Luna's STORY

ONE OF POSITIVITY, HOPE AND GRATITUDE

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Preface

Thank you for coming to read Luna's story.

Spoiler alert, as of January 2025, Luna is doing great, but that wasn't always the case and her story has been a real roller coaster. We're going to explain this in the least technical terms possible. That means we'll oversimplify the complicated nature of her treatment, but if you ever need to geek out or dig deeper, please feel free to contact us and we'll provide whatever knowledge or resources we have. We are going into detail here, so this is going to be a bit long, but we want expecting parents to get the most out of this and friends and family to have a place to get most of the story.

Routine Ultrasound

Dunia (mom) was 21 weeks pregnant when she went in for a routine ultrasound. Up until then, everything had been going smoothly, and these visits were full of joy and excitement. We had a friendship with the technician performing the ultrasound that day, so it was easy to tell when her mood changed. Within minutes, our lives changed forever. She stepped out for a consult, then they came in and delivered the vague news that there was an issue with the development of the heart. She was immediately referred to a pediatric cardiologist. Renny (dad) was out of town at a conference but immediately flew home for the emergency appointment with Dr. Aldousany the following day, who confirmed there were some very serious issues with Luna's heart. It was too early to tell just how bad it was, but that first echo (echo is short for echocardiogram—a heart-specific ultrasound), in utero, revealed a diagnosis of DORV and TGA. This meant that both her main arteries were on the right ventricle (Double Outlet Right Ventricle) and they were switched (Transposition of the Great Arteries). At this point, we were told that the transposition wasn't a huge deal because the aorta could just be moved over and connected to the left ventricle, and she should be okay. Of course, this was a devastating, huge deal for us, but we were catapulted into a different world, and in the realm of congenital heart disease, it could be much worse. Again, we're oversimplifying here, but in essence this could be solved with one open heart surgery soon after birth.

We quickly learned that CHD is usually a cluster of issues, and it seemed like every time we went back to the cardiologist for an echo, the diagnosis became more and more complicated. Dr. Aldousany was fervently positive about Luna's ability to thrive despite the challenges she would face. That man has a poker face and an overall positivity that, to this day, affects how we process our challenges regarding Luna.

Early on, we knew Luna would need at least one open heart surgery within days of being born. It's worth mentioning that while Dr. Aldousany was optimistic, other medical professionals were not. At this time in her story, it's important to note that on several occasions, medical professionals cautiously reminded us of the legal timeline to terminate Luna in our home state of Florida and in alternative states where we could abort her later in the pregnancy. None of what we're saying here is meant to judge any decision anyone makes. Luna's story is one of positivity and hope, and despite what our beliefs may be, we don't want her story associated with any negativity. This pregnancy, for us, was already a gift. Luna wasn't born yet, and she had already impacted our lives with unimaginable joy from the day we knew she was coming. She was also teaching us about ourselves, our faith in God, and our resilience. Luna was helping us grow in ways we didn't know we needed. We had no idea how long we would have her, but we didn't care if it was for 5 minutes or 100 years—Luna had a purpose, and we were both terrified and elated that we had been chosen to usher in that purpose. Challenge accepted!

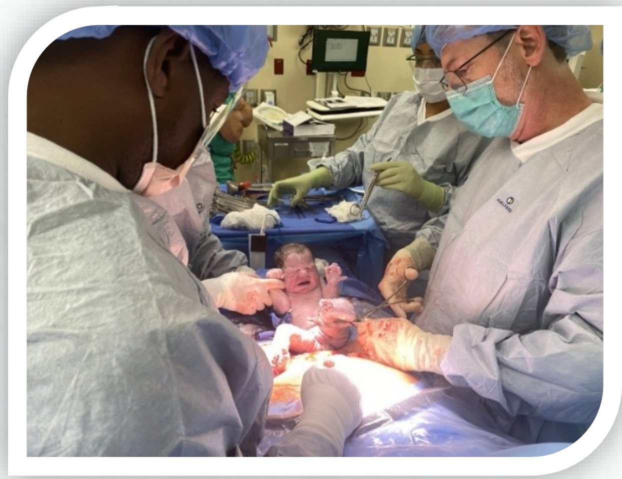
Let's clarify something here. At this point, we are an ordinary, imperfect family with a teenager trying to run our businesses and manage the challenges of life like a game of dodgeball. There is nothing special about our ability to handle adversity. While we have our own individual ways of processing a higher power and our spiritualities, we are not a family rooted in any specific religious beliefs from which we can pull to help explain any of this. That said, we had both been on a journey for several years prior to this to repel a victim mentality and view everything—good and bad—as a blessing. By no means had we mastered this, but at no time did we ever feel like something bad was happening to us. There was a life inside of Dunia, and this was good. The complications that were coming were part of our story and something—the soul we had already named Luna—had to go through. There wasn't a lot of discussion about how we would perceive this; we just both kind of saw it this way. Don't get me wrong, there was plenty of fear and tons of tears, but the overall theme was gratitude, and we knew that no matter what happened in the future, we already had much to be grateful for.

The Diagnosis

By the time Luna was born, we pretty much had her full diagnosis: DORV, TGA, Hypoplastic Aorta, Hypoplastic Aortic Arch, Hypoplastic Left Heart Syndrome (HLHS). She also had a straddling mitral valve, an ASD, several VSDs, and stenosis of the pulmonary artery. Bottom line, her plumbing in and around the heart was a hot mess, but it could have been so much worse. "Hypoplastic" means underdeveloped. The most serious of these complications was the small left ventricle, which occurs in about 1 in 1,000 babies born in the US. We learned that hypoplastic left heart is a spectrum, and while Luna's left ventricle was too small to be viable, at least it was there. We were told that, while rare, there was a chance she could, at the last minute, disproportionately grow her left ventricle before being born. This is important because most of her other issues could possibly be solved with a single open heart surgery and subsequent catheter procedures, but a nonviable left ventricle meant saving her would require a minimum of three surgeries over several years, with a compromised lifestyle and a strong possibility of needing a heart transplant in her 20s to 30s. This is called single ventricle palliation, which basically means they convert her into a person who functions with only the right ventricle—half a heart.

