most terrifying moments, you will provide hope and light to families coming after you. Thank you for giving back!

THE IMPORTANCE OF GOOD INFORMATION

Congenital heart defects are often associated with Down syndrome, impacting the health of 40-50% of infants. While sometimes these defects can resolve on their own, many can have serious implications if untreated, so it is essential to seek appropriate medical care, including surgery where needed.

Rapid advancements in cardiac care and increased accessibility of this care to children with Down syndrome have greatly increased life expectancy and overall health. The average life expectancy of individuals with Down syndrome has increased from about 20 years in 1980 to 60 years today, in great part due to these advances in cardiac and other medical care. As daunting as most of us find the idea of heart surgery, families facing this prospect should be confident and optimistic in their treatment options.

Most common heart defects in children with Down syndrome

The most common defects seen in infants with Down syndrome are Atrioventricular Septal Defect (more commonly referred to as AV Canal), Ventricular Septal Defect (VSD), Persistent Ductus Arteriosus (PDA) and Tetralogy of Fallot (ToF). You can find a Glossary of Terms at the end of this booklet.

In all cases, these defects affect the ability of the heart to deliver blood to and from the lungs effectively. This is compounded by the fact that the lungs of children with Down syndrome often do not develop as fully as in the general population, with narrowed arteries in the lungs leading to increased pressure and lessened blood flow throughout the lungs.

Diagnosis and treatment

With advances in prenatal care, many more women are receiving diagnoses of heart problems via ultrasounds and fetal echo cardiograms. However, as the heart continues to develop throughout pregnancy, some heart defects are not discovered until after birth. It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echo cardiogram shortly after birth.

Some newborns with Down syndrome and congenital heart disease, depending on the size of the defect and other factors, will quickly present with heart failure, difficulty breathing and failure to thrive; others will show few symptoms until the body and heart become larger and are required to circulate more blood.

Heart surgery to correct defects that will not resolve on their own is generally done before six months of age in order to prevent lung damage. Some children with smaller defects may simply be monitored for signs of heart failure throughout infancy and wait until later in childhood for surgery. Occasionally, heart defects may require a series of procedures within the first few years of life.

As you will see from the stories collected here, the experience of heart disease and surgery is as varied as the families and children themselves. It is important for new parents to recognize that one family's story, even with the same defect, may be different from what will be recommended for their little one.

Guidelines for choosing a cardiac care center

Choosing a center to perform your child's surgery is a very personal and very important decision. In Oregon, we are fortunate to have two pediatric heart programs in Portland that have significant experience in performing heart surgery on children with Down syndrome, including infants. These are OHSU/Doernbecher Children's Hospital and Legacy Emmanuel/Randall Children's Hospital. In addition, there are superior-rated cardiac care centers in Seattle, Stanford, and San Francisco that families may also wish to consider.

In researching the center that is right for your family, consider the following:

Surgical volume
How many procedures for your child's particular heart defect does the center perform in a year? Bear in mind that higher surgical volume typically correlates to better outcomes and fewer complications (read this article for more information and data: http://tinyurl.com/6uendaq)

The surgeon and surgical team
How many similar procedures has the cardiothoracic surgeon performed? What is their success rate? How does that compare to national averages for the procedure? It is important that an experienced anesthesiologist be selected, as children with Down syndrome often have airway problems. If the center is a teaching hospital, how will you as the parent know that your procedure is being done by the surgeon with the most experience?

Post-operative care
Post-op care is a critical area to consider. Ask the cardiac care center about protocols for nurse to patient ratios, number of visitors allowed, infection control and statistics, and how your child will be monitored, especially in the ICU. Will your child be treated in a cardiac intensive care unit or a pediatric intensive care unit with specialized nursing staff in cardiac care? Your child is at high risk of infection and complications right after major surgery, and close monitoring is often linked to patient outcome. Check with your cardiologist for recommendations on the use of prophylactic antibiotics for surgeries and dental procedures, both before and after heart surgery.

Location of the center
Location can play a big role in deciding where to have the surgery performed. Some families depend on being close to friends and relatives during a hospital stay – for childcare, ease of access, cost-effectiveness, etc. Other families opt to travel to a top center, especially if there is a large difference in surgical volume and experience. Most children's hospitals have Ronald MacDonald Houses within easy access, with very minimum per-night rates, so look into that as an option.

Insurance
No family should have to go into financial hardship to pay for life-saving surgery. NWDSA recommends that parents preparing for open heart surgery talk to their insurance provider as early in the process as possible to get the best sense for what a hospital stay might cost out-of-pocket (there are often per-patient max deductibles) and where the insurance plan allows the family to go.

Bear in mind that even if the facility you wish to go to is out-of-network, doctors can often petition insurance providers to cover surgeries at those facilities, especially in the case of a lack of hospitals under the plan that perform a high level of similar procedures.

Families without insurance coverage should inquire about the children's health plan of the state in which they reside: In Oregon, contact Healthy Kids (877) 314-5678 and in Washington, contact Washington Children's Health Program (877) 543-7669.

More information
US News and World Report publishes a list of top pediatric heart centers in the US annually and is a good starting point when considering cardiothoracic centers. http://tinyurl.com/k7uvcos.

Knowing what to expect

Ask questions. An educated and informed parent is the best advocate. Demand specific answers, and ask for clarification if you don't understand something. Also, remember you have the right to request a second opinion if you wish. Always trust your instincts, nobody knows your child better than you.

Make sure you understand how the surgeon and center staff will communicate with you—and how often—during surgery. How long will the surgery take, when will you get updates, who will deliver updates, when will you meet with the surgeon?

The average length of stay for open heart surgery is 3–7 days. However, that varies widely depending on the age of the child, how quickly he or she recovers, and how strong the child was to begin with. Ask what milestones your child has to reach before being discharged. In planning your hospital stay, plan on a longer stay and be pleasantly surprised if you are discharged early.

You may be asked if you would like to speak with a chaplain or social worker. Know yourself and what would help in this difficult and emotionally exhausting time. Take all the help that you are comfortable with and gratefully accept or refuse help as you see fit.

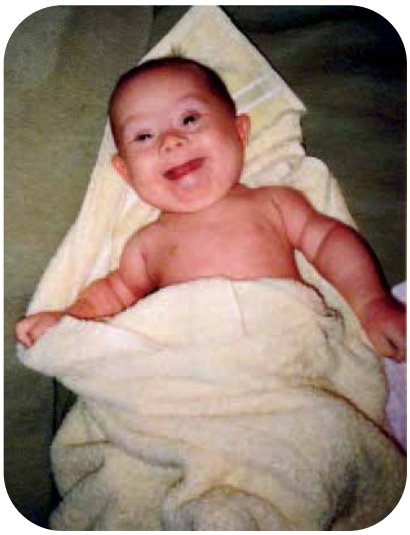
Never missed a beat

Karley's story by Jamie Burch

When Karley was born, at thirty-eight weeks along, I waited for her cry of life but it did not come; she did not make a sound.

I yelled at her, "Karley, breathe!"

The hospital staff put her in a bassinet beyond the foot of my bed and I noticed her feet and hands were purple. She was not receiving enough oxygen. The room felt like it was closing in and the voices in the room sounded further and further away. The only thing I could see was my baby lying motionless under a bright spotlight, being flipped, patted, rubbed, and suctioned, and everything else faded away to gray. The ticking second hand on the clock was the only thing I could hear and the time between every second felt like an eternity. Moments later, I heard a little sound like a newborn kitten crying, and we both began to breathe again. Everything slowly came back into view around Karley and then me. The nurses and doctors were rushing around but I knew whole-heartedly that everything was okay with her now. As long as she was alive nothing else mattered.



Karley received an Apgar score of six at one minute, and nine at five minutes. She was fine. All night Karley slept in my arms in bed. I woke myself up every few hours to nurse her but I noticed she wasn't as hungry as her older sister was after she was born.

The next morning, my husband Kristian went with Karley for a thorough check-up and a chest x-ray. She also received some oxygen to increase her blood oxygen saturations. The two of them soon returned and there we were, the three of us together. Kristian and I were standing next to our daughter's bassinet, marveling over her beauty and perfection. We were feeling blissful and overjoyed.

After a while, a doctor came into our room and closed the door behind her. She said she had examined Karley, and consulted with other staff members to get their input about her suspicion that Karley had features consistent with Down syndrome.

Karley was transferred to a bigger hospital in Portland shortly thereafter. I signed myself out of the hospital early to ride in the ambulance with her and be by her side. She was admitted to the neonatal intensive care unit (NICU) where we met with specialists who had expertise in genetics and in pediatric cardiology, as her chest x-ray showed an enlarged heart, a possible sign of heart disease.

She was given oxygen for twenty-four hours due to vascular resistance until the flow of her blood became strong enough to push blood through her circulatory system. Karley also received phototherapy to treat jaundice. Through an echocardiogram it was discovered that Karley had two holes in her heart; one atrial septal defect (ASD) and one ventricular septal defect (VSD). Finding out our new, little daughter had holes in her heart was one of the scariest times we have faced. A heart issue could end her life and was much more frightening than probable Down syndrome, which was something she could live with.

When Karley's geneticist advised us a few days later that her genetic test revealed an additional chromosome twenty-one, confirming Trisomy 21 (Down syndrome), we were relieved. We had pretty much already confirmed her diagnosis ourselves and all of the waiting, wondering, and not knowing for sure was dreadful. It was good to have an answer.

We were released home after our stay in the NICU, told to get CPR training, and instructed to wait and see if her heart would repair itself over the next few months, or if she began to show symptoms of heart failure.

At home I continued to breastfeed Karley, and also pumped extra milk for bottle feeding. Though she was a good nurser, she tired quickly and broke into a sweat from the effort it took to nurse. The lactation specialist at the hospital gave me a Haberman nipple to use for her supplemental bottle feedings every two hours.

Our days at home together strengthened us both. She steadily grew, worked toward milestones, and amazed us every day.

Then one evening while my husband was holding Karley and sharing smiles, she suddenly went limp and

stopped breathing. Even though she started breathing again a few moments later, she was pale and lethargic, so we called 911 right away. We went by ambulance to the hospital to find out what was going on. She had pulmonary edema, a build-up of fluid in the lungs from congestive heart failure. We stayed in the hospital overnight and they were able to temporarily help her.

A few days later we went to a follow up appointment with Karley's cardiologist. The good news was that Karley's ASD had gotten smaller and there was no leak in her mitral valve cleft, but her VSD was the same size and it was discovered that her patent ductus arteriosus (PDA) was still open. A determination was made that Karley would need open-heart surgery by the time she was four months old.

Until her surgery we did everything we could to keep germs away from her, including limiting visitors at home and feeding her as much as possible to help her gain weight to prepare for surgery.

We had to come to peace with the fact that when the time came we would be literally putting our daughter's life in someone else's hands and that we had to do this in order to save her life. We began preparing ourselves for her surgery by meeting with the surgeon and asking questions, reviewing the information about her pediatric congenital heart defects, talking to family members and friends about her upcoming surgery, and by arranging time off work for Kristian for the surgery.

When the day came we arrived at the hospital at 7 AM on a Thursday, ready for a week-long stay. An hour later our family was gathered together in a small room to see Karley off. A hospital chaplain stopped in to say a prayer for our family. We talked, hugged Karley, and kissed her before the anesthesiologist came. I held my baby close and whispered in her ear, telling to her to be strong, she could do it, and I loved her and I would see her soon. Karley left in the anesthesiologist's arms; they walked through double doors that swung shut behind them.

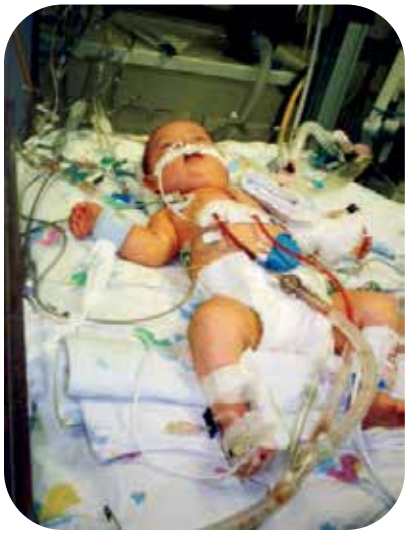
It was the first time we had ever been apart and I already missed her desperately. Now all we could do was wait. Two hours later a nurse came into the waiting room to tell us Karley's tubes were in place and she was hooked up to the machines for surgery to begin. In between updates from the nurse we visited with family, read, looked through optical illusion books, had lunch, and walked around the hospital.

Even though we had family that came to support us and we were told the statistics of success were on Karley's side, I felt so alone not knowing anyone else who had gone through the same thing we were going through. I wished there was someone there to talk to who could reassure us with their story of their child who made it through surgery.

Another update came that Karley was on the heart-lung machine, and an hour later we were updated that she was off the machine.

When the nurse came in the final time she let us know that Karley's breastbone had been wired back in place and they were almost done stitching her chest closed.

Another hour went by and then we got our first glimpse of our little girl as her surgeons transferred her down the hall to the Pediatric Intensive Care Unit (PICU). She was alive. She made it. I couldn't wait to hold her hand and talk to her.



Within ninety minutes we got to be with her in her room. She had a central IV in her neck for medicine and fluids, a breathing ventilator tube in her mouth to her lungs, a nasogastric (NG) tube through her nose to drain stomach fluid, a blood drainage tube coming out of her chest, pacemaker wires attached to her heart in case an irregular heartbeat was detected, a catheter to drain and measure urine, and an arterial line in her arm to monitor her blood pressure.

I didn't care about those things though; I just wanted to be near her and use the power of my touch and sound of my voice to help her heal faster and to let her know I was there.

By 10 PM that night her arterial line was removed, the next morning her breathing tube was taken out and it was then that she began to vigorously kick her feet. Saturday morning she grasped my finger and her catheter was removed and replaced by diapers. Kar-

ley's chest tube was removed forty-five minutes later and then half an hour after that she received sugar water as nourishment. That afternoon an oxygen mask was put on Karley because she was not breathing deep enough.