The three surgeries in the single ventricle palliation are called the Norwood, Glenn, and Fontan. These procedures are remarkable in that they reroute the flow of blood to give these kids a chance at life they would never otherwise have. If you're reading this and your baby's left ventricle is too small for other possibilities, there is ongoing stem cell research aimed at strengthening the right ventricle to better handle the burden. You may qualify for free cord blood and tissue banking. Nevertheless, this was not our case; we had a small window of hope in her little left ventricle but we did freeze her stem cells in case future interventions were developed they'd be more likely to succeed. Clic go to https://tinyurl.com/Cordblood4CHD for the company we used. We became obsessed with the possibility of disproportionately growing her left ventricle. While there are innovations and studies to try to do this in the fetal stage with a catheter, there was no option available for us to help Luna before she was born.

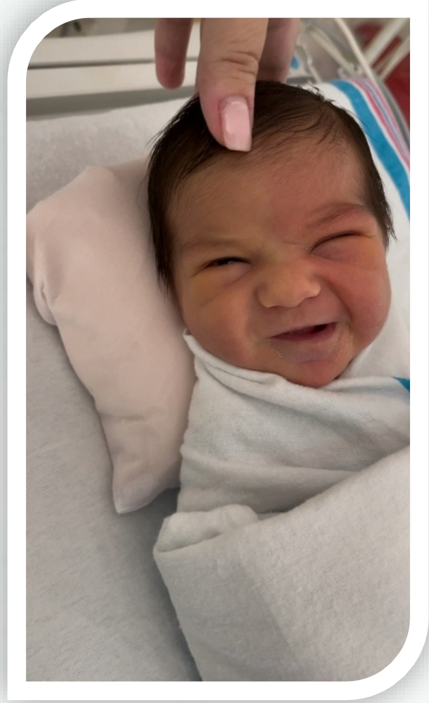
Before the Surgery



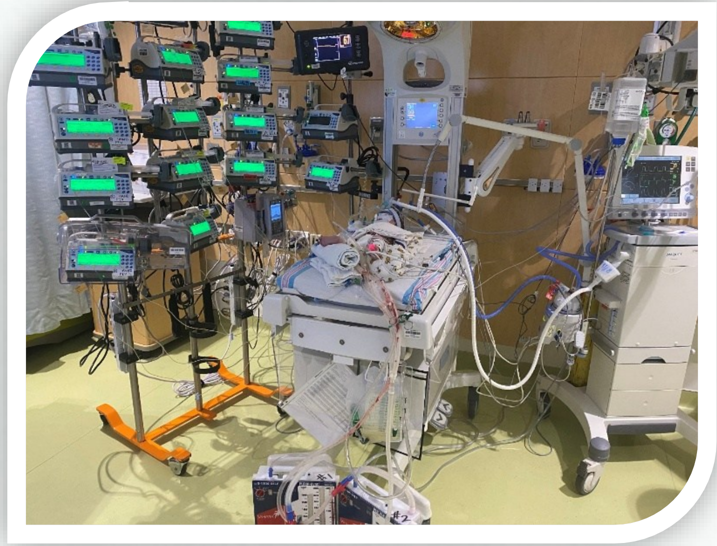
Dunia gave birth via what turned out to be a pretty complicated C-section, and within a few hours, Luna was transported to Nicklaus Children's Hospital in Miami, FL. Dunia, fresh out of surgery and with high blood pressure, was considered high risk and would stay in the hospital for several days before being reunited with Luna prior to her first open heart surgery. Renny was in the ICU with Luna around the clock while a desperate Dunia did everything she could to prove to the doctors that she was ready for discharge in order to be with her baby.

Getting Luna strong for her surgery was a huge priority for us, so Dunia was keeping up her breast milk production while family members made frequent trips between hospitals with bottles in a cooler. We did everything we could to avoid Luna having to drink formula because NEC is a very real concern. NEC is an intestinal disease treated by stopping feeding and administering antibiotics. It is more prominent in infants with CHD and in premature babies. It's important to note that the complexity of the CHD is directly related to the probability of developing NEC. Some studies show that with Luna's complexity, the chances of getting NEC could be as high as 10%. While it can occur even with breastfeeding, it's more common with babies on formula. Not having the baby with her made the production of breast milk much more difficult. You can imagine the guilt associated with that, all while dealing with postpartum hormone changes and C-section pain. There were times when we were running a few

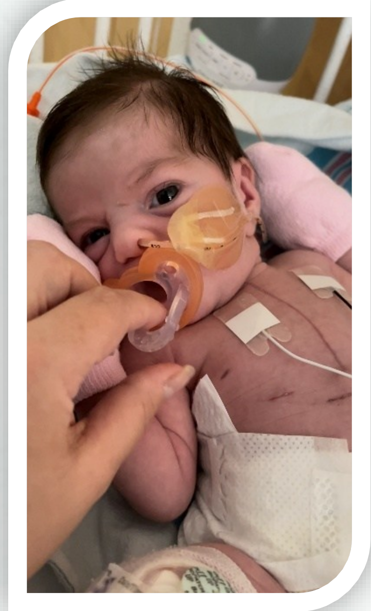
ounces of breast milk between hospitals to get just enough in before Luna's next feed, which were two hours apart. Keep in mind that the main issue keeping Dunia admitted was her blood pressure, which she was trying to bring down while managing the responsibility of having to produce breast milk away from the baby, all while counting down the days to what is one of the most complicated surgeries performed on an infant. The nurses taking care of Dunia at South Miami Hospital were a godsend and made all the difference. These few days were agonizing. Renny was with the baby, experiencing the first bottle, the first diaper change, and the first bath, while praying that Dunia's health would not take a turn for the worse. We figured out early on how to install a Fire Stick, which helped us stream music in our room. Renny was alone with Luna the first few days, and he had no idea how much time she had to live. Being a musician, he became obsessed with exposing her to as much music as possible. The nurses loved it. Luna's room was the hang. We didn't have synthesized baby Mozart playing, programmed through the hospital's TV system. This room was a mix of Miles Davis, Earth, Wind & Fire, Bob Marley, and Beethoven being performed by the best orchestras in history. At any given time, you could walk in and hear Jacqueline du Pré performing the Elgar concerto or Trio Matamoros playing traditional Cuban music. Music therapy became a huge part of Luna's life. Dunia would eventually be discharged and able to spend three full days with the baby before her first surgery. The agony of what was to come was overshadowed by the gratitude we had to share this time together. Luna's smile when she heard her mom's voice for the first time after being separated was priceless.



The Norwood



The first echo of our newborn baby Luna was performed by Dr. Stephen Girgis and revealed that she hadn't grown her left ventricle to the point where it would be viable, so the three-surgery single ventricle palliation was the way to go. We looked at her perfect little chest, knowing that it would be the last time we'd see it without a scar. Luna had the Norwood surgery at one week old, performed by the surgeon—and real-life superhero—Dr. Redmond Burke. There is no feeling like being told your baby is on bypass. The thought that her little pumping heart, which we celebrated so much in that first ultrasound during the pregnancy, was not beating was unbearable. This surgery would address the reconstruction of her aortic arch and bypass the left ventricle, which is what the Norwood basically does, allowing oxygenated blood to reach the body. The DORV actually worked in her favor since moving the aorta to the right ventricle is part of the typical Norwood process. Of course, hers was already there. The Norwood is a very temporary solution, meant to last 4–6 months before she needs a second surgery, which is the Glenn.



After the Norwood, they left her chest open. Yes, our baby was there with clear tape covering her pumping heart in the event that something would go wrong and doctors needed to "go back in" right in the ICU room. Hours after her surgery, this is exactly what happened, and Dr. Burke and his team needed to go back in to control the bleeding.

Nurses tending to dozens of machines and reacting to alarms, coupled with round-the-clock bloodwork, created a life-saving synergy that can best be described as a modern-day miracle facilitated by angels living amongst us. Nurses who handle these babies are exceptional human beings who hold a very special place in our hearts.

Thankfully, Luna had survived her Norwood with minor complications. Remember when they told you that if your O_2 was under around 93, you should go to the ER? Luna was living in the high 70s and low 80s on a good day. This is to be expected coming out of the Norwood and is temporary. It actually gets worse before it gets better because the Norwood requires the insertion of a plastic tube that does not grow with the baby. So, during those 4–6 months of life, as the baby grows, the O_2 levels will decrease, which is when the next surgery (Glenn) comes in to save the day. This waiting period is dangerous, and hospitals have developed protocols for checking in with parents, which has made a world of difference in babies surviving this period. The biggest threat is a clot in the shunt. This shunt is the only way the baby is receiving oxygenated blood to its body, and if it clots, things can get bad really fast. Monitor O_2 often and get to know your baby's color.

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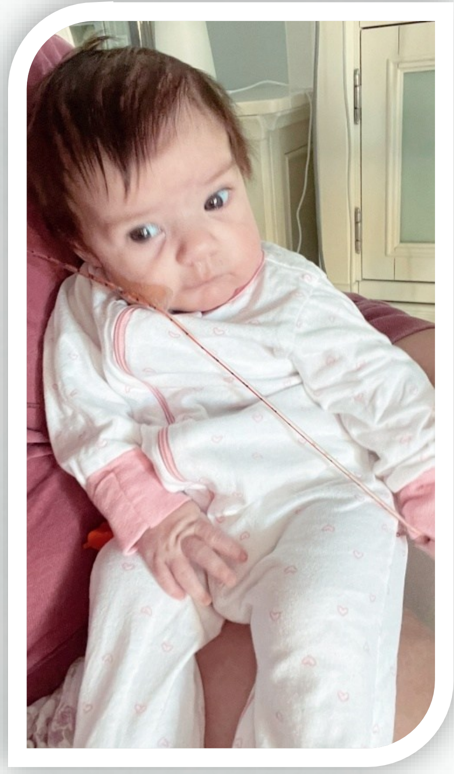
The Infamous Swallow Study and Feeding

Working in such a small space, it's predictable that the nerves and muscles involved in swallowing can be damaged during surgery. If the baby isn't swallowing correctly, food will get into the lungs and can cause pneumonia, and obviously avoiding this is a major priority. ENT came to check out the vocal cords. Luna's were fine, but we were told that even if there were paralysis of the vocal cords, it's often temporary. Then comes the infamous swallow study. We absolutely hate this study but appreciate the importance it has in avoiding pneumonia. Luna had her first bottles right away after being born and was eating fine. Our Norwood was done one week after birth, so she had a chance to practice drinking from a bottle and even breastfeeding. However, when we went down for her first swallow study, she had not had a bottle in at least two weeks and had been on an NG tube (a feeding tube inserted through the nostril). The swallow study is a live x-ray where they give the baby barium so that the liquid will contrast in the x-ray. You can see live where the liquid is going. They prepare this with different thicknesses. Sometimes they don't pass with thin fluids but they might pass with a thicker one. There's also the size of the nipple to consider. Bottom line: you want to finish this test having passed with a thickness and nipple size that the baby can handle, because if not, she won't be able to feed without help.

After several swallow studies over a couple of weeks, Luna passed, but with a thickness and nipple that didn't work for her. She would burn more calories trying to pull from the bottle than she could take in. We had already been in the hospital for about three months. Heart babies burn lots of calories, so breast milk needs to be fortified with formula. After trial and error with bloody stools and debates about possible milk allergies, we landed on a combination of Neocate and breast milk. Considering only calorie count, it makes more sense to just use Neocate, but there are studies that show that even a small amount of breast milk helps. With a prolonged stay in the hospital, the threat of NEC was looming over us. Any chance that breast milk could help avoid NEC was a tool we didn't want to leave unused. We'd seen other babies take a turn for the worse after an NEC diagnosis. Many were okay, but it could mean staying in the hospital for another couple of months. We had several people who didn't agree with the use of breast milk, but you decide what your baby eats, and if the hospital doesn't agree, find another one. You'll learn from reading more of Luna's story that sometimes a push is needed from time to time—it brings out the best in everyone who ultimately wants the best for the baby, and everyone will be friends in the end.

NG Tube Pros



Needless to say, we were ready to leave, but Luna wasn't drinking enough from the bottle to stay hydrated. Most hospitals won't let you leave with an NG tube because it can come out easily and needs to be reinserted quickly to avoid dehydration and malnourishment. The alternative is a G-tube (a port directly to the stomach), but that requires a small surgery and, while it can eventually be removed, it's a bit more permanent. We were convinced she'd be drinking from a bottle soon and persuaded the team that we could be trained and would be able to handle NG tube replacement. This meant practicing on a doll and ultimately having to prove competence on Luna, which was nerve-wracking, but we learned to do it. In the hospital, they verify proper placement with an X-ray. We wouldn't have that luxury at home, so we had to learn to listen for air with a stethoscope and know the difference between the NG being in her lungs or stomach. For obvious reasons, we were told to avoid letting her pull it out.