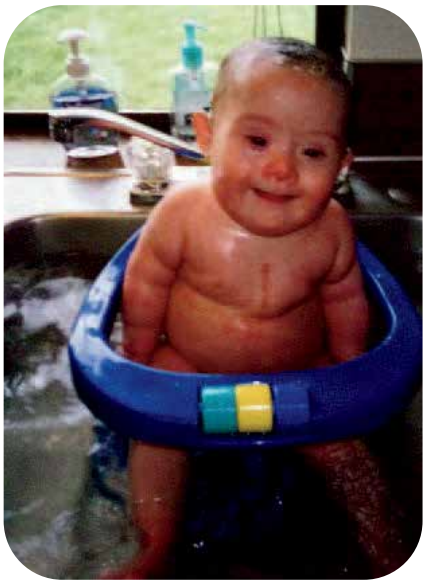
I watched her smile in her sleep and was so grateful.

A few hours later, she was given a breathing treatment because her carbon dioxide levels were high. A few hours later her potassium was low so she received another breathing treatment and antibiotics, and thick, yellow mucus was suctioned out of her nose.

That night Karley received a third breathing treatment and she opened her beautiful brown eyes for the first time.

The next morning she received sugar water and my breast milk by bottle. That afternoon I got to hold her and feed her a bottle of breast milk for the first time after surgery.

By five that evening she was moved out of intensive care and sent to general pediatrics. Two hours later she was cooing, drank a sixty-milliliter bottle of breast milk and nursed for ten minutes.



That night Karley kept trying to pull the oxygen tube out of her nose. Just after midnight she received her last dose of Morphine. Four hours later she was given Tylenol with codeine for pain, Lasix diuretic to reduce the amount of water in her body, and an antibiotic. Finally, her pacemaker wires and the telemetry box (EKG monitor) were removed.

We spent our last night in the hospital and the next morning she was discharged and we went home; it was the best Monday. We were so excited to watch her blossom minute-by-minute now that her blood was flowing properly with the help of a repaired heart.

It seemed like the moment we got home I could see Karley growing in front of my eyes, as if she had never missed a beat. She looked, lifted, rolled, reached, gurgled and grinned with more purpose and poise than ever. She was like a caterpillar that morphed into a beautiful butterfly and had just found her wings; she was now able to be free and explore the world from a new perspective with a new strength.

From then on Karley's baby-tude kicked in full-force and her big personality really began to shine. She amazed us every day with her courage, will, independence, and intelligence, captivating our family and catching the attention of others around us.

We still have a hard time fathoming the precise and delicate skill needed by the pediatric heart surgeon to work on her tiny little heart, only about the size of her tiny fist.

We are so grateful for the technology and expertise that saved Karley's life. Most of all we are forever indebted to Karley for coming into our lives. The experiences we have had since her birth and the journey we are on now because of her have enriched our lives more than we could have ever imagined.

Today Karley is ten years old and only has to check in with her cardiologist every five years. She is a Girl Scout, friend, classmate, performer in her school Musiking group and is a fourth grader in a general education classroom at her neighborhood school. She has been in community cheer, taken hip-hop dance, and played t-ball. At home she is a daughter, sister, pet lover, reader, artist, dancer and the list could go on. Karley is so full of life and love.

We wouldn't want our lives any other way. There have been trying and scary times like heart surgery, but those moments will never outweigh the joyous and amazing times we have had and get to have with Karley for the rest of our lives.

A sigh of relief

Isaac's story by Carrie Hutchinson

When our family decided it was time to add another member, we thought it might take up to two or three years for the right situation to come along. Instead, less than three weeks after our home study for adoption was completed, our newest son was born.

The e-mail from the agency was brief: "Biracial, baby boy, 6lb. 6oz., 17 in., APGARS: 8.9, minor heart murmur. He has more than one marker for Down syndrome..."

With my husband and 15-month-old son, I flew to Kansas to meet our baby boy. He was tiny and beautiful, and being prepped for intestinal surgery when we arrived at the hospital. I worked hard to stay calm amidst the high-running emotions: elation, excitement, fear, uncertainty.

Isaac made it through his first surgery with flying colors, and we brought him home to Portland shortly after. His first appointment with a cardiologist was two weeks later. Isaac's scans showed that his patent ductus arteriosus (PDA) had already closed, but his atrial septal defect (ASD) was fairly significant.

His cardiologist was great and took plenty of time to explain the details. The good news, his defect was shunting left to right, which is better than the opposite. There was tissue in the hole, so even though the gap was eight to nine millimeters, the blood wasn't coming through in one big gush, but split into at least three different little channels. There was a possibility that as he grew that tissue would stop up the hole more and more.

We set an appointment for six months later. In the meantime, we enjoyed our 'babymoon' and settled into being a family of seven.

At the next appointment, I was really hoping the ASD would have become smaller, but no such luck. It was the same size and was not going to resolve itself. The right side of Isaac's heart was more enlarged.

The doctor thought he would be a good candidate for a procedure where they insert a device through a catheter in his groin, so not technically "surgery". He would only have to spend one night in the hospital. The cardiologist wanted to do the catheterization procedure sometime in the next nine-to-twelve month range, but he also wanted Isaac to gain more weight. I was disappointed that things hadn't resolved on their own, but confident in the doctors, and actually getting anxious to get his little heart working more efficiently.

Isaac was a big eater, but his weight gain was really slow. Also, I was nervous because he'd had several weeks of being sick (with so many siblings, there are a lot of germs that travel through our house). He seemed to have a harder time kicking a virus than his sister or brothers, and I couldn't help but feel that I needed to be more careful with him than my other kids, like he was 'delicate' in some way because of his heart issues. Though I tried to let him be as rough-and-tumble as he wanted, I was a bit over-protective. The next appointment with his doctor was three months out.

We found out that his ASD had grown bigger, and we scheduled his cardiac catheterization repair. The increased size of the hole put Isaac at a higher risk that the repair wouldn't work, and if that happened he would need to immediately have open-heart surgery.

The catheterization procedure would be much simpler and he'd only spend one night in hospital, as opposed to the likely two-week stay for surgery. Recovery would be easier, there'd be no need for bypass or transfusion, and it didn't frighten me nearly as much as surgery.

On the day of the procedure, my husband and I, along with Isaac and his baby brother, hung out while we waited for them to get things ready. We let the boys explore in the hospital playroom a bit before heading to our room to get Isaac gowned up. He didn't seem to mind that the only available gowns had pink whales!

While we were there, we realized that a friend from NWDSA was having her heart fixed the same day, by the same doctor!

We ended up waiting quite a bit longer than we expected to get things moving. The boys napped, and I kept friends and family updated online.

Then it was time.

I gave Isaac a kiss, and handed him over to the team of nurses. We waited, and hoped, and prayed that the catheterization procedure would be successful.

As time went by, we got more nervous; they were taking longer than they had anticipated. Finally, a nurse came to give us the good news—they were able to close his ASD with the device! They had to try three different sizes before finding the right fit, but were fi-

nally successful. I breathed a sigh of relief, and eagerly followed the nurse to recovery, so I could snuggle Isaac up in my arms.

Isaac had one episode of pain/agitation/hysteria after coming out of anesthesia, which was really scary.

After ten minutes of consistently rating '10' on the infant pain scale, and my own episode of getting a bit hysterical, they gave him Fentanyl and he was able to rest more easily. He had a number of tubes and wires hooked up to him, but we managed to work around them so he could breastfeed, which helped calm him and I both down. A bit later he seemed really swollen, which I hadn't expected, and that was scary, too. The nurse explained it was from the IV fluids, and gave him Lasix, which helped him look more like himself.

Less than twenty-four hours later, he gave us lots of smiles and was even kicking around and playing. He clearly felt better, and was ready to get back home.

The day after we got home, Isaac sat up by himself for the first time! He started putting weight on more quickly, and didn't tire out so easily.

Four days after his heart fix, Isaac celebrated his first birthday at home, eating pie. Over the next year Isaac was followed by his cardiologist, while we waited for his repaired heart to completely close up (there was some shunting around the device for a while). Our next appointment wouldn't be for three years, and we expect that after that point, he won't need to be followed by the cardiologist.

Now, at four and a half years old Isaac is a healthy, sturdy little boy, climbing, running, singing and dancing, keeping up with his siblings with energy to spare. We can't imagine our family without him.

Blossoming

Abigail's story by Carmelle O'Dell

My husband and I first learned that Abigail had an extra 21st chromosome when we received our amniocentesis results. While we were still grappling with that news, it was suggested to us that we get a fetal echocardiogram, because with Down syndrome, she had around a 50% chance of having a heart defect as well.

At 18 weeks gestation we had the fetal echocardiogram. The procedure was very similar to all the ultrasound screenings I had before, but much longer and more detailed. The technician was very thorough, methodically moving through each chamber of her heart, explaining everything he saw. He assured us he didn't see any heart defects. We left our appointment feeling relieved that her heart was healthy.

The days were fast approaching to Abigail's due date. Even though we had a plan, Abigail had her own ideas, and I ended up going into labor at thirty-six weeks, two days and we rushed to the hospital.

Because of our prenatal diagnosis, and her slightly premature status, the staff from the neonatal intensive care unit (NICU) was waiting and as soon as she was born, they whisked her away and put her in the care of the NICU.

They ran a lot of tests and monitored her closely. She had a very weak suck and couldn't breastfeed, so they placed a nasogastric (NG) feeding tube through her nose and into her stomach. When she was three days old, the doctors told us that they discovered a heart murmur.

The next day, she had an echocardiogram that showed two large holes in her heart – a ventricular septal defect (VSD) and an atrial septal defect (ASD). The doctors in the NICU thought they may close on their own, and we hoped that would be the case. How could this be? Her heart was supposed to be fine. We were in shock. The doctors explained how there were different pressures on the fetus' heart while in the womb compared to being outside of it and that is why the fetal echo didn't pick up the holes. Reality began to sink in…our precious little girl was going to require major surgery if she was going to make it.

Over the next six weeks, Abigail was in and out of the NICU. Her biggest barrier to staying out of the hospital was not being able to drink enough from a bottle.

Our only option for taking her home was to embrace the NG tube. My husband and I looked at each other and knew that is what we had to do, so the medical team taught us how to place the NG tube on our own, and check for correct placement with a stethoscope. It was critical that we did this correctly. If the NG tube went into her lungs and we did not check placement, we could fill her lungs with milk instead of her tummy.

I cannot say enough about the hospital staff. They were very involved and supportive. The neonatologists always found us and talked with us, and the social workers checked in with us, making sure we had all of the resources we needed. It was a difficult time and they knew it. They were simply doing their job, but their skill and compassion made it bearable.

I remember very clearly Abigail's first appointment with her cardiologist. The doctor informed us that her ASD and VSD were large holes that would not close on their own. We were so surprised that she needed surgery so soon. They wanted Abigail to gain enough weight to have the surgery by around five months old. Abigail had to take Lasix and Digoxin to help prevent her from going into congestive heart failure. We were already wondering about the financial implications of her time in the NICU and what our insurance would cover, and now we would have to add heart surgery to our medical expenses.

In order for Abigail to gain the weight she needed to, I pumped and supplemented my breast milk with preemie formula every three hours around the clock. It felt like Groundhog Day, as my husband's sport watch chimed every three hours. We were going into the pediatrician's office every few days for weight checks. We were exhausted and emotionally a wreck. I remember breaking down in tears in her pediatrician's office, wondering how long we could keep doing the feedings every three hours and how long she would have to have the NG tube for feedings.

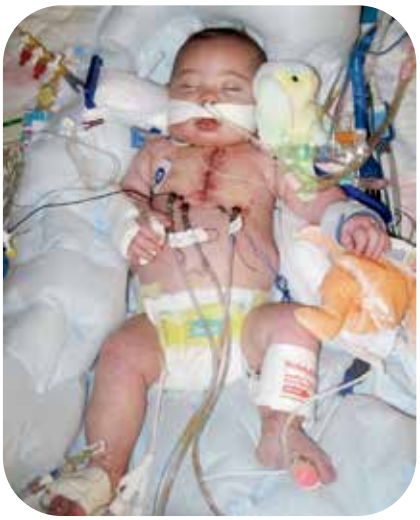
Her doctor promised me we would get through this, but she may need the NG tube until she had her heart surgery. She was just too weak to drink from a bottle or nurse on her own.

Around a month before Abigail's surgery, we went to a seminar put on by NWDSA. It was a great morning of networking with other families of children with Down syndrome. We met a family whose son had

open-heart surgery. It was great to be able to hear about their successful experience. Later, they emailed pictures of him after surgery. I was so glad to be able to hear their story and see pictures of their son as he recovered from the surgery. The pictures were very graphic and a little gruesome, but something I was so very grateful to see.

When Abigail was close to five months old, she had finally gained enough weight for surgery. Her cardiologist took her case to the physician's board where she was assigned surgeons and was scheduled for surgery on December 22.

The day before surgery, we went to the hospital for a preoperative clinic appointment where Abigail underwent several tests. We met the surgical team who thoroughly explained the operation and what to expect, and we met with the Child Life Specialist for a tour of the Pediatric Intensive Care Unit (PICU). We were also given a very detailed notebook with contact information of the surgery team, what to expect during the surgery and recovery period, and several detailed diagrams.



At last, the day of Abigail's surgery was here. We filled out even more paper work, including the consent form, which had some very somber language. We said our goodbyes and watched them wheel her away and the double doors close in front of us. At that moment I was powerless but hoped and prayed for the success of the surgery. It was a very surreal experience to know my baby was having her heart stopped, repaired, and

restarted, and I just had to wait and hope everything was going well.

The staff checked in with us several times throughout the surgery, updating us on the progress. I am so thankful for the expertise of the surgeons, all of the other doctors, nurses and medical staff.

Seeing her in her PICU room was a bit of a shock. She was so tiny and helpless, hooked up to so many tubes and wires. We hardly recognized her. We couldn't hold her for several days as she couldn't be moved.

We knew we would be spending Christmas in the hospital so we brought in a small artificial Christmas tree. We tried to make things as cozy and "normal" as possible. There were several volunteers who made sweet posters for Abigail's room, and brought in some ornaments for the tree.

We were relieved the surgery was over, but our ordeal wasn't over yet. Abigail's heart rhythm wasn't normalizing after surgery; it was in junctional ectopic tachycardia (JET), which means her heart was beating fast, rather than at a typical rhythm. The doctors described that this is to be expected in a percentage of cases, but it was still concerning to us.

They had two options, drug therapy or they could induce a mild state of hypothermia which would slow her heart naturally, and they could reestablish the proper rhythm with the use of the external pace maker.

With an ice water bed beneath her, and a blanket inflated by fans blowing cold air on top, doctors carefully brought her body temperature down to about ninety-two degrees. The room was so cold, we had to wear coats and hats and sit covered with blankets.

After a few days, her heart slowed down, but the rhythm was still irregular so she was connected to an external pacemaker. After a couple of days, her heart finally reestablished a proper rhythm.

Abigail recovered from her heart surgery as well as could be hoped for and she finally could drink from a bottle.

After a six-week recovery period, Abigail resumed physical therapy. She certainly had some setbacks due to her surgery and recovery time, but she was making progress! She had so much more energy and stamina after her heart surgery to be able to exert the effort to do physical tasks; it was like she was a new child. We were grateful to have this chapter behind us.

We are so glad Abigail had a second chance at life because of her heart surgery and moved beyond that to meet life's next challenges. Currently she is attending two preschools. We have seen her grow and blossom socially and academically. Nothing has been easy for her, but she has determination and a strong will to keep trying and eventually she achieves her goals. She is blossoming and meeting her milestones. She is growing, learning, communicating and excellent at interacting. Abigail is truly a ray of sunshine. Anywhere we go, she smiles and waves at everyone she sees, and gets many smiles back. People that we see on our daily and weekly outings go out of their way to make sure they get their "Abigail fix" of smiles, waves and hugs.

Looking back as I write this, remembering how daunting receiving the diagnosis of Abigail's heart defects was, I can say that we made it, and she's better than ever! I am thankful for being able to connect with other parents who have been through the surgery as well, and hope we can offer our story as encouragement to other families as they face surgery for their child.

Taking action to fix her heart

Anna's story by Janine Paschal

After our daughter Anna was born we received her diagnosis of Down syndrome. Almost immediately, we were referred to a pediatric cardiologist so her heart could be checked for defects. We were told that this was standard practice for babies born with Down syndrome because of the high incidence of heart defects in the Down syndrome population.

During the echocardiogram, the cardiologist and ultrasound technician were conversing and it became obvious to us that they saw something. Upon comple-

tion of the exam, we met with the cardiologist who confirmed that they had found an atrioventricular canal defect (AVCD) of the atrioventricular septum of the heart.

An AV canal defect essentially means that there is a large hole in the heart and that the valves are not working properly. We also learned that Anna had only one large valve rather than separate mitral and tricuspid valves. The cardiologist explained very clearly that her heart was working too hard and that she would need surgery to repair the defect. He discussed the symptoms that we should watch for and told us our observations and reports would help him know when it was time to schedule the surgery.

It was a lot to take in given that we were still reeling from the Down syndrome diagnosis. The difference was that the heart defect was something that could be fixed. It was something about which we could take action. Taking action felt good. At the time, we didn't really know what to do with the Down syndrome diagnosis. There wasn't a fix. There wasn't a doctor who could take away that extra chromosome. So for a short while we focused on the heart problem.

From the start, Anna wasn't eating well. She wasn't gaining weight. She was eating from a small tube attached to my finger and we prayed that she wouldn't need a nasogastric (NG) tube. When I told the cardiologist how thrilled we were when Anna finally started nursing, he cautioned that it might be too much effort for her and to watch closely for signs that it was taxing her system. After a few short months, those signs became apparent. Anna would eat for a minute or two, pausing often to catch her breath, and immediately fall asleep. By four months, she had only gained three pounds. It was time to fix her heart.

The staff at the hospital talked us through the procedure and helped set our expectations for the day of the surgery. Everything went as planned and it was time for us to hand our beautiful little girl to the surgical team. That was the hardest part. We kissed her goodbye and told her we love her and we'd be waiting.

While Anna was in surgery, we were shown pictures of other children who had similar surgeries so that we would be prepared for what we would see when Anna emerged from the operating room.

It was helpful to see all the machines and tubes and understand what the function of each was. We waited, time passed slowly then we were told that the surgery was complete and they would be wheeling Anna to the pediatric intensive care unit (PICU) soon. We were able to stand in the hallway and glimpse at her as they transported her from recovery to her own room. It was difficult to see her and not be able to spend time with her, but really good to know that she had done well.

The doctor told us that the operation was successful and that they had closed the hole and reconstructed Anna's heart valves so that she had working mitral and tricuspid valves. It took another hour or so for the team to get Anna settled into her room and to monitor her before we could go in and sit with her.

Within a couple of days, Anna was eating much more than she ever had. We watched as her skin took on a healthy color and she became more alert. After five days, we were able to take our girl home. While we still had to be careful about exposing her to germs and illness, life became more routine for all of us.

After Anna was released from the hospital, she gained weight quickly and became a lively, delightful baby. What a change from her first few months! Her heart functioned perfectly and we no longer wonder what action to take about the Down syndrome diagnosis. It's who Anna is, she doesn't need to be fixed, no action necessary.

Today Anna is an active seven year old who participates in whatever activities interest her. There are no medical restrictions that linger because of her heart defect.

Moving forward with Baby B

Beatrice's story by Stacy Renfro

To get pregnant, my husband and I did in vitro fertilization. We found out at five weeks along that we were having triplets. It was very exciting, except to the doctors who seemed appalled and apologized to us. It was suggested that we selectively release because of high risk but we didn't want to stop the pregnancy. We agreed to only non-invasive testing.

The results were normal for all our babies and we didn't want any more genetic testing. Later I was hospitalized because baby Beatrice had issues with her umbilical cord being wrapped around her. We were monitored and released and there were no other indications of complications for the duration of my pregnancy.

Beatrice was baby B, the second of three of our babies born June 30th. Immediately, I noticed Beatrice's protruding tongue when she, her brother and sister arrived. Beatrice's siblings came out of the NICU just a few hours after they were born, but not Beatrice. We asked question after question about baby Beatrice but no one was willing to say anything until genetic testing was done. When the genetic results came in we found out she had Down syndrome and while they were taking a look over her, they found two problems with her heart, a ventricular septal defect and an atrial septal defect. When we found out she had holes in her heart, we knew right away she would be facing open heart surgery.

After nine days in the NICU we were able to take Beatrice home. Before Beatrice could have her surgery we were told she needed to be big enough and strong enough to handle the procedure so that became our focus. In the fall, when our babies were about four months old, we attended NWDSA's Reciprocal Learning Community (RLC) session. We met a baby there who was also facing an upcoming heart surgery and a couple of families who had children that had been through surgery. They explained that they were scared too, but no matter how scary heart surgery seems, it is necessary. These families helped us see that even though our daughter was going to have a major surgery, she would be so much better on the other side. It opened the door to understanding that this is what she needed to be able to thrive.

That winter, as we entered cold season, we needed to keep Beatrice healthy for her surgery. This was challenging because she continued to have a runny nose which set back surgery dates. However, it allowed us more time to work together with a physical therapy team to get her stronger for surgery.

We were able to compare Beatrice to her siblings and realized she was out of breath and having trouble with little things more so than her brother and sister. It was apparent that she need more oxygen and wasn't getting it. Finally, in January, we had a window during which she was healthy and we scheduled the surgery.

We prepared for surgery by concentrating on what Beatrice needed to succeed, which was her physical strength. We took care to keep her strong and healthy in the hope she would have a short recovery time. Our emotional preparation was by building in family time and giving each other sanity checks. As far as mental preparation we asked a lot of questions of our medical team. I think our advantage was being able to really understand that the surgery was so important and that her surgeon was an experienced professional.

We had to believe it was the right thing and what she needed. We knew we would get through it and move forward after that.

On surgery day, I packed a book to read and the care package my older son's teacher put together to take our mind off things, which included a throw, magazines, some chocolate and a bottle of water.

We had already arranged for family to take care of and entertain our other kids and my husband was able to take time off work. Before the surgery my friend and I drank some stress decompression tea to help me relax. I actually went in to her surgery feeling centered and calm. During Beatrice's surgery we went on walks around the hospital and tried to rest while we waited. We learned that Beatrice had a third defect that was found and needed to be repaired as well.

When I got to first see Beatrice after surgery, I was

shocked to see the drain tubes coming from her body. I knew she would be bound up and her small incision site was just a little line, but I wasn't prepared to see her somewhat upright with tubes coming from big holes in her chest.

During her recovery I stayed at the hospital with Beatrice and was pumping for all three babies. It was a couple of days before she was able to have milk or formula, though. There were concerns with her developing mucus and it took her a while to stabilize.

When they removed her intubation tube, Beatrice became hysterical. I got upset and had to leave the room. When I returned the doctors said they decided to re-intubate her. For five minutes I held Beatrice's hand and used my brainwaves to tell her to calm down, breathe, and that she could do this. The doctor returned and said her carbon dioxide levels were too high. Twenty minutes later they tested her again and everything was back on the right track. Fortunately, she did not have to get re-intubated again.

The next day we were ready to go home. Beatrice had been in the NICU for over a week.

She was such a different child after surgery. She was always happy and sparkly but after her surgery she was like a firework. Her energy level went up tenfold and her engagement and interest in everything was dramatically different. She shifted into high gear and we could see it immediately. Beatrice was on medication for a year after her surgery for hypertension but she did great. We had regular checkups with her cardiologists, then annual check-ups and now have transitioned to check-ups once every three years. Her heart surgery prepared her well for another medical challenge she faced later when she had a stroke.

Beatrice was diagnosed with a rare disease called Moyamoya that is a degradation of arteries in the brain that diminishes blood to the brain. Her brain was deprived of oxygen but not because of clots from her heart. Her strong heart is what has kept her going.

A year later she is in preschool, and even though her right side was affected, she is working hard on walking and talking. Cognitively, she didn't lose any progress from the stroke, but she did physically. We are working on building her skills and developing tools for her to use. Without the heart surgery we may be telling a different story.

This little girl is our ambassador. Beatrice loves people and finds new friends wherever we go. She loves to wrestle with her brother and sister. She dives right into family life and shouts our names. She plays with her toys, games, and puzzles. She loves art and Play-Doh. She crawls fast and climbs the stairs and chases the cat and dog. She does get frustrated though because her body doesn't always do what she wants it to do but she continues to try.

People always say that no question is a dumb question and that is really, really true. If I could give advice to other parents who have a child facing heart surgery it would be to ask questions and if they aren't being answered, ask them 15 different ways to get them answered. Heart surgery is a very specific fix and there is no mystery behind it so find out every detail and what to look for. If you run in to someone who says, "Well, she has Down syndrome so we don't know," then you need to advocate for your child and suggest they find out and treat her as if she didn't have Down syndrome, just like any other child. The excuse of not knowing an answer because of Down syndrome does not fly. Surgery will make your baby better.

Bless his heart

Bob's story by Brenda

I was 'old'— in a higher risk category for complications and possible birth defects—when I became pregnant with my Lil' B. The doctor suggested an extensive ultrasound to rule out complications.

When the doctor observed extra skin folds on the back of my baby's neck and Lil' B's 'short' femur measurements, the doctor recommended an amniocentesis.

We waited a week for the results of the amniocentesis. I got "the call" at work in the middle of my workday. I was caught completely off guard and I began to sob as I ran to my supervisor's office and told her that my baby had Down syndrome and that I needed to go home. I drove straight to my husband's employer. I told him of our Lil' B's diagnosis. We wavered between shock and tears. That same afternoon we went to talk to a genetic counselor who presented us with very limited clinical information regarding the cause of Down syndrome.

I remember having a very similar conversation when we were later advised of Lil' B's heart defect. He had an AV Canal defect and a leaky heart valve. This would need to be repaired soon after birth via open heart surgery. We didn't know whether this would be the moment he was delivered or several months later.

I remember the birthing room being stuffed full of people. Not friends and family though, but lots of medical professionals in white lab coats. It seems they had scheduled every specialist to be there just in case something went awry, or if my tiny one needed his heart repaired the moment he arrived. However, as it was, when Lil' B was born he was fairly healthy. It had been a difficult, long labor but he was finally here and our adventure began. I remember my hubby being proud of his Apgar score. Lil' B was six pounds even and beautiful.

Our Lil' Bob had difficulty latching on and nursing due to his low muscle tone. This was troubling for me at first but nonetheless we used a Haberman feeder—a special tiny bottle for him to suck very small amounts of pumped breast milk. This became our routine for six months where I would pump and he would drink. We were working on getting him strong enough to have heart surgery. The goal was to wait until Lil' Bob was six months-old.

We had a few scares when we noticed Lil' Bob having trouble breathing. My husband had to perform CPR on him twice to revive him at home when his breathing stopped all together. We rushed him to the hospital where they eventually placed him on oxygen full time. When he was discharged about five days later he came home with monitors and oxygen tanks. As you can imagine, the nights were not restful.

The alarms would sound even if he just moved wrong and a lead came off. My stress level was pretty high dealing with feeding difficulties, oxygen and monitors.

At three months old, the doctors decided he was big enough and the heart defect troubling enough causing a lack of oxygen flow, that Lil' Bob could wait no longer for his surgery. It was time. I may have gone into some form of shock where I just did what I had to do each day to keep him alive until the doctors could 'fix' his heart. Looking back, I don't really know how I did it. I knew deep down he may not survive the surgery. The doctors explained in great detail the procedure, they gave us another book to read and I think there was even a video. I didn't have the energy to understand a lot of it; I was overwhelmed and frankly tired. I was still feeding him every three hours around the clock as he was gaining weight very quickly. I left what felt like the complicated stuff to the doctors and my husband—he seemed to absorb more details and technical information that was important to understand while I was caught up in postpartum depression and breast pumps.