Of course, in less than a week of being home, Luna yanked her NG tube out. She thought it was hilarious—we were both there when it happened and just looked at each other and laughed with her. Without the safety net of a nearby nurse, our skills were put to the test—and we passed. We never stopped bottle feeding her despite the NG tube. While it was too little for nutritional purposes, we were doing this for practice. About a month and a half after we were home, we had trained Luna to drink formula thickened with cereal by thinning it very slowly, albeit still very thick. At one point, she pulled the NG tube out and we just never put it back in. We were 100% on the bottle. Most of what she was drinking was Neocate because breast milk supply was low, but we'd sneak some in, especially if she wasn't tolerating her formula well or there was a chance she could be getting sick.

Lessons Learned

Here are some important lessons we had learned by this point:

- **Swallow studies are not an exact science** and must be taken with a grain of salt.
- **The flow of a nipple** is not the same even if it's the same brand and number, so it can't be exact.
- **Cereal thickens over time,** so how fast the baby drinks will make a huge difference. At times, we would use 2–3 bottles for a single feed, mixing small amounts of cereal right before we gave her milk, which meant we would not have to work harder than necessary.
- **It helps to have tubes filled with cereal** already measured and ready to be mixed with the corresponding number of ounces of formula.
- **When a baby lies on its right side,** its stomach empties more efficiently and gravity helps the swallowing process.
- **Not all hospitals will offer** the swallow study using a side-lying position.
- **If you need to be discharged or transferred** to another facility because you feel this is best for your baby, do it.
- **Be prepared for battle.** Do your research and arm yourself with information. Print out studies and other hospitals 'protocols or at least have links ready.

The biggest lesson of all: never underestimate the power of your gut feeling. It will piss most of the doctors off when you have a crazy, irrational reason to dissent and question something but speak up anyway. Remember, many times "the science" is later proven wrong by "the science," so while their input is essential in your decision-making process, empower yourself to be the decision maker—this is your baby. If something doesn't feel right, ask questions. Get them talking and make sure everyone is thinking it through.

Strategizing the Future

Before Luna was born, we read about and discussed staged recruitment of the left ventricle with her cardiologist. This is when, instead of a traditional Glenn surgery, modifications are made to the flow to actually reintroduce the left ventricle to the circulation, creating pressure in it that sometimes causes it to disproportionately grow. If it catches up to the rest of the anatomy enough, Luna could become a candidate for a biventricular repair. This means that instead of the Fontan surgery, she would deviate from single ventricle palliation and undergo a full repair, essentially making her a true two-ventricle with normal blood flow. Dr. del Nido and his team at Boston Children's invented what they call the Super Glenn, and we had high hopes that Luna would be able to go this route. While Luna had several different anatomical anomalies that would create extra steps in the biventricular process, none of them ruled her out. It's important to note that this isn't straightforward. Single ventricle palliation has been around longer, and outcomes are more predictable than trying to recruit the left ventricle. Luna had some complications, like her multiple VSDs that had already been described to us as "Swiss cheese." A VSD is a hole between the left and right ventricles. When you have two ventricles, these are not supposed to communicate, and the goal would be to close any VSDs. Nonetheless, the plan was to go to Boston and attempt to recruit the LV.

COVID-19

Luna was doing great, but her oxygen saturations were dropping—as to be expected—signaling that it was time for us to get to Boston for the second surgery. As we were planning this and getting final insurance approval, the whole family came down with COVID. With Luna's saturations already being low (in the mid and even low 70s), we decided to have her checked out at the hospital. ICU rules at the time were that nobody was allowed in or out for two weeks, so Renny and Dunia spent 14 days in the ICU room with Luna, having laundry and food delivered. Almost immediately after checking into the hospital, we were told that the protocol for Luna—because of her condition—was to give her remdesivir. I can't stress how hard this was sold on us. At one point, while we were questioning this, we were told that the consequences would be on us if we decided not to do it.

We were concerned with the effect on her kidneys and liver, and they promised us that the risks were minimal. The problem is that what we were reading contradicted this. Ultimately, we caved to the pressure and allowed the first dose, but under the condition that we would test her serum creatinine levels routinely and monitor the GFR along with checking her ALT and AST levels. These are the markers that would tell us if remdesivir was affecting her kidneys and liver. A few of the doctors, nurses, and NPs were uncomfortably amused at our dissent, and most of them were outright annoyed, but there were always a few doctors or nurses who showed admiration and support for how we advocated for Luna. We're convinced Luna would not be alive today had it not been for the support of these people who empowered us to speak up and question everything. Common sense often escapes the analytics, and the process needs a clear head that doesn't care about what was taught in med school.

After the first dose, we immediately saw that the markers suggested remdesivir was elevating them significantly, so we had them stop the treatment. She was already starting to feel better from COVID, and we felt strongly that the side effects of remdesivir would be far more consequential than doing nothing. This triggered another, more intense round of shaming. Heads of departments came in to talk to us; at one point, someone from the County came in. To the praise of heroic medical staff who will remain nameless, we stuck to our guns.

Luna had some COVID symptoms, but she felt better after a couple of days. That said, we were pending a trip to Boston, but Boston wouldn't take a COVID patient until two weeks had passed after diagnosis. Boston has limited bed space, and it was explained to us that they wouldn't take a baby to be housed in the ICU for weeks or even days prior to being able to have the surgery. Luna was delicate, her O_2 was low, but we couldn't prove that she was fine from COVID—and it was because she was desperately in need of having the Norwood plastic shunt removed that she had outgrown. This was frustrating because her O_2 was low, but not lower than it had been before the COVID diagnosis.