It seems so surreal now. We had Lil' Bob baptized weeks before the surgery in a private ceremony with a pastor we had just come to know. Days later, my husband, my rock, and I took our tiny Bob to the hospital for a hopeful complete heart repair very early in the morning. I was numb as I answered insurance questions and changed Lil' Bob into his little gown. I wasn't crying but I was very heavy hearted just going through the motions and wanting to get through this.

A pastor met with us and prayed before they took Lil' Bob in for surgery. I also remember insisting my dad be there, from out of town. We were there together, these three strong men, me and my tiny one.

I still remember the moment I handed my infant over to four masked doctors for what could have been the last time. It really bothered me because I didn't want my perfect baby scarred for life.

After Lil' Bob was out of sight I wiped my tears and we settled into a waiting room, which was our home for the next five hours. We were fortunate to have a host of family and friends gathered there to support us that day. There was conversation and attempts at jokes to lighten the mood, anything to take our mind off of the reason we were all there. I remember feeling removed from everyone as I wondered how they were able to carry on a conversation.

The waiting time was not as bad as I expected it would be, however. It went by relatively quickly with everyone there to distract me. A nurse gave periodic updates throughout the hours we waited, which was nice but a little scary at the same time.

When it was finally time for him to go into recovery after surgery I rushed to see him the second I could. The nurses advised me he would be swollen but I was not prepared for what I saw. His whole body was blown up like a balloon and it seemed like every part of him was hooked up to something foreign. I was taken aback for a second and then I pushed forward. He was my baby and I needed to be close to him.

The next few days are a blur to me now but I know I refused to leave him; I didn't want him to ever be alone. My husband and I don't have any other children so we were able to stay at the hospital with Bob. We attempted to sleep on two cots in his room amongst all the machines and doctor and nurse visits.

Lil' Bob did have one complication; a doctor had to place a tube directly into his stomach (abdomen) to drain fluid off his heart right there in his hospital bed. (Today we say he is special because he has "two belly buttons".) I remember how difficult it was not to hold him for several days and how wonderful it was when I finally could. We were only in the hospital for five days which is pretty remarkable considering that it was major heart surgery.

When we got home, a health nurse came out and checked on him which was reassuring. I remember sitting there sometimes thinking, "Who is this baby? What have they done with Bob?"

He seemed so different as he healed. He was hungrier and able to eat better and he sure let us know! He was fussier but in retrospect that was probably more like how a healthy baby behaved. Before surgery he was so weak and now he was able to speak up even though his body was still recovering from all the trauma of surgery and all the different medications.

Today, Lil' Bob is a wonderful, funny, healthy young man. He loves to wrestle with his dad and giggles a lot. He keeps us laughing too. His diagnosis and heart condition has made him a little more susceptible to respiratory troubles but each year he gets sick less and less often. Bob's incision site stretched a little during the healing process but it doesn't seem to affect him. He sees the cardiologist for an echo cardiogram every two years because his heart valve leaks slightly. He will continue to be monitored as he grows to make sure the hole doesn't get any bigger and no further repair needs to be done.

Reflecting back, I remember the things that helped during this process such as having family around while we waited during surgery. I am now grateful that we found out in utero about Bob's diagnosis so we could prepare ourselves as best we could with knowledge and doctors to help us make a plan of action. Knowing the church community was praying and visiting meant a lot to me too. It was also wonderful to have my husband by my side at the hospital the whole time without the added stress

of having to go to work. There is very little I would've done differently. I do remember being bothered by the lack of privacy. The hospital room was essentially our bedroom yet we had people walking in at any time, at all hours of the night. I was still using the breast pump so it was a challenge to be discrete. I think it would have been better for my psyche to get out of the hospital more. I think I only left one time for my quick birthday dinner.

Perhaps I should have accepted other people's help a little more often, too. I encourage families to get support sooner rather than later. I waited six years to find a support group and now I wish I would've found them years earlier. I was so very alone, many hours at home just me and my baby. It doesn't have to be that way. Find a friend for your sake and for the sake of your family. You are not alone!

All kinds of wonderful

Charlotte's story by Faith Hayes

I was packing my bag to go to the hospital to have a C-section for new baby Charlotte; baby goodies and a cute outfit to wear with my red shoes. I packed a Sonlight read aloud from our home schooling 'to do' list because I had visions of all of us snuggled up with the new baby finishing our weeks' reading. I cooked some meals for the fridge and freezer and was feeling confident in our ability to bring in baby number four, albeit nervous about the actual surgery—boy did I have that backwards. My expectations were to party in the hospital room and I was giddy.

We didn't know Charlotte had Down syndrome until after a very quiet pediatric examination, about an hour or two after she was born. I think my heart stopped at the words, "Has anyone mentioned that Charlotte may have Down syndrome?" Soon after, the pediatrician listed a battery of tests that they were going to start in order to rule out certain issues.

Charlotte had an electrocardiogram done within the first 24 hours of her life to check her heart and we found out she had a defect. They didn't get specific about it and said details would come later at her one month follow-up appointment with a cardiologist.

Our bigs—our three older children—did okay with this news. We all knew this wasn't an optional surgery for itty bitty Charlotte. Some days there were quite a few tears over the 'what ifs' but we learned a very big lesson in 'one day at a time'. I will say that parenting the regular day to day stuff, while having a medically fragile baby, was a balancing act like no other; it felt more like swinging from one end of a pendulum to the other—it caused a wee bit of metaphorical motion sickness to be honest.

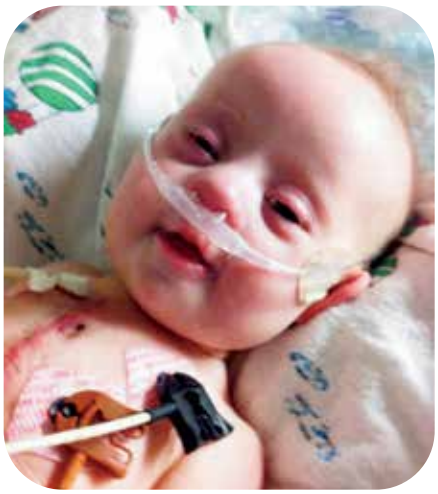
When Charlotte was about four weeks old we found out that she had an atrial ventricle septal defect (AVSD), with a PDA that hadn't closed. Basically, AVSD is two holes in the center wall affecting all four chambers of the heart and that meant open heart surgery was needed. One thing about this was that it was a blessing and a curse. The defect caused pulmonary hypertension (high blood pressure in the lungs) so the blessing was that it kept her congestive heart failure at bay. However, the curse—it was doing damage to her lungs. Since lungs are like sponges Charlotte's were filling with blood more than oxygen.

This meant having surgery earlier rather than later. My husband and I had to have hard conversations with our other kids to prepare them for the best and worst case scenario about heart surgery.

A few days before the surgery we went to the hospital to do all our pre-admission testing and paperwork. That was NOT fun. Charlotte had to have several tests done. Chest X-rays, EKGs, blood draws—It was very surreal holding her while allowing someone to poke, prod, and in general make her scream like we'd never heard. Part of me sat there whispering to her and trying to offer some comfort, praising God that these people knew how to do this kind of stuff and the other part of me wanted to smack the phlebotomist and run for the van. Once the entire test trauma was complete, we met with the surgeon, signed paperwork, and tried to ignore the list of possibilities.

The surgeon was a big guy and I couldn't help but look at his hands and wonder how in the heck he was going to patch holes in my teeny Bitty's heart. We prayed for him like crazy, big hands and all.

Then there were the surreal moments of packing for surgery day. Thirteen weeks after Charlotte's birth, almost to the hour, they would start the surgery to mend her heart physically. I packed for the hospital again but wasn't feeling excited this time. I packed fuzzy socks and jammies for Charlotte, with snaps all the way up the body because she would have tubes, wires, and major tenderness limiting what she could wear. I uploaded music to play while in the hospital and packed my Kindle to occupy myself with while I waited. The big kids picked out one goodie each for Charlotte; her older brother picked a little jingle bug he bought her for Christmas and the girls picked out a soft blanket each to send with her.



I tried to make some food for my family to eat while I was at the hospital and not on duty at home. All the while I ate stupid amounts of chocolate to try and distract my mind but it didn't work. I started a blog where my words, heart and mind collided.

We got to surgery day and walked through doors to check-in. It was not optional and turning tail and running would accomplish nothing so we held hands and marched on. Our pastor and his wife were there and helped us take pictures, made small talk, prayed with us, and chatted up the chaplain.

A friend who is a nurse in the Pediatric Intensive Care Unit (PICU) who was just coming off her shift came in to say, "Hi," and that she picked a good nurse for us. Eventually it was time to give Charlotte to the OR nurse and her daddy did the actual handing off.

Then we headed to the waiting room to WAIT; painful and good at the same time. Several friends came in and hung out, waited with us, chatted with us about other things, I called the big kids and chatted, and blessed the care nurse who kept coming in and letting us know how the surgery was going. I can't say with certainty how long this whole day was but I remember it being shorter than I'd expected and that when the surgeon came in and said, "It went great!" I finally exhaled fully.

After a bit we were able to go into the PICU to see her. Nothing can quite prepare you for seeing all that equipment surrounding your baby, but I am thankful for those friends and online support group members who had either posted their pictures or talked me through some of the elements we were going to possibly run into. I wasn't completely knocked over with the shock of it all. I remember two things vividly: She was so still and she was pink. Her nurse was awesome and did a great job helping us understand how to keep our Itty Bitty alive.

After a day they were able to take her off the ventilator. She had oxygen for a while to keep her going. Every morning they did chest x-rays to see how things were looking and by the next day she needed some help getting her lungs fully functional. High flow oxygen was ordered along with regular CPAP treatments. The respiratory therapist likened it to a dog hanging his head out the window of a car careening down the highway tongue out and mouth open. This air was humidified so her lungs wouldn't dry out so she basically bubbled her way through the next hours. It was between really funny and really sad watching her. Her little cheeks would just blow out continually like you'd just popped a balloon.

Eating with all that going on was pretty futile, but thankfully it wasn't prolonged. All told, we were in the hospital just over a week and that was only due to a slight hiccup she had with her arterial line site. She had either a clot or a bit of damage there. This put her on Heparin to prevent other clotting.

She stayed on blood thinners for about two months but never had any permanent damage from it.

Today Charlotte is 20 months-old and is truly all kinds of wonderful. The open heart surgery seems like it was a LONG time ago. We had a fun family dinner to celebrate her healthy heart date and Charlotte has had her one year post-op appointment. She passed every test with flying colors and had a super cute smile so that at the end of her appointment the cardiologist said, "See you in three years!" She has grown strong and healthy. Even her scar looks amazing.

The other day one of my girls was talking about it and commenting that it looks like an exclamation point. We think it's a pretty exciting reminder of the blessing that open heart surgery was for her and for us. Exclamation point indeed!

In bliss with my daughter

Cora's story by Leah Thompson

The moment I looked into my newborn daughter's eyes after a long home-birth, I knew that she had Down syndrome. It was an unexpected shock.

When the midwife finally broke the news, she listed the primary medical concerns, heart defects at the top of the list. At the time, nothing too disconcerting seemed apparent. We were planning to take her into a pediatrician in a couple of days for a battery of tests and referrals to specialists.

But the next day she began to repeatedly turn blue. We rushed her to the emergency room and she was admitted to the neonatal intensive care unit (NICU). A couple of hours later a cardiologist came in and an echocardiogram was performed. At the time I was so exhausted and still in shock. I could barely make out what he told us. He drew us a picture of her heart and told us she had a defect known as a complete atrioventricular canal defect (AVCD), also known as atrioventricular septal defect (AVSD). Her ventricular septal defect was huge. There was considerably more hole than wall. There were at least two atrial septal defects. In my mind I was imagining an irreparable diagnosis, so I finally managed to ask if it was something that could be fixed. For a split second I could have sworn he said no. When I realized that indeed it was fixable, I could breathe again. He told us that she would need open heart surgery between two and four months of age, and listed off what we could expect in the meantime as she progressed into congestive heart failure. The idea of waiting and watching my only child deteriorate seemed impossible to fathom, but at least there was something to be done.

Cora spent the next 18 days in the NICU to treat jaundice and to try and learn to eat enough to go home. Those days were hard. We spent every day next to her bed, trying desperately to get her to eat. While she was there it became clear that heart failure was already starting, so she was put on medication. I cried when I realized it was all starting so soon. Eventually after much back and forth we were able to persuade the doctors that we were responsible enough to take her home with a nasogastric (NG) feeding tube. We underwent trainings and took our girl home with an apnea monitor and lots of feeding tube supplies and continued the process of waiting for surgery.

Our lives became all about feeding our daughter. Every milliliter taken by bottle was recorded, every episode of her profuse vomiting estimated, every wet diaper recorded on our clipboard. I was committed to providing her my own milk, so I pumped constantly.

I was initially devastated that she wouldn't nurse, but I held out hope that maybe she'd start to nurse after surgery was done. We processed and stored my milk, adding formula and skimming fat from reserved breast milk for extra calories. Cora was able to eat without the feeding tube for a few weeks, but gradually her feeding worsened and the tube came back. She became pale and began sweating all the time. Eating just half an ounce by bottle would drench her from head to toe. Her reflux became horrible: retching, gagging, heaving and vomiting at all hours, and not just after feeding. Her breathing was labored. I could see the skin around her ribs sucking in with each breath. Her medication dosage was increased.

When we took her back to the cardiologist at ten weeks old, I expected to be told he wanted to do surgery within a few weeks. For some reason I never really believed that the time would ever arrive. So when he told us that he wanted to do surgery as soon as possible I was surprised. We were in on Thursday and we scheduled Cora's surgery for the following Tuesday.

When we went for her pre-operative appointment we met the pediatric cardiothoracic surgeon. He gave us a consent form to sign and had written three big words in the "risk" section: "bleeding, infection, death." The third word shot like an arrow through my heart. He explained that he performed this surgery often with very good results and that the risk of death was very small: less than five percent. I know now that the statistics are even better than that, but my mind kept coming back to the thought that my risk of having a child with Down syndrome was less than that. I tried so hard to practice positive thinking and to picture her recovering from surgery and healing at home; anything to keep my mind away from the worst case scenarios, but in the back of my mind, it was impossible to ignore it. I was so afraid.