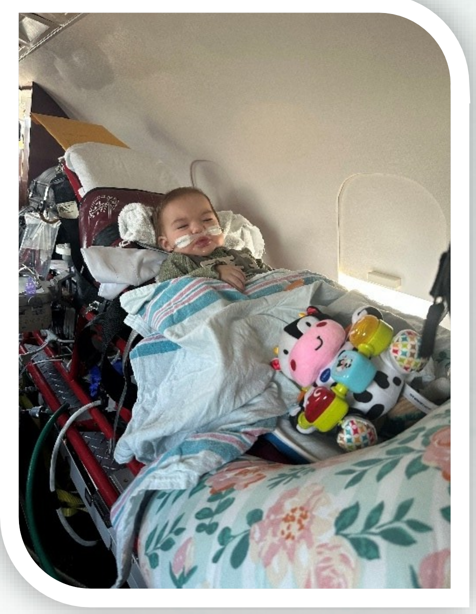
No Good Choices

Options were presented to us. Dr. Burke in Miami could perform a traditional Glenn, but this would mean no recruitment of the left ventricle at this stage, which means that if we wanted to go the biventricular route, we'd have to do an open heart surgery just for that. Nobody even knew if the insurance company would approve an open heart surgery that wasn't already part of the traditional treatment. In short, handling the recruitment during the Glenn, at the very least, meant one less open heart surgery and, at worst, would mean the biventricular option was no longer viable. This made the option of a traditional Glenn devastating for us. Another option was a temporary fix—nobody wanted to do this one because it hadn't been tested by the Miami team. This was to dilate and stent the existing shunt placed during the Norwood via catheter. Remember, she's about 7 months old at this point; they'd be going through her groin, getting all the way to the shunt, blowing up a balloon to almost double the size of that shunt, then placing a stent to permanently make it wider. In theory, this would drastically increase the amount of oxygenated blood to her body and increase her O_2, thereby buying us enough time to clear the schedule and get us to Boston. They explained to us that it was risky because the shunt could rupture. When we asked what would happen if it ruptured, they said it would be "catastrophic." So that option was off the table too. We just needed to get to Boston, now.

An emergency Glenn in Miami was the safest route, and they would have wanted to get as far away from the COVID diagnosis as possible before doing an open heart surgery. At the time, while Boston's rule for surgeries was two weeks, Miami's was six! In an emergency, they would have done it sooner, but the justification for waiting gave us a shot at making it to Boston. The big question was: will Luna's shunt allow enough oxygen to her body to clear the two weeks and wait for a bed in Boston to become available?

Getting to Boston

Luna, with oxygen support, made it past the two weeks, and Boston had a bed ready. Now we had to get a med flight. The number of moving parts was insane. Once the flight time was confirmed, Renny flew to Boston commercially ahead of time because the med flight only has space for one parent, doesn't allow luggage, and we knew we'd be in Boston for at least a month. Renny was already in Boston when an emergency delayed the availability of a bed at Boston Children's, and we were back to the drawing board regarding a date. Renny flew back to Miami because Luna was in a very delicate state with O_2 in the high 60s, and there was always a chance she would end up having emergency surgery back home. A few days later, we got a bed in Boston; the flight crew was scheduled, but the only available pilot had flown his quota for allowable hours in accordance with FAA regulations, and we missed check-in. Time to wait for another bed. We got one, and Renny went up hours before Dunia took off. Renny was in Boston waiting for the med flight when he received notice that there was something wrong with the plane and it had to turn around and go home about an hour after taking off.

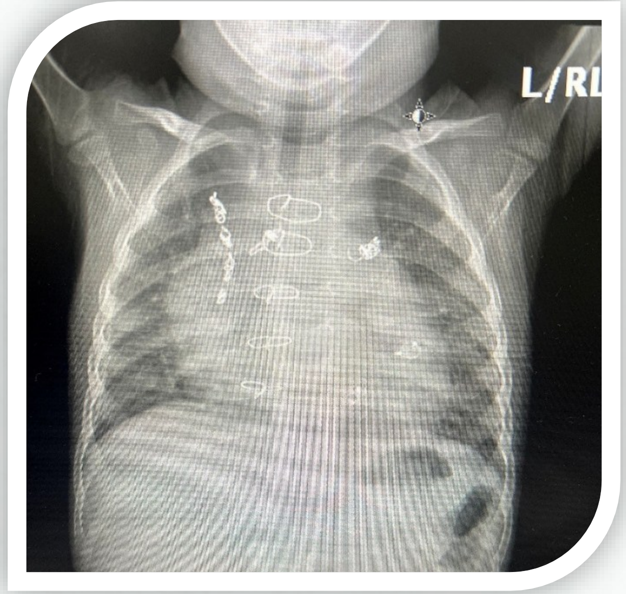


Luna was transported back to the hospital because no other med flight was available; this time, Boston had a room ready the following day, but Luna had become too delicate to fly. Things were getting bad really fast. There was a meeting with the flight crew and the Miami team, and they decided to intubate Luna the following day to make the trip safer for her. Renny was back in Miami by then, and everyone decided his anticipated trips were a bad omen, so he would stay back and fly up after the baby was safely in the hospital. The morning of that flight, they did a routine COVID test, and Luna tested positive. This was absolutely devastating because it probably meant that Boston would reset the two-week clock, and there was no way Luna was going to make it.

Infectious disease was testing the sample to determine if the positive test was potent enough to suggest this was a new COVID infection or if the test was merely picking up virus remnants from the previous infection. That test takes time, which we didn't have. If it was a reinfection, then open heart surgery was considered that much more dangerous—remember, Nicklaus at the time had a six-week post-infection wait time for surgery. They would have done it if it needed to be done, but we were told that since our initial arrival, the cath team had been discussing and testing how much they could stretch that shunt inside of her, should it come to it, and that they felt they could pull it off. The options were limited anyway. We can't stress how devastating this moment was for us. We were minutes away from getting on the plane, and here we were handing Luna off to the team to do a procedure full of unknowns that everyone was previously against. Dr. Burke, our superhero, came in and assured us that he would be in the next room with the bypass machine ready to go should there be a rupture. That said, other doctors had already told us that there would more than likely be nothing Dr. Burke could do if there was a rupture. There just wouldn't be enough time. With that information, we walked Luna to the cath lab, leaving the entire CICU in disbelief and tears. By now, even the cleaning staff was like family. While we waited, the test results came back confirming Luna didn't have COVID.

Several hours later, we received notice that the team was able to almost double the size of the shunt successfully, and Luna was safe. She was still asleep when we saw her, but we both looked right at the monitor and couldn't believe what we were seeing—Luna's O_2 was in the high 80s and peaking in the 90s, which we had never seen since she was born. A few days later, we were told they didn't see any reason to continue holding her in the ICU. Just like that, about a month and a half after coming into the hospital with COVID, we were back at home. This was still temporary, but she would now go into her Super Glenn surgery stronger than she had ever been.

Collaterals



We no longer qualified for a med flight because Luna was safe, but we were also advised not to fly commercially because if she picked anything up, it would delay the surgery. Driving came with its own risks because of the lack of hospitals along the way that could handle Luna if something went wrong, so we started reaching out to friends, and a couple of dear friends arranged for a local philanthropist to get us safely to Boston in his private jet.

The surgery was in the books, but Boston needed to confirm through their own studies that Luna was a candidate for the staged recruitment. One of these was an exploratory catheter procedure—these are routine before an open heart surgery. While they're basically going in there for measurements, there's always a chance they see something that can be done at this stage to make the upcoming surgery safer. Luna had already undergone a few of these, and we had endured the emergency stenting of the shunt via cath in Miami, but there is still nothing routine about it. It turns out that Luna had developed what they called "collaterals." When something is obstructing blood flow, like an underdeveloped artery, the body can spontaneously create alternate pathways to get oxygenated blood to ensure tissues and organs receive what they need. Luna was loaded with collaterals that she had created to help keep her alive, but they posed a serious threat and complication in surgery. Thankfully, the cath team in Boston was able to insert coils into them to stop the blood flow and help mitigate this risk.

Our cardiologist in Boston, Dr. Powell, notified us that we were good to go, and we finally met the man we had been reading about and praying for: Dr. del Nido. Dr. del Nido is originally from Chile, and he's the Chairman of the Department of Cardiac Surgery at

Boston Children's Hospital, as well as a Professor of Child Surgery at Harvard Medical School. He and his team pioneered biventricular repair. Luna's straddling mitral valve made this particular Super Glenn more difficult, and with his years of experience in complex biventricular repairs, it was a relief that he would be on the case himself. With this decision, we were officially leaving the traditional single ventricle palliation and going the route that could potentially give Luna a shot at a more normally functioning heart and blood flow.

The Super Glenn

So what exactly is this Super Glenn and how is it different from a traditional Glenn? There is no exact answer to this because these babies come with different issues that need to be addressed at different stages, so Luna's Super Glenn will be different from someone else's. The traditional Glenn takes down the Norwood and routes blood coming from the upper body directly to the lungs, bypassing the left ventricle, leaving the patient with a single functioning ventricle (in this case, the right ventricle). It does this using her own anatomy so that it grows with her, unlike a shunt. The Super Glenn routes the blood to the lungs but also sends blood to the left ventricle so that it has an increased workload and grows. In many cases like Luna's, this means creating baffles between the ventricles in a way that balances the need for communication between them while also causing some resistance to force the left ventricle to grow. In Luna's case, they used a BT shunt. As in the Norwood, whenever a foreign object is used to shunt, there is an increased risk of a blood clot. At the Norwood stage, this is much more dangerous because the shunt is the only way she's getting oxygenated blood to her body. Luna had her Glenn and the BT shunt now, so a blockage wouldn't stop her from being able to breathe, but it would mean no way to grow the left ventricle and a nominal decrease in O_2 saturation.

The morning of the Super Glenn was different for us. Luna had already undergone a very serious surgery and other dangerous, life-threatening procedures, but those were all when she was in distress. This morning, she was healthier than ever, and it was extremely difficult to hand her over, but we knew she would outgrow this shunt if we waited and felt that all the trauma of our delayed trip to Boston would be worth it so that she could go into this surgery strong. We handed her over and braced ourselves for a long day of waiting. Again, being told she was on bypass is always difficult. All we could think about was, "Please let her heart start up again."

The surgery was a success, and aside from performing the Super Glenn, we were told that Boston Children's had innovated a high-resolution electrophysiological mapping technique that mapped the electrical flow in Luna's heart. Dr. del Nido explained to us that some of his students had roommates who were doing this with the brain, and they thought it would be cool if they could apply what they were doing to the heart. Dr. del Nido challenged the "kids" to figure it out—and they did! It's not uncommon for interventions to affect the electrical flow of the heart and cause arrhythmias, creating postoperative complications. Having a detailed map of how the current flows in Luna's specific heart would significantly enhance future post-surgery outcomes. To these "kids"—whoever you are—we can't stress how grateful we are. This innovation has already drastically reduced the number of kids needing a permanent pacemaker after a complex surgery due to damage to their electrophysiology.

Luna's recovery was quite remarkable. She extubated quickly and easily, and Dr. del Nido ordered her chest tubes to be removed the day after the surgery, stunning even senior ICU nurses. Within a few days, we were out of the ICU and in what Boston Children's calls their step-down unit. It was a Saturday—less than a week had passed since her complex open heart surgery—and she was doing so well that her cardiologist told us she would likely be discharged after the weekend, on Monday or Tuesday, ahead of schedule. She was coughing a bit with some stubborn phlegm, a result of having been intubated for a couple of days, but other than that, she was in great spirits.

Discharge Already?

About an hour after the cardiologist left her side, Luna was acting a bit strange. She was struggling to get the phlegm up, and we could see she was off. We kept asking the nurse to call someone because we could tell something was up. The step-down unit at Boston Children's looks like the ICU, but it's quieter and less intense—which is a good thing, unless something is going wrong. It was also around shift change, which means the NPs and doctors were meeting to brief each other on the different patients, so getting someone at her bedside was taking a while. Her O_2 was well within the range of a typical baby coming out of a Glenn, but Luna had been peaking in the low 90s and, for no reason at all, we noticed she was lower. This wouldn't set off alarms with the staff, but as parents who know her better than any doctor or nurse, we knew something was up.

Nothing about what I have to say here is meant to criticize the amazing place that Boston Children's Hospital is. In all hierarchical situations, there is a power dynamic. You cannot expect a nurse in a step-down unit—who may be a travel nurse or new on the job—to step over that hierarchy and yell at someone to get their access to the room. This is the parents 'responsibility. There is an emergency button that staff press when a person codes, which immediately draws dozens of people to the room—a button that you should never touch. I wish we had known this button existed.