The morning we took her in for surgery we got up at about 2 AM to get to the hospital on time. She was eleven weeks old. We went through check-in and waited, then walked her down to the room and handed her off to the surgical nurse. I staggered away crying. Then we waited. When the nurse came back to update us on her status, though, she said that there was an emergency with another child and that Cora's surgery would be postponed. But she had already been anesthetized, ventilated and had been given a central line, so they kept her in the hospital until the next day.

For some reason, things felt so much better on the second try. It was somehow easier to hand her to the nurse. I felt more at peace, calmer, and more certain that she was being protected. In my own heart, I knew that she would be fine that day. And the wait was easier too. We eagerly anticipated each update, and cheered when the surgery was done.

Later we were able to visit her in the PICU. Luckily I had prepared myself by reading blogs written by other parents of children who had undergone open heart surgery, and had looked at a number of postoperative photos. So I knew what to expect when I saw her lying in her bed. But as prepared as you try to be, you can't know how you'll really feel when you see your own child covered in tubes and lines with a wound on her chest. Every time she would flail and try to open her eyes my heart would lurch.

But she was already pinker. Her blood was flowing properly for the first time. Things went uphill from there. Within a couple of days she was taking full bottles for the first time.

She got better and better and we took her home five days later, thankfully with no complications.

A week and a half later, she began to breastfeed. I was overjoyed and amazed. Within days she was refusing bottles entirely. She began to grow. She showed us that she could actually cry (whereas before she didn't have the energy to do so) and she was fussy for a couple of weeks post-surgery. But gradually that went away. She started to smile and then laugh. She started actually living.

Our lives started too. Once she was home I was in complete euphoria, for the first time truly recognizing how difficult the prior three months had been. Finally able to be out of survival mode, I was in bliss with my daughter. It took several months for the euphoria to die down and for me to start to feel the usual stresses of life again.

She's had a few relatively minor health issues since then, and of course she has doctor and therapy appointments fairly regularly, but is overall healthy.

She is now almost two years old and captures hearts constantly, and amazes people with her intelligence, her beauty, her charm and her sensitivity. Although she is reluctant to get moving and isn't quite ready to learn to walk, she is so motivated

to communicate and express herself. We have been focusing on learning and teaching her sign language and she uses over 100 signs, adding new ones to her repertoire every day. She loves to read and to sing and to spend time with those of us who love her. She is the light of our lives. And she has changed many lives already.

We were so fortunate to have access to so much after she was born. Her team of specialists and therapists are amazing. I will forever be grateful for the pediatric cardiothoracic surgeon who repaired her tiny little heart. How can you really say thank you to someone who literally saved your baby's life? Luckily we happened to live just 15 minutes away from the hospital ready to provide the incredible care that she needed. And luckily we live in a time when most of the heart defects diagnosed in babies with Down syndrome are treatable and are not likely to prevent our children from living full and healthy lives. Yes, it's a scary thing to take on, but the rewards are so great. Seeing your child on the other side is a beautiful thing. Getting through it all has made us so much stronger as a family, and has really helped us see how very precious life is. We have been so blessed by having Cora in our lives and we wouldn't change a thing.

Healing faster than expected

Evan's story by Kathleen Youell

Our son, Evan, was diagnosed with the congenital heart defect called Tetralogy of Fallot (ToF) at three days-old. The pregnancy had been trouble free, but in hindsight there had been signs: his heartbeat was hard to detect in early prenatal appointments, and induced contractions were so small that I couldn't feel them and they would cause his heart to slow to the point that the heart monitor couldn't detect anything. We decided to stop the induction and have a C-section. That went beautifully. His Apgar scores were nine and ten. He latched on well in recovery and continued to nurse well as we roomed in.

On that third day, Evan was taken to the nursery to be weighed and measured and instead of getting my son back in the room, a cardiologist arrived. I was told that an echocardiogram was done on Evan and TOF was found. The cardiologist explained what the defect was and drew a picture of what a heart was supposed to look like and how Evan's looked.

I don't remember much of what he said after, "I've sent your son down to the NICU where he can be monitored better." I forced myself to focus on the seriousness of my son's situation but was very upset I wasn't informed he was going to the NICU beforehand and been part of the decision making process.

At some point I do remember the cardiologist saying, "...surgery at around four to six months of age," and my husband asking, "What are our other options besides surgery?"

The cardiologist replied, "Children with this defect that don't have it surgically repaired live for an average of four years, maximum of seven."

That was that. Other things are fuzzy but that sentence is etched in my mind and burned into my heart.

I remember the doctor also mentioned that they had called in a geneticist because they suspected Down syndrome. My husband summed up perfectly on the spot what soon became a keystone to our point of view. He said, "That's not really an issue; you can live with Down syndrome, but not without your heart."

We were fortunate that Evan only stayed in the NICU a few days after birth and that no other problems were found. We were unfortunate in that he ended up needing two surgeries. We came to find out he also had stenosis (narrowing) of his pulmonary artery. Evan had two heart catheterization procedures, first a pulmonary valvuloplasty to repair a stiff pulmonary valve, then to inject dye. The second catheterization determined his ventricular pressures were equal due to narrowing of his pulmonary arteries as they approached his lungs. I wish I would have known that the catheterizations would be harder than we expected.

We were mentally prepared for surgery to be hard, but the catheterizations were presented as no big deal, the second done as an easy outpatient procedure.

However, the catheterizations were done under general anesthesia and Evan had a really hard time coming out of the first one. I was not at all prepared to walk in and see that they had needed to help him breathe with a bag valve mask. After the second catheterization he was admitted for 24 hours because they couldn't hear a heartbeat (feel a pulse) in his foot below the entry site. They put him on Heparin overnight and checked again in the morning. Still no audible pulse so his stay was extended for another 24 hours. This continued

for a total of four days. With both surgeries we expected a long stay but he healed so quickly that he was discharged early both times.

Looking back there were some things that I am glad we did. We learned some Latin and Greek (you never know when it will come in handy). We had family on-call to deliver food to us when we just couldn't eat another hospital meal. We also asked family to not come to the hospital during the actual surgeries so we only had to wear our Mom and Dad hats, and focus on our baby.

My husband and I set up a Care Page so we didn't have to call each grandparent and family member individually to give them updates.

We also tried to take care of ourselves by taking breaks to go home and shower while the other parent was with Evan while he was recovering.

I napped a lot with a good pillow from home in the fold-out chair/bed at the hospital, which wasn't too bad. Other times I stayed busy with crosswords and Sudoku puzzles.

We were sure to thank the nursing staff—nothing fancy, just remembering to say, "Thank you" a lot and showing interest in them as people, including remembering them from previous stays.

Things I wish we'd known or done differently include understanding that Apgar scores apply only immediately after birth and indicate nothing about the long-term health of the child.

I would have liked my husband to be better prepared for the possibility of a C-section. It wasn't a part of our plan, but he was in denial that we could need one at all.

I also wish I would have connected with the other mom who had a baby with tetralogy of Fallot by C-section the same night we did. By the time I called the mom's room she had been discharged.

I attempted to teach myself to knit during Evan's recovery from his first surgery but I just didn't have the mental energy.

It would have been good if we would have also thought to ask family members not to visit Evan unless we were there or asked them to. One night my husband and I went to a late dinner knowing Evan had two nurses with him in his room; we came back to a nurse and Evan's Grandma discussing things we hadn't been told yet. This made for a lot of hurt feelings all the way around which was not what we needed.

I wish we had tried to coordinate it so that either my husband or I was always present during a staff shift change. One morning, we took long showers in the hospital's family housing and arrived back to Evan's room later than usual. We found our ten-month-old sitting up in bed, crying, alone. He was healing faster than expected so he no longer had his own nurse assigned to him. We found out he had been alone for over an hour. It is important to not assume anything and always know everything by asking questions.

Today Evan is happy and healthy. He knows the alphabet and can count up to 12. He loves to run and run and run, with no evidence of any shortage of energy because of a heart problem. He may need a pulmonary valve replacement in his late teens or early twenties, but he may not. For now we just keep an eye on things with regular check-ups and enjoy our boy.

A significant life

Kristin's story by Lynn Bonife

The evening Kristin was born, a nurse watched her constantly since it was suspected she had Down syndrome and had a low heart rate. We had chosen not to have an amniocentesis. The nurse noticed uneven, labored breathing and within a few days it was confirmed that Kristin indeed had Down syndrome; an echocardiogram revealed she had an atrial septal defect (ASD). We were immediately put in touch with a cardiologist and were told that Kristin's weight and heart would be monitored on a regular basis.

I spent every evening for months listening and counting Kristin's breaths. We were told it was not necessary to have a heart monitor; I functioned as that

monitor. We knew the right time for surgery would be when Kristin's weight would begin to plateau.

That time came sooner than expected when one week prior to the scheduled heart surgery at four-and-a-half months of age Kristin went into mild heart failure. We almost lost her. She spent five days in the hospital to get stabilized and then was sent home for the weekend to put on any extra ounces for surgery.

On surgery day our family and friends gathered in Kristin's hospital room to "wait out" the surgery.

There were times of prayer, eating, laughter, and being solemn. When we were told Kristin was put on the heart-lung machine, prayer quickly ensued again. The surgery to repair the two holes and leaky mitral valve was successful.

However, a week later, Kristin returned to emergency due to post-pericardial syndrome (an inflamed heart). She was put on high dosages of Ibuprofen and within five days we brought her home.

As each day passed, Kristin became stronger. No longer was she docile when we changed her clothes. Kristin would constantly roll over on her left side, grab a diaper, and chew on it. As time went on, she had crawling races down the hall with her dad.

Currently 22 years of age, Kristin is active in church, Special Olympics, volunteers weekly at a preschool, works one day a week at a local restaurant, and is engaged in a variety of other activities. Needless to say, she has a zest for life.

While hearing other people's experiences can be beneficial, be careful to remember that each story has its own level of success. Try not to compare your situation with others. Gather medical personnel, family, and friends that are supportive and wise. If you can, keep track of doctor visits and journal your thoughts and feelings. It will be interesting to look back on those entries when your child is a teenager or young adult.

We were given excellent medical resources and advice from the beginning of this journey. Kristin's pediatric cardiologist gave us wonderful care and provided us with superb information. The hospital staff viewed us as a family, not a number. We have never seen Down syndrome or heart surgery as something negative. We have met amazing people on this pilgrimage filled with valleys, still waters, and mountain tops. We are constantly reminded that her life was extended for a purpose far greater than we could have imagined.

Our rainbow through the storm

Madelyn's story by Kelsey Thomas

May was one of the most life-changing, blessed months of our lives. We did not know until Miss Madelyn was born that she had Down syndrome. She was our first born, so being new parents had many uncertainties for us. But we did our best, loved her to pieces and went with our gut feelings. This, in the long run, has helped us through many obstacles.

When Maddie was a few weeks old, we met with a team of physicians that scored her traits of Down syndrome. At that time they suggested she have an echocardiogram since about 50% of babies with Down syndrome have some type of a heart defect.

Up until this point they did not feel she did, because of no murmur. However, when she was a month old, we were given the hardest news yet. She had atrioventricular (AV) canal defect and a ventricular septal defect (VSD) as well. The reason they didn't hear a murmur was because the hole was so big. Up until this point I had not cried about the Down syndrome, but I cried about the heart defect, a lot. I have always felt

and still do, that we can help with the hurdles of Down syndrome, but I cannot help the way her heart beats.

The doctors told us she would need to have her surgery between three and four months old so we set the date and took her home to go on with our life with our "typical" child, because that is how we treated her. Maybe we were just on autopilot with our day-to-day routine. Maybe we were in denial of what was happening and what she was going to have to go through.

She was the happiest baby with bright sparkling blue eyes who loved to nurse, smile and just hang out! It was hard to imagine what lay ahead for her and us. Looking back now I realize that she could have had more complications in those months leading up to her surgery, but she had adapted to her ailing heart, therefore causing the complications after surgery.

In September, when she was nearly four months old, we met with the surgery team. It was then that everything came into focus about what was really going to happen. As the doctors talked about how long the surgery would take and ALL the possible side effects, I just held her. Kissed her. Squeezed her. How can anyone so precious, innocent and loving have to endure what they were explaining to us? Then they said the two words that I will forever remember: Bypass machine. What do you mean a bypass machine? "We have to put her on the bypass machine in order to be able to do the surgery. So the biggest risk at the end of the surgery is when we take her off of the bypass machine and wait for her heart to start beating on its own again." I remember being numb after that. I had NO CLUE that was a part of this procedure. I don't remember hearing about this before. Again, in denial I guess.

The night before surgery we stayed at a hotel with her. We had never let her sleep with us before, but that night she slept right in between us, both of us with our hands lying on her small body. I remember looking out the window for hours in the dark, just wanting it to be the time for us to go to the hospital. It was definitely the longest night of my life. We were ready to get this over.

In the morning we checked in to the hospital. They put her in a tiny gown. She was so happy, even though she hadn't nursed in twelve hours. She made it very difficult to be sad, with her sweet disposition.

Then it was time to take the walk. Down the white sterile hallway with nurses who do their very best to keep you calm, with their arms around you, telling you she is going to do great and they will stay by her side the whole time. And she can even take her binky with her. As we watched them walk away through the double doors, I too felt that my heart was broken and just prayed that in hopefully a few hours when we would be reunited so the ache would go away.

Waiting seemed like a lifetime. We came prepared with games, cards, magazines and food. Though never hungry, I wish I had taken the time to actually eat because once you are back together after surgery, you will need your strength to sit through what might be long nights and days. Maddie's surgery took longer than they projected. She lost a lot of blood and had to have a few blood transfusions. Getting her situated in recovery took even longer. Once we were allowed to see her, it was a wave of emotions. She was so puffy with so many tubes—you learn very quickly what is where and why. Still it was our little girl lying there, with her angelic little face. I didn't think about the fact that I wasn't going to really get to hold her for a few days, which made sense, but was much harder to not have those urges once we were by her side. We stayed by her side all day and night, though I know not all parents can or do. If she had to go through this, I was going to go through as much as I could with her.