We kept asking for someone to come and take a look at her, and about an hour had gone by and our requests were getting more intense. Luna wasn't looking right; we were reassured by the monitor's saturation being in the 80s, but she was weak, her attitude had changed, and especially Dunia was feeling like something just wasn't right. Dunia was already starting to yell that something wasn't right, but aside from our nurse, there was nobody to talk to. We should have known about and pressed that button.

Code Blue

Renny was holding Luna as a more senior nurse and an NP were on their way. Just as they were walking in, Luna coughed up a mucus plug that went right back into her mouth. Within seconds, while Renny was holding her, Luna's life faded. Her O_2 dropped, and Luna was in full cardiac and respiratory arrest. There was no pulse. Renny got out of the way, and the NP and nurse started CPR while someone pressed the Code Blue button and people came from everywhere within seconds. These nurses were pumping her chest, which had been opened for surgery less than a week before. Time stopped; Dunia was on her knees, begging for someone to do something, and Renny was looking around in disbelief. We had come this far, and Luna's inability to clear phlegm was what would end her life?

The team wasn't having it; Dr. Salvin came running in and took over. He wasn't wearing a cape, but his sense of purpose was unapologetic and heroic. The room was in total chaos, and Dr. Salvin immediately started kicking people out and screaming for information on Luna. She was new to the step-down unit, and they didn't really know her anatomy, so Dr. Salvin was flying blind, yelling for someone to tell him what was going on. Dunia was on the floor, praying with a nurse tending to her, which is exactly where she needed to be. We strongly believe that the intensity of our energy directed at Luna's survival in that moment—call it what you will, prayer for us—had a huge impact on Luna's survival. Renny somehow pulled it together and went into a full technical download of Luna's medical history while they were intubating her and administering at least two shots of epi. The scene was straight out of a movie, and a full five minutes after she coded, Dr. Salvin called out that they had gotten a pulse. Luna was gone for five minutes—it was the worst five minutes of our lives to date; nothing compares to losing a child in your arms.

She was rushed back to the ICU. Dr. del Nido was pulling into his driveway at home when he got the call and turned around; Dr. Powell rushed over as well. By the time we gathered ourselves and made our way down to the ICU, her doctors were already there. She was stable, her heart was seemingly okay, but nobody knew what damage had been done to her body and brain. Our strength left our bodies, and we called our closest family and our son back in Miami to let them know what had happened. If ever there was a moment when our gratitude faded, this was it—but Luna had a pulse, and she was still at one of the best hospitals in the world. This could have happened after discharge back at the hotel, and so we started to focus on the blessings again. The next day, Luna was sedated and intubated, so we still didn't know what we were dealing with. Even if she were awake, she was about eight months old, so we knew it would be a while before we could tell if she had suffered any brain damage. They came in to do a brain scan, and miraculously, everything seemed normal. Luna was weaned off sedation and extubated easily. Things were looking promising, and we were positive our girl would be okay. Within a couple of days, we were back out of the ICU in the step-down unit, watching cartoons.

Not Her Normal

Luna's O_2 was within the range for a Glenn baby, but we couldn't shake the feeling that she wasn't hitting the 90s anymore and was instead in the low 80s. We were reassured that this was to be expected with the Glenn and that she was okay, but while she was presenting as okay, we had a feeling something was wrong. Before discharge, they always do an echo, and sure enough, it revealed that the BT shunt was not patent. This means blood was not flowing through it to the left ventricle. Nobody knew exactly what caused this—it could have come from an interruption of blood flow during her cardiac arrest, but this also occurs sometimes without that drama. The occlusion could have come before she choked on the mucus plug; they would have been unrelated anyway, so the cause wasn't the focus. We were presented with options. One was to do nothing—her O_2 was "normal," and there was no certainty that the left ventricle would grow and make her a candidate for the biventricular repair anyway. This option would render her Super Glenn no longer "Super"; nothing would be stimulating her left ventricle, and she would almost certainly end up going the single ventricle route. Or, we could send her to the cath lab and they could try to remove the occlusion there, establishing blood flow through the shunt. We didn't have to think too much about it; she came back from the cath lab with a patent shunt and higher O_2 readings. Luna still had quite a bit of phlegm, but talk of discharge was in the air.

Wash Your Hands

We were not okay—any change in attitude or a slight change in color was a red flag. We weren't far from the room where Luna coded, but we would go the long way to get places to avoid walking past it. The teams were all aware of what had happened, having been among the crowd of people that initially responded, and they were patient with us. At one point, Luna started acting strangely, and at first it was blamed on a new medicine she had been given. She was looking very tired and almost lethargic. Then, at one point, she started to vomit phlegm—which is a good thing—but seeing her so weak, coupled with the phlegm coming up, triggered the trauma, and Renny rushed to the button. In came the crowd, but thankfully it was a false alarm. The medication was pulled, but it had a short half-life, and Luna wasn't exactly herself yet. Knowing the staff limitations of the step-down unit, Dunia and Renny both advocated hard for Luna to go back to the ICU, where she could be monitored more closely. Most of the team disagreed, but there was enough support from nurses winking and giving eye approval that we stuck to our guns. By now, she wasn't just tired; she had diarrhea and was very weak. We were back in the ICU. Doctors tested and debated, but nobody could explain what was going on. One nurse in particular, on our second day back in the ICU, asked if anyone had tested for norovirus. Really? After all this, a stomach bug? Sure enough, Luna came back positive for norovirus, which was a relief. Dehydration is one of the leading causes of occlusion in shunts, but being in the ICU we could keep her hydrated and wait it out. We were still on edge because she had lots of phlegm and was still weak, so we requested to stay in the ICU for a few days, and the team agreed.

Eventually we were back in the step-down unit, optimizing medication dosages and talking about discharge. Another swallow study was done around this time, and Luna was still not able to clear thin liquids, but she could have her thickened milk. After about three months in Boston—a stay that initially looked like it would be less than 10 days—we were back in Miami.

Will It Grow Enough?

Up to now, most of Luna's story is relevant to both single ventricle palliation and biventricular (BiV) repair, and it'll remain this way until it becomes clear that she is a candidate for the BiV. The recruitment of her left ventricle is not a given and sometimes takes more than the step taken at the Glenn stage. We were made aware that if it did not grow enough after the Super Glenn, other measures—either via cath or even another open heart surgery—might be necessary before a definitive decision to either continue with the BiV or give up and go the single ventricle route could be made.