The morning rounds of doctors were always so helpful for us to listen in on. That way if we did or didn't realize something was progressing or not, we could take notes and ask the medical team later.

The other emotionally draining part of all this is one hour may be miraculous, and then the next takes you back a few steps. It is so touch and go. You don't get used to all the machines beeping or alarming, but you learn which ones to be concerned about.

One lesson we learned in the first few days after surgery was to go with our gut instinct. Maddie has never had any problems with her eyes. And one evening

I noticed that she was getting a little red in the face, and then her eyes slowly would cross for a second. It made me so uncomfortable to watch. Since she was such an easy going baby, it was hard to know if she was in pain. After about 30 minutes of this, I begged the nurse to check with a doctor.

The doctor came in and told us that crossing eyes can be a medical condition that kids with Down syndrome may have and not to worry. As he spoke I could feel myself getting jittery. I KNEW this was not the case. Her eyes had NEVER been weak before. I got a little bit abrasive with the nurse and asked her about the pain relief and when her last dose was administered. Well, it had been eight hours since morphine because she wasn't showing any discomfort. We asked her to give Maddie some pain relief because we really felt this was all from pain. Thirty minutes later she no longer had a red face and her eyes never crossed again. I know we don't have a medical degree, but at that time I knew my baby enough to know that something wasn't right. From that point on they asked us how we felt her pain level was.

Maddie was in the hospital longer than they had projected. They told us three to four days, and it ended up being ten days. Personally, I'd rather be there a day or two longer knowing all is well when we leave than be more worrisome when we get home. Maddie was the best patient. At the hospital and once we got home to recover. She would just hang out, sleep and nurse. I remember her trying to roll over a few days after we got home. That was when I got nervous! Twisting her body with this long scar down it! When I called the doctor's office they said that she would only do what she was comfortable with. Kids are good at gauging themselves when in pain… unlike adults. From that point on we just went with it. She was back to her happy giggling ways in no time.

We unfortunately had some rare side effects after her surgery. With a lot of persistent doctors and mommy and daddy, we got it all under control and she thrived the way she was meant to.

Thinking back to our days and nights in the hospital, I remember so many people wanting to come up and see her and us. I know it is because we are so loved. But there were days and times that we needed it to just be the three of us in the PICU. I always worried about hurting someone's feelings if I said we didn't want visitors, but I learned that your baby is priority number one! Those who love you should understand. Allowing friends to bring over meals once you are home is so helpful; if that is the type of help you want. After surgery at home we were good about asking people to not bring over little kids or anyone with a sniffle to keep our house as healthy as possible.

Maddie is nine-and-a-half years old, in the third grade and may be very petite in stature but has a big personality to make up for that! She is mainstreamed in school. Reading is definitely her favorite and strongest school subject, and also one of her hobbies at home.

Maddie is our rainbow through the storms! She continues to show us how to love others without judgment. She is also so easy to forgive others… unless it's one of her younger sisters, who has borrowed a Barbie or favorite Build-a-Bear doll without asking! She loves to dance and even choreographs her own dances for fun. She has been so willing to try different team activities, though prefers to stick with swim lessons and gymnastics.

Having her on organized team sports has been a blessing with the support, encouragement and love from girls her age and their families!

We have faced a few more hindrances with the health of Madelyn's heart since her first surgery but as you can see, it has never held her back from enjoying life to the fullest! We are BLESSED

Successfully operated on

Monique's story by Launa Peloquin

Every time I went to a pre-natal appointment, my doctor would listen to my stomach and say, "The baby has a good, healthy heart!" On October 31st, three weeks before her due date, my daughter came into the world. She was blue and was immediately rushed away. She was finally allowed with me in my room, only to be whisked away again when the nurse didn't think she was breathing right. I was told she had about two

holes in her heart, I've never been good about the precise terms, maybe my unconscious denial at work, and also that it was strongly suspected she had Down syndrome.

It was a very lonely time those four days spent at the hospital—no one came to talk to me about having a child with Down syndrome and the lactation specialist told me there was no way I would be able to nurse my baby. I told her I had nursed three babies before this one, but she kept talking about tongue thrusting and all the negatives. I went down to the nursery, where my daughter was on oxygen, and was able to nurse her.

The pediatrician informed me that he was transferring my daughter to the baby section of another hospital. I said I would rather have her go to a different hospital of my choice, but he said he knew people who would take good care of her. I was so beat down and depressed and in shock that I did not argue.

The nurses at the hospital we transferred to were very kind. The students studying to be doctors though… they would do rounds and talk about her like she was non-human right in front of me.

I finally got to bring her home after about a week but had an appointment soon after with a pediatric heart doctor. The doctor informed me that if my daughter was not operated on within three months she would die. I cried all the way home. I just had a bad feeling.

I remembered how the interns had talked about my baby, and I just felt like they wouldn't be interested in actually saving her. I kept thinking about it being a teaching hospital, and I was very uneasy with that whole scenario.

I switched to a pediatric heart doctor at the hospital I wanted and I felt much more comfortable with him. I took comfort in the pictures on the wall of kids who he had successfully operated on—and a good percentage of them had Ds.

My daughter had frequent appointments and echocardiograms. The cardiologist wanted to operate on her heart by the time she was one-year-old, and by then I was ready and I trusted him. He did not do the actual operation, although he assisted.

My parents and a pastor from the church I worked at waited with me. The doctor came out and told me it went well and he repaired the holes. I was relieved.

My daughter did not get as cold as she used to and I could see improvement in her overall health. She went for check-ups and a couple years later the doctor told me she would need another surgery to repair a leaky valve before she was four-years-old or she wouldn't have energy to run and play. I was devastated.

My daughter thrived and grew and had boundless energy. I used to think that if this was not being able to "run and play" I would never be able to keep up. I must admit I quit going to see the pediatric heart doctor when she was four.

Last April, when my daughter was 12-and-a-half-years-old she had a day surgery to correct a plugged tear duct. The anesthesiologist checked out her heart and didn't like the results. I went back to the pediatric heart doctor I hadn't seen for over eight years. He did an echocardiogram—her first one in years—and he said she was doing really well and wouldn't recommend any further surgery at this time.

I wish I'd had someone to talk to when my daughter was initially diagnosed with the heart condition and Down syndrome. It was a very lonely place 13 years ago and I am happy there are organizations in the area now that provide resources and hope to new parents!

Developing into her own person

Allison's story by Nick Deatherage

Our little Princess Allison was born in late July. This pregnancy didn't seem different than the one with our son, until eight weeks before Allison's due date, when her mother went in for a checkup. The ultrasound tech began to focus on her heart. We could see her beating heart on the screen, and everything seemed normal.

The technician asked us to wait, and left to consult with doctors. When the doctor came in and looked at the screen he also left to make some calls to discuss the situation. Eventually, after a long wait we were told there were some "abnormalities" with Allison's heart and that we needed to go to a different hospital that had prenatal doctors.

At the second hospital, we found out Allison had major holes in her heart, and three valves that were deformed. The doctor also told us that she measured Allison's femur, and the shortness of her femur compared to the rest of her leg along with the heart defects were commonly seen in children with Down syndrome.

We were also told that Allison had fetal hydrops. This is a condition that normally terminates a pregnancy early on. It is rare for a pregnancy to go seven months without noticing fluid accumulation issues from hydrops. They indicated that Allison might not have even developed lungs because the fluid in her chest cavity may have taken the place of some organs because there was a significant amount of fluid built up in her chest, abdomen, skull, and under her skin, and all throughout her body. The doctor was honest and told us there was a very strong chance Allison would not survive.

She left the room again to go make calls to the hospital and we just kind of stared at each other through tears. Down syndrome was definitely a curve-ball that we were not expecting, but compared with the hard-hitting news about our daughter not surviving outside the womb, it was a secondary issue. We just wanted our daughter to live and be a part of our family. After much discussion with colleagues, the doctor decided we needed to go to the hospital.

This was all so shocking and definitely a surprise since our daughter wasn't even expected for another two months. We were admitted to the hospital that day. Several tests were run including an amniocentesis. Two days later we were told she almost certainly had Down syndrome.

They still didn't know if she had developed lungs and due to the size of the holes in her heart she may not tolerate a vaginal delivery so we discussed delivering her by C-section. Over the next week and a half we had several ultrasounds and a lot of contractions.

At 34 weeks Allison made the choice to make her grand entrance and because her heart had been stable the two weeks we were in the hospital, they agreed to let us deliver her vaginally. We were warned that Allison would need to be resuscitated immediately after birth and have some of the fluid drained from her chest.

Right after she was born, she was rushed away by pediatric doctors to the neonatal intensive care unit (NICU). She had fluid drained from her left and right side of her lungs and was put on a respirator.

Allison spent one month in the NICU and her mom spent most of her time there. I had to return to work during the day but came to see Allison every evening.

After a month, on August 29th little Allison came home, weaned off the respirator and now on a nasal cannula (NC) for oxygen. She also had a nasogastric (NG) feeding tube due to reflux and aspiration. Our family made several trips to the cardiologist to make sure Allison was continuing to do well enough to remain home.

Two months later in October, we went in for a cardiac catheterization procedure to get a better idea of how her heart was functioning. They also wanted to see how high her pulmonary hypertension was. They found her hypertension was extremely elevated and decided to put her on Sildenafil to reduce it before heart surgery so it was easier for her heart to pump blood through her lungs.

In January, we went back in for another cardiac catheterization, to see if the medicine had helped change blood flow but unfortunately the hypertension was still extremely high and even non-responsive to nitric oxide gas administered during the procedure. The stubbornly-high pulmonary hypertension almost made her inoperable, and definitely would make her surgery more risky.

Two weeks later we received a call from her cardiologist and were informed that they wanted to proceed with Allison's open heart surgery. The pre-operation testing and waiver signing was scheduled for January 17th at 7:45 AM along with a sedated echocardiogram. Surgery was scheduled for the next day.

Preparing to take her in for surgery was extremely hard and we cried often. When you are facing a scary situation and you have no idea or control over how it will turn out, it is easy for the mind to imagine the worst possible outcomes. This was the nature of our anxiety. However, we had to be positive for our sanity and for our son too.

Allison had a complete atrial septal defect (ASD) and ventricular septal defect (VSD) with two very large holes in her heart and she also needed a complex mitral valve repair. We were told she had a ninety percent chance of coming through the surgery and it was going to take about six hours. The surgeon was confident

but we were warned Allison's pulmonary hypertension would complicate her recovery significantly. We knew getting her to surgery was the only thing we could control; everything else was out of our hands. We just had to get her the best treatment possible, and pray for the best outcome because without the surgery Allison had a zero percent chance of surviving.

The day before the surgery, we made arrangements for our son to stay with his Grandma. We took Allison to her appointment and we were allowed to stay while they administered the medication but not during the echo. We informed them that in the past Allison did not do well with sedation and had to stay overnight every other time. We waited for what seemed like forever and finally, one of the doctors came out and told us there were some issues with the sedation; they were having difficulties waking her up. Her tongue had rolled back and blocked her air way so they had to ventilate her with a manual bag respirator. She was stable but would be require an overnight stay. Her surgery was scheduled for the next day at 10 AM so we didn't sleep well at all that night.

The next morning it was snowing heavily as we arrived at the hospital bright and early. We were told Allison was the second scheduled surgery and that the patient before her was taking longer than expected; if it took too long, they would have to postpone Allison's surgery. We did the only thing we could and waited. As we waited we played with Allison and watched her smile and wiggle around. We played music and cartoons for her in the room and her brother played video games when he got bored.

At 2 PM the medical team was ready for Allison. We walked down the hallway that ended at a busy operating room and had to hand our child over to a masked doctor. It was one of the most excruciating things we've ever had to do. It was impossible to hold back the tears. We recommend families prepare for this moment; it was one of the most difficult parts of the journey for us. We were told a nurse from the operating room would call us when the surgery started but that it could be a couple hours because the anesthesiologist had to come in and get all the pre-surgical stuff done.

About 45 minutes later we were on our way out to the car to say goodbye to Grandma and our son. The phone rang and panic set in. We were told all vein and artery lines were set faster than they thought and they were going to begin surgery. They promised to call again in about an hour to give us an update. We walked around the building, went to the cafeteria, sat in the room designated for family members and read books, played on our phones, and we tried not to think about the worst case scenario. The calls came as promised; the hospital was very good to us.

At 8 PM we got the call letting us know they were almost done. The surgeon would be closing up her chest soon but wanted to make sure her swollen heart could tolerate the pressure from her chest wall. A lot more time passed and then we got another call saying there was too much swelling to close her chest up so they'd have to leave her chest open and protect her beating heart by sewing sterile cloth around the opening to cover it.

Overall, the surgery was very difficult and took a long time but they were able to close the major hole in her heart, using material from a cow, and the other hole was mostly closed. A tiny hole was intentionally left to act as a "release valve" due to high pulmonary pressure in her heart and lungs. Three valves were repaired and surgeons were very pleased to see they were no longer leaking at all after repair because it is common to have slightly leaking valves even after repair with this type of surgery.

She had four drainage tubes in her chest after surgery and when we finally got to see her it was heartbreaking, she was swollen and had tubes everywhere. She had boxes and pumps surrounding her bed pumping medications into her. Her skin was ice cold, and she was motionless except for a machine breathing for her and the beating of her heart below the cloth covering her open chest. They warned us about how she would look after the surgery, but there isn't a way to prepare parents for a scene like that. I am glad we had family members to watch our son. He saw her like this later but at least we were able to prepare him first.

The next night Allison was stable but they weren't going to wake her up any time soon due to being intubated. She was on a paralytic drug to protect her from

all of the medicine lines, monitors, and drainage tubes connected to her. We decided it would be safe to go home, we were going on very little sleep and wanted to check on things at home before coming back again in the morning. We left to pick up our son and went to have some dinner. After dinner we headed home to Vancouver, but when we reached Delta Park the phone rang. The charge nurse on the phone told me that Allison had taken a turn for the worse, things were very bad. There was a team of doctors in the room trying to save her, but they felt it was dire enough to have us return. The drive back to the hospital was rushed and emotional, but we tried our best not to panic because our son was with us.

We were told to go wait in another room for the doctor who did her surgery and that he would be in shortly to speak with us. We peeked in the ICU through a window and looked into Allison's room. It was crowded with doctors and nurses and her surgeon was standing in the room, dressed in a blue suit; he had been out to dinner when Allison went into cardiac arrest and was paged into the hospital for the emergency.

When he came in to the room he told us that her pulmonary hypertension caused the vessels in her lungs to close down and did not allow blood to circulate from her heart. When she went into cardiac arrest the doctor that did her preliminary cardiac catheterization test was in the room examining her. Outside the room one of the surgeons that operated on her happened to be walking by.

The surgeon came in and opened the cloth covering her heart, poured iodine in her chest, and immediately started to massage her heart between his fingers. After a lot of work, they stabilized her but the surgeon informed us she was far from being out of danger. If the doctor and surgeon had not been there, and her chest had not been left open, Allison may have died that night. We are convinced someone was watching out for her.

Doctors didn't want to close her chest right away in case they had to put a pacemaker. A few days later Allison ended up needing a pacemaker put in because she was in heart block, a problem with the electrical system in her heart which controls rate and rhythm of beats.

After three long months in the hospital, due to multiple complications such as blood clots, respiratory issues, pulmonary hypertension, and fluid buildup, Allison was cleared to go home.

She was discharged in March. Only one week later though I rushed Allison back to the ER. She went from having a slight cold, to being very distressed. As soon as we arrived they rushed her back to a room. Her heart rate was two hundred beats per minute (BPM) and her oxygen levels were dangerously low. Doctors said she was in respiratory failure and they intubated her right away. This near death experience, after her long recovery, was triggered by a common cold.

After that stay Allison was admitted to the hospital three more times in the next month.

She was admitted once for electrolyte abnormalities and again for respiratory distress. At the end of April Allison seemed to be distressed again, so we took her to the hospital. They let us know that she was in congestive heart failure. This was a real kick in the gut to us; we were hoping for a typical recovery and some good news after so many setbacks and complications.

Allison was presented again to a cardiology/cardiothoracic surgery conference in May where they decided to do another surgery to help bring her out of heart failure. A bigger pacemaker would be installed that leads to both ventricles instead of just one. They said this should help her heart beat with a better rhythm and give her a better chance of surviving.

We were also told that there is a 10 to 20 percent chance that she would show no improvement after her next heart surgery. We had to explain to our son that we'd be staying at the hospital again.

Two and a half weeks later, Allison went back in for her second surgery. We were very scared, again, and were beginning to feel emotionally drained. We knew her chest would have to be opened back up so this time we knew to come more prepared, with reading materials, laptops, and things to keep us busy. We also knew Allison was a fighter and that at this point she was most definitely meant to be here with us for a long time. It was still a heartbreaking process to hand Allison over to the doctor and wait for her outside the operating room.

This surgery went a lot quicker, only about three hours. Allison's recovery also went more smoothly; she only needed to spend two weeks in the hospital. We noticed a huge difference in her after the surgery. She was energetic, tried new things, and began to develop into her own person.

Today, Allison is a spunky 16-month-old and we continue to see progress as she gets stronger and is weaned off medication. She only requires oxygen at night. We still use the feeding tube but attempt to feed her daily. However, she is very stubborn and likes to spit food out all over the place, but I wouldn't change that for anything. We've also got to hear her say "mama" and "dada"—two priceless events.

The medical staff at the hospital in the NICU, PICU, and all the wards Allison stayed in were fantastic. We are forever thankful to them. They saved Allison's life.

The advice we would give to other families going through this is to relax as much as you can. You can't control everything; you're going to have to trust in your personal faith, and in your team of doctors. Educate yourself on the problem and possible solutions. Write down all the questions you have, and make sure your doctors and surgeons answer everything to your satisfaction. Keep a journal and document what happens as often as possible and write down conversations with the many different doctors and nurses you will speak to. Spend all of the time you can with your child, but also try to find a balance with the other important things in your life.

Heart surgery is a scary but a common pediatric heart procedure. There is a 90% success rate, and maybe even better than that over the last few years as technology has improved. Allison had a lot more complications and challenges than most kids do—a friend's daughter was out of the hospital in just four days and another friend's daughter stayed just a week.

Your child will almost certainly recover and be a healthy little kid. Even if they do have a long recovery time ahead of them, they can still pull through like Allison did. The odds are in your family's favor for everything to be okay.

A big, beautiful heart

Calder's story by Juliet Ferruzza

Calder surprised us by coming three weeks early on St. Patrick's Day. We had both an amazing and relatively uneventful home birth in a cozy, peaceful water tub—only a seven-hour labor on a bright, beautiful Portland morning. Having tried for six years to conceive, we were beside ourselves with joy to meet him.

Sara, our midwife, did the well-baby check about two hours later and found he was presenting signs of Down syndrome. She had never delivered a baby with Down syndrome before so she made an appointment at a pediatrician's office for the following day.

The next day, after borrowing a car seat from a friend, we crammed into a doctor's small office for confirmation. As I tried to nurse him my sister spoke up, "He's turning blue! He's turning blue!" The doctor casually stepped out of the room, then back in to tell us to immediately head to the neonatal intensive care unit (NICU). We zoomed through traffic, still composed, but unsure what to expect next. It felt surreal to go from a peaceful home birth to the beeping and buzzing of a busy, cramped NICU.

There in the bright lights we soon met Calder's cardiologist and found out he had two small little holes in his heart. He would soon need a ventricular septal defect (VSD) repair as the holes were too big to close on their own. VSD? What did that mean? Open heart surgery? Really? It wasn't supposed to happen like this. We just had a baby, a beautiful, healthy baby. How could this be happening to our precious child? Those five days in the NICU were the most difficult but it was there that we learned Calder is a strong little guy.

In what were then very uncomfortable conditions for new parents, where I struggled to breast feed, recover from childbirth, and absorb the diagnosis of Down syndrome and heart surgery we knew we loved him so much already, and Down syndrome didn't take that away. We cried, yes, we cried many times but we loved Calder dearly. We held him close when he was not under bright blue bilirubin lights, skin-to-skin when possible, and sang him Bob Marley's "Three Little Birds," over and over. We never left his side. Finally, after five of the longest days of our lives, Calder was cleared to go home to the place he was born, and we could start being parents on our own. We weren't sure when his

surgery would happen because his cardiologist wanted him to be strong enough to handle the trauma. We looked forward to it though as we wanted it behind us.

At home, Calder slept most of the day, and he struggled to stay awake long enough to get enough food. His skin was a mottled bluish color. He was struggling for oxygen. He was also adorable with a head full of hair that stood up straight in a Mohawk. He couldn't nurse, but I wanted him to have breast milk for every meal, so I pumped several times a day.

After eight weeks of struggling to breathe and eat, his heart was ready to be repaired. A couple of days after my first Mother's Day we brought Calder back to the hospital. We signed a lot of papers but the one I remember most said this whole process could result in death. It was a chilling reality.

On the day of his surgery, I vividly remember waiting in the pre-operation room. A little girl was there for her tenth surgery for intestinal issues, and she was so sweet and encouraging to Calder.

We saw Calder's surgeon, who showed up in jeans and a leather jacket...did he ride a motorcycle to work? As I held Calder close, the chaplain came and asked if we wanted to pray. Although we don't practice any religion, I grew up Catholic and I wanted the support. He said a short, sweet blessing and tears fell down my face. A few minutes later the anesthesiologist showed up and gave us the game plan. I wrapped Calder in a warm blanket and I handed him over to a team of people I had only briefly met. I hated handing over my baby but needed to trust their experience.

The following few hours actually went by quickly. My sister and brother came to keep us company and distract us. There was laughter, tears, eating, texting, and so on. The nurse liaison kept us informed of what was going on. She watched from a little video monitor and passed the info on to us every hour.

The actual bypass and repair only took about three hours, and when it was over they wheeled Calder past us on the way to the recovery room. He was still ventilated and the anesthesiologist hand-pumped an airbag into his lungs. So many tubes, wires and beeps. People dressed in blue surgery scrubs surrounded him. We thanked the team and they shuttled on down the hall.

We had to wait an hour until we could see him again, and that was the most difficult part. He was puffy, and it was so hard to find him under all the wires and tubes but he was there fighting hard. Within a few hours, he actually already looked stronger. Then I heard him cry for the very first time, a big hearty "I'm hungry mama!" cry. I was so happy!

Calder recovered in just five days. We took him home with tubes draining excess fluid from the pleural cavity of his lungs. The cardiologist gave us instructions on how to drain them ourselves. It felt so good to be through the hardest part.

My entire extended family has a web forum where we talk every day and my brother posted right after the surgery: *"Calder is such a strong, awesome baby. He got all his wires and cords secured and bundled up then put in Juliet's arms. He was so happy he smiled and looked up at her. She gave him fresh milk and he drank it right down....delicious. It was the most beautiful moment; Baby and Momma happy, calm together.*

Then Juliet told me this story and I got goosebumps: 'Our great-grandfather had a cousin who was a cloister nun and had no outside contact. Our Grandma Jean would write her letters and so did my mom. Her name was Sister Theresa.'

So literately on the day of Calder's surgery a letter addressed to Grandma Jean (who died many years ago) came in the mail to her daughter Sheila's house, and inside is a picture of Jesus holding his exposed heart, along with a note saying a Novena prayer has been said for our family. What are the chances? Calder is loved in the spirit world, too."

Today Calder is a thriving three-year old toddler. He loves books more than anyone I've ever seen (and I worked at Powell's Bookstore for a decade!). He also loves to dance, climb and play with his little sister and cousins. He's going to start preschool in the fall. The scar from his surgery is a thin white line now, it is hardly recognizable. His chest is a little uneven where his breast plate was opened and sewed back together. We see it as physical proof of what a strong kid he continues to be. I often ask him, "Calder, where's your heart?" He puts his hand right there on his chest on his big beautiful heart.

55 Hours

Abigail's story by Amy Geoffroy

In late June 2003, pregnant with our second child, we received a prenatally diagnosis of T21. Ten days later, we were sent for an echocardiogram. After a good 45 minutes of what seemed to me completely indecipherable ultrasound imaging, the cardiac fellow told us that yes, our daughter had a transitional atrial-ventricular canal defect. She explained that the baby had a hole in her heart that would require surgery. The hole was small and heart function looked good, and that probably meant surgery would be between age 2-5 years, possibly sooner if things deteriorated. We were told that the surgery was fairly straight-forward and the survival rate was extremely good.

My mind, while she was telling us all this, was still stuck on "there is a hole in her heart." I was picturing blood pumping into her chest cavity. Trying to focus and listen, I asked, "So, you're telling us that this can be fixed? There's no chance that it won't work and she'll end up needing a heart transplant or anything?" Her response: "No, she won't need a heart transplant, but anyway, that would get us into the ethical question about whether a child with Down syndrome would be a candidate for a heart."

My husband Kevin and I were upset at the insensitivity of the comment, judging our child not worthy of a heart. It was really that moment that brought me away from self-pity about the T21 diagnosis and into full-blown protective mother hen mode. I wanted my baby here, safe, healthy and respected as her own individual.

Two months into the diagnosis, we moved from Massachusetts to New Jersey. I had another series of echocardiograms so the new care team could check out the baby.

Abigail was born by C-section at 39 weeks on October 24, 2003, a whopping 8 pounds 4 ounces. She was promptly whisked away to the NICU. Our cardiologist saw her later that day and came to tell us that she was doing fine and he would see us in a month. I felt a bit numb and disconnected, especially not really being able to hold her yet. Of course, I'd also had just had major surgery and was on pain meds.

Abigail was in and out of NICU for four days because of jaundice. One pediatrician also thought he heard a skipped heart beat, so we were sent home with a contraption I soon began to hate: a heart/lung apnea monitor. Abigail had to stay hooked up to it around the clock for the first 3 weeks, and then when sleeping for another 3 weeks. The smallest thing (always just a node coming loose) would send it into ear-piercing alarm, through which Abigail somehow managed to sleep but which scared the living daylights out of everyone else. We gratefully gave up the monitor after the docs confirmed that she had not had a single apnea episode in six weeks.

Abigail was a content baby, sweet, cuddly, almost never crying. We fell in love with her easily but throughout the newborn period, she was not a great eater. She had a poor suck and trouble maintaining weight. Abigail tired easily and I could rarely get more than 2 ounces in to her at a single feeding, even with a bottle. Our pediatrician wanted us to feed her around the clock, but nothing would wake her up at night—she would sleep for 6–7 hours if you let her.

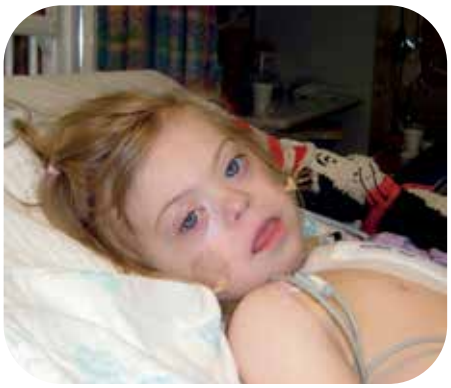
After two weeks straight of trying unsuccessfully to keep her awake long enough at night to eat even an ounce, I gave up on the nighttime feedings. Despite her feeding issues, Abigail met developmental milestones and began to maintain a shallow growth curve, so things finally calmed down.

We met with the cardiologist for an echo at one month—her heart was performing efficiently. She had a large piece of tissue blocking her AV canal, which effectively minimized her symptoms. At six months, we were told that the goal was to get her to 20 pounds before surgery. At 20 months, I proudly returned with my 20 pounder only to be told that we would continue to wait. As glad as I was that she was doing so well, I just wanted to get heart surgery over with. Most days I could forget about the looming procedure, but periodically, my heart would start pounding and I'd feel dizzy from the stress of anticipation, worry and fear.

Just after Abigail turned three, both her preschool

teacher and I noticed that she was tiring easily. I could feel her heart beating fast in her chest. I called the cardiologist, and they got us right in. Watching the echo monitor, I could immediately tell the difference from prior tests. The doctor confirmed that Abigail was beginning to go into heart failure. Hearing it was hard even though we expected it. We began a course of Lasix to help her heart work as efficiently as possible, and we started talking about surgery.

In New Jersey, there were three heart centers available to us. We chose the hospital based on the experience of the surgeon, the number of procedures the center handled, and the quality of post-op care. They quoted us a nurse to patient ratio of 1:1 in the cardiac intensive care unit, and told us that our surgeon had never lost a child with AV canal on his operating table. The center's overall survival rate for AV canal was 99.9%, compared to 97% nationally. Both our cardiologist and surgeon had stressed the importance of the post-op care in survival rates.



Surgery was scheduled for Monday, May 21, 2007. That Friday, we drove down for Abigail's pre-surgery tests and we met with the surgeon. His demeanor was quiet but respectful, and he answered all our questions. We felt very comfortable with him. We got a tour of the CICU and the step down unit. We were also shown the family resource center, which had quiet areas, computer lounges, coffee and snacks. It seemed like a peaceful and caring place.

My mother and Kevin's parents arrived over the weekend. Kevin's parents were to be our support in Philadelphia, and my mom stayed with Emily.

We returned to the hospital Sunday afternoon and checked in to our rooms at the Ronald MacDonald House. The staff was wonderful there, and Abigail spent an enjoyable evening being entertained with some other kids. In our suite that night, we all tried unsuccessfully to sleep.

The next morning, we walked over to the hospital and were greeted at intake. Abigail got to choose a handmade pillow in the shape of a heart that local school kids had made.

We were brought back to pre-op shortly after. Kevin and I were able to stay with her while initial preparations were made. We got some alone time to snuggle before the nurse gave Abigail something to make her sleepy. Within 10 minutes, she was fast asleep on Kevin's lap. Abigail's CICU nurse for the day came to introduce himself, waited with us while she was wheeled towards the surgical wing, then took us down to the cafeteria. He explained that he would personally be updating us every hour from that moment through to when we could go to CICU.

Surgery was expected to take about 3–4 hours plus an extra hour to do pre-op. He told us to get a late breakfast and then come up to the family waiting area where he would give us our first update.

He returned 45 minutes later to say that they were ready to begin. I forced myself to stay busy—I logged in to our CarePages site to post an update, checked email and got coffee. Kevin and his parents all sat like zombies or tried to read, from what I can remember. Another hour went by and the nurse came to tell us that the first incision had been made and Abigail was on the heart-lung bypass. More waiting, more trying to stay busy. Less than an hour later, the nurse came out to say that the surgeon was wrapping up, and he'd be out in a few minutes. He escorted us to a consultation room, where the surgeon met us and told us that things had gone beautifully. He had closed the hole and repaired her mitral valve, which was leaking only a tiny bit, normal for a repaired valve. He told us that the hole was closed permanently and that the valve had a 90–95% chance of lasting through adulthood. If it started to fail, it would be a simple replacement.

We were all crying with relief—my father-in-law fairly guffawed. Shortly after, we were brought to CICU. They had told us to expect an intubation tube and

chest tube, but Abigail was doing so well that they had removed the intubation tube, and her chest tube was not visible through the gown. She was coming out of sedation and was groggy. Her stuffed Cat in the Hat had accompanied her through surgery, and he was there up against her. When she woke, we could tell she was sore, but she remained calm and let us comfort her. She couldn't eat or drink anything that day, but she was too in and out of sleep for it to matter.

Kevin wanted to stay with her that night, so when it began to get dark, I left with his parents to grab dinner and sleep peacefully for the first time in days.

Tuesday morning, when we arrived at 8 AM, Abigail's chest tube was gone and she was already like a different kid. She had a lot more energy, so we called my mom to have her bring Emily to visit.

The girls were so excited to see each other—Abigail kept whispering her sister's name—so the reunion was very sweet. Only 24 hours after surgery, we were moved to the step down unit. Abigail got to eat frozen pops and Jell-O during the day, and she was cleared to eat dinner. She had a few bites while watching a movie and giggling. She had a peaceful night.

Wednesday morning, the cardiologist stopped in to see Abigail and decided she could get out of bed and make the short walk to the play room. We lifted her very carefully and helped her walk across the unit.

She quickly became engaged with the toys for an hour or so. As our lunch was brought in, the nurse told us that Abigail had met all the milestones they needed to see, and that we could be discharged later. We were stunned. We had been told initially to expect a 3–7 day stay, and we were only 50 hours in. The staff told us there was no rush if we preferred to leave in the morning, but that medically, they were fine with discharging her that evening. Kevin and I looked at each other, looked at Abigail, and said, "Let's go home."

Fifty-five hours after the first incision, Abigail was swinging her feet and bopping to music in the car, and as soon as we entered our house, she saw Emily and said two words: "Emily! Happy!" That pretty much summed it up. We cried again.

Abigail's recovery was quick and relatively painless. She was cleared by the cardiologist a week after our return for regular activities and returned to preschool exactly two weeks after surgery. Three weeks later, she threw the opening pitch at a minor league baseball game. Six years after surgery, we see a cardiologist once every other year for follow-up.

Abigail is fully included in a general education classroom with kids who adore her. She enjoys books, especially about princesses, and reads well. She is graceful and loves to dance—she takes ballet and is on a cheer team. She swims all summer and enjoys taking family hikes with our dog Olive.

Abigail's heart works pretty darn perfectly, and we are so grateful to the surgeon and cardiac care team who gave her the strength and stamina to live out her life in good health.

GLOSSARY OF TERMS

APGAR Score
A test which occurs in the delivery room right after a baby's birth, designed to quickly evaluate a newborn's physical condition and to determine any immediate need for extra medical or emergency care. It measures appearance, pulse, grimace, activity, and respiration on a scale from 0 to 2. Doctors, midwives, or nurses add these five factors together to calculate the APGAR score, with 10 being the highest possible score. The APGAR test is usually given to a baby twice: once at 1 minute after birth, and again at 5 minutes after birth.

Apnea Monitor
A piece of home medical equipment that records a baby's heart rate and breathing pattern, and alarms if a baby's heart rate slows down (bradycardia) or if he or she stops breathing for a period of time (apnea).

Arterial Line
A thin catheter inserted into an artery, most commonly used in intensive care medicine and anesthesia to monitor the blood pressure real-time, and to obtain samples for arterial blood gas measurements.

Atrial Septal Defect (ASD)
A "hole" in the wall that separates the top two chambers of the heart. This defect allows oxygen-rich blood to leak into the oxygen-poor blood chambers in the heart.

Atrioventricular (AV) Block
A heart block occurs when electrical signals between the heart's chambers are impaired or don't transmit, disrupting the heart's ability to beat properly.

Atrioventricular Canal Defect (AVCD)
A condition that occurs when there is a central defect in the walls between the atrial and ventricular chambers. The valves and muscle walls that separate the heart's chambers did not form completely while the baby was in the womb.

Balloon Pulmonary Valvuloplasty (BPV)
Performed as part of a procedure called a cardiac catheterization. During this procedure a catheter with a balloon on the end is advanced under fluoroscopy (X-ray) from a blood vessel in the leg into the narrowed valve. Once the catheter is in place, the balloon at the tip is rapidly inflated and deflated to dilate, or open, the valve.

Cardiac Arrest
Also known as cardiopulmonary arrest or circulatory arrest, is the cessation of normal circulation of the blood due to failure of the heart to contract effectively.

Cardiac Catheterization
A procedure used to diagnose and treat cardiovascular conditions. During cardiac catheterization, a long thin tube called a catheter is inserted in an artery or vein in the groin, neck or arm and threaded through the blood vessels to the heart. Using this catheter, doctors can then do diagnostic tests as part of a cardiac catheterization.

Cardiothoracic
Of or relating to the heart and the chest.

Central Line
A central venous catheter, or central line, is a long, thin, flexible tube used to give medicines, fluids, nutrients, or blood products typically inserted into the neck during a hospital stay.

Congestive Heart Failure
A chronic condition that occurs when the heart can't pump enough blood to the organs. When a heart begins to fail, fluid can pool in the body; this manifests as swelling (edema), usually in the lower legs and ankles. Fluid also may collect in the lungs, causing shortness of breath and rapid breathing.

Continuous Positive Airway Pressure (CPAP)
The use of continuous positive pressure to maintain a continuous level of positive airway pressure.

Echocardiogram
An ultrasound movie of the inside of the heart. It can detect nearly every congenital heart defect or any problem of the heart muscle function. An echocardiogram usually takes 40-60 minutes to perform.

Electrocardiograph (EKG)
An instrument used in the detection and diagnosis of heart abnormalities that measures electrical potentials on the body surface and generates a record of the electrical currents associated with heart muscle activity.

Fetal Hydrops
A condition in which abnormal amounts of fluid builds up in two or more body areas of a fetus or newborn.

Gastroesophageal Reflux
A condition in which stomach contents leak backward from the stomach into the esophagus (the tube from the mouth to the stomach) after eating.

Heart-Lung Machine / Bypass Machine
A machine used during open heart surgery to keep blood pumping through a patient's body. Blood is diverted from the heart and lungs through a heart/lung machine and oxygenated blood is returned to the aorta.

Hypotonia
A state of low muscle tone (the amount of tension or resistance to stretch in a muscle), often involving reduced muscle strength.

Intubation
The placement of a flexible plastic tube into the trachea (windpipe) to maintain an open airway or to serve as a conduit through which to administer certain drugs. It is frequently performed in critically injured, ill or anesthetized patients to facilitate ventilation of the lungs and to prevent the possibility of asphyxiation or airway obstruction.

Junctional Ectopic Tachycardia (JET)
A rare syndrome of the heart that manifests in patients recovering from heart surgery, characterized by cardiac arrhythmia, or irregular beating of the heart.

Mitral Valve
Located between two of the heart's four chambers: the left upper atrium and the left lower ventricle. Similar to a swinging double door, the valve has two flaps that open and close as the heart pumps.

Mitral Valve Cleft
A valve with a separation or cleft down the middle, associated with an atrial septal defect.

Nasogastric intubation
The insertion of a plastic tube (nasogastric tube or NG tube) through the nose, past the throat, and down into the stomach, used for feeding and administering drugs and other oral agents.

Patent Ductus Arteriosus (PDA)
An unclosed hole in the aorta. When a baby is born, this hole is supposed to close.

Phlebotomist
Professionals trained to draw blood from a patient for clinical or medical testing, transfusions, donations, or research.

Pleural Cavity
The space that lies between the pleura, the two thin membranes that line and surround the lungs. The pleural cavity contains a small amount of a thin fluid known as the pleural fluid, which provides lubrication as the lungs expand and contract during respiration.

Post-Pericardial Syndrome (PPS) / Inflamed Heart
A medical syndrome referring to an immune phenomenon that occurs allowing fluid to surround the heart days to months after surgical incision of the pericardium (membranes encapsulating the human heart). PPS can also occur after a trauma, a puncture of the cardiac or pleural structures, after a stent placement, heart attack, or pacemaker or pacemaker wire placement.

Pulmonary Edema
Fluid buildup in the lung, usually due to mitral stenosis or left ventricular failure, causing difficulty breathing, coughing up blood-tinged sputum, excessive sweating, anxiety and pale skin.

Pulmonary Hypertension
High blood pressure in the arteries, capillaries and veins within the lungs. This condition is different from hypertension, or high blood pressure. Pulmonary hypertension causes the right side of the heart to work harder due to higher pressures, causing fatigue, dizziness and shortness of breath.

Pulmonary Shunt
A respiratory problem where gas exchange fails to take place in the lungs, leading to low oxygen levels in the blood, most commonly occuring as a symptom of a larger respiratory problem.

Respiratory Failure
A condition in which not enough oxygen passes from your lungs into your blood.

Respiratory Therapist
Respiratory therapists are clinicians who specialize in airway management during trauma surgery, emergencies, or intensive care. Respiratory therapists often are in charge of initiating, managing, and stabilizing life support for people in intensive care units and emergency departments.

Tetralogy of Fallot
A heart defect that features four problems: a hole between the lower chambers of the heart; an obstruction from the heart to the lungs; the aorta (blood vessel) lies over the hole in the lower chambers; and the muscle surrounding the lower right chamber becomes overly thickened

Tricuspid Valves
A valve on the right side of the heart, between the right atrium and the right ventricle. The function of the valve is to prevent back flow of blood into the right atrium.

Vascular Resistance
A term used to define the resistance to flow that must be overcome to push blood through the circulatory system.

RESOURCES

National Down Syndrome Congress • (800) 232-NDSC (6372) • ndsccenter.org
Healthy Kids Oregon • oregonhealthykids.gov

EARLY INTERVENTION AND EARLY CHILDHOOD SPECIAL ED (EI/ECSE)

Each county has an EI/ECSE referral and evaluation agency. Call the agency in your county for referrals.

Multnomah County (503) 261-5535
Clackamas County (503) 675-4097
Washington County (503) 614-1446 Eng., (503) 614-1263 Esp.
Clark County (360) 750-7507

DEVELOPMENTAL DISABILITY SERVICES

Multnomah County (503) 988-3658
Washington County (503) 846-3150
Clackamas County (503) 655-8640
Clark County (360) 397-2130

HOSPITALS IN THE PORTLAND AREA WITH PEDIATRIC CARDIOLOGY CARE CENTERS

OHSU / Doernbecher Children's Hospital
(503) 346-0640 • ohsu.edu/xd/health/services/doernbecher/programs-services/heart-care/

Legacy Emanuel Children's Heart Program
legacyhealth.org/health-services-and-information/health-services/for-children-a-z/heart.aspx

"After her surgery she was like a firework. Her energy level went up ten-fold and her engagement and interest in everything was dramatically different. She shifted into high gear."

"Today Evan is happy and healthy. He loves to run and run and run, with no evidence of any shortage of energy because of a heart problem."

"Now Isaac is a healthy, sturdy little boy, climbing, running, singing and dancing, keeping up with his siblings with energy to spare."