We were back at home, and Luna was safe, but we were traumatized. She was still weak; the norovirus had kept us in the hospital longer than her surgery. She still had lots of phlegm, and every cough triggered our anxiety. We bought suction tubes and distributed them around the house, in the car, in our bags… you couldn't open a drawer without finding a suctioning tool. We did have a couple of legitimate scares, and we learned a hard lesson about Luna: she develops lots of phlegm and struggles to get it out. It's difficult to keep her hydrated because she can't drink water and was taking diuretics. We were on Neocate formula, which she hated, and we couldn't give her regular milk because she had a sensitivity to dairy. For food, we would make malanga root-based purees with different proteins and veggies for variety.

When to Go Rogue

We mentioned this before, but a big part of Luna's development and positive outcome was knowing when to go rogue. There is amazing communication going on between the doctors and hospitals that treat these kids, along with well-established protocols. We're not ignorant people, and we can appreciate the value of good science. For the most part, the protocols led the way. That said, you have to understand what "science" you're looking at. When the metrics are all over the place and there are averages involved, chances are your relationship with your individual child and your knowledge of their behavior is going to be a better guide than a national average. A great example of this was Luna's O_2 saturation before she coded, but this can apply to weight, clearing milestones, feeding, etc.

Some of the changes we made that went against recommendations included slowly using less cereal in her milk to make it thinner without falling below a particular level of thickness in a swallow study. We also very carefully tried different nipple sizes. This made it easier for her to pull milk. We eventually used a sippy cup with a restriction valve for water. This was scary. We had been told that distilled water posed less of a threat if she were to aspirate, so we started giving her distilled water in her sippy cup, very little at a time. Luna absolutely loved water; taking it away from her was always painful, but we slowly worked up to where we felt she was definitely safe. We also made routine visits to the pulmonologist. The milk was another departure from advice. We moved away from Neocate and went with organic goat milk. This was the best move we made and played a huge role in her positive results. Goat milk is much easier to digest, closer to breast milk than cow's milk, and smells and tastes much better than Neocate. You might wonder, why not just breast milk? It's because breast milk breaks down the cereal, drastically affecting the thickness and creating a much higher risk for aspiration; besides, by that time, Dunia's ability to actually breastfeed had stopped.

The Best Year Ever

Assuming the Super Glenn would disproportionately grow her left ventricle to a viable size, her biventricular repair would be in about a year. During this time, we had the safety of the Glenn and weren't as terrified about a shunt occlusion as we were between stage 1 and stage 2. We were warned that complex CHD babies should be expected to develop more slowly than average, especially if they had long stays in the hospital. Then there were the five minutes she was without a pulse—we didn't know how this would affect her, but we were optimistic and worked hard. We spent this year enjoying Luna as much as we could. She loved every bit of it, from the frequent outfit changes to extended cuddle time. We were extremely protective of her health; this meant staying away from crowded places, having few people visit at any given time, and even annoying family members by verifying that they had no symptoms of anything before letting them come over. We were on a mission to help this baby grow, and any small cold would send her to the hospital and set us back weeks, if not months.

Dunia worked with Luna relentlessly on her milestones, and Luna was already ahead of average kids with her ability to speak sentences, recite the alphabet, identify shapes, and recognize sight words. We spaced out doctor visits as much as possible but kept a curious eye on her LV development through echoes. It's important to note that more frequent echoes are recommended because you want to make sure the BT shunt supplying oxygen to the LV is patent. We felt comfortable spacing these out because we didn't see a drop in her O_2, and having already experienced how an occluded BT shunt would affect her saturation, we were confident in using the pulse oximeter to assume it was patent. These are the kinds of calculated chances you have to take to avoid the baby getting sick in a busy doctor's office.

Luna celebrated her birthday, did Halloween, an Easter egg hunt, and went to her big brother's high school graduation—all while her O_2 saturations were in the 90s. This was a good year.

To BiV or Not BiV

After a while, we did a sedated MRI to determine if the LV had grown enough, which looked promising but was not conclusive. A sedated echo was done as well, and the results of both tests made both Dr. Aldousany and Dr. Powell feel that we should get the BiV surgery on the schedule, pending tests in Boston which included a cath.

We made our way up to Boston and were torn with this decision. Luna was doing so well. We were experiencing Boston with her like we never had been able to before. She was chasing squirrels in the Public Garden and running around the Wharf looking for bunny rabbits while we watched her, knowing that one of the most complicated surgeries that exists for a child her age was possibly going to be performed within a few days. Truth be told, with all the anticipation we had since she was born to get to this stage, we were perfectly okay with being sent home once test results came back. There were several technical issues to consider: she had a small left pulmonary artery, and we weren't sure if that had developed enough; then there were the "Swiss cheese" VSDs that might need to be closed, since the ventricles should no longer communicate once she's functioning with two ventricles.

We met with Dr. del Nido to discuss the test results and her candidacy for the BiV, and he confirmed she was not only ready but optimal. Luna was healthy and at the perfect age for this surgery. We could wait, but babies her age did better with this surgery than older kids. Everything we had hoped for since before she was born—with the team we wanted—

was within reach and scheduled. This was amazing news, but how were we supposed to find the strength to hand over Luna for this surgery? The complexity of her anatomic anomalies would make this surgery extremely difficult—not because of any one issue, but because of the sheer amount of work that needed to be done. Aside from taking down the Glenn and the BT shunt, there was work to do on the left pulmonary artery, the aorta had to be moved over to the left ventricle, which had never functioned that way, and the VSDs had to be closed. Nobody was hiding how difficult this was going to be, but it was reiterated to us that she was in the hands of the absolute best. It was an impossible decision. Neither of us was certain either way, but together we decided that Luna deserved the chance at a regularly functioning heart, and she had worked so hard to conquer so many obstacles that we wouldn't be able to justify not doing this for her later.

The BiV

We handed her over with tears in our eyes and braced ourselves for a long day, knowing that again, in a few hours, they would notify us that she was on bypass. Luna was in the OR for over 12 hours, during which time we were sick to our stomachs. Finally, we got word that the surgery was over. Things had mostly gone according to plan, but there were some residual VSDs—meaning some that they couldn't close during the surgery. Remember, these are the holes between the ventricles described as "Swiss cheese." They took her off bypass and restarted her heart, only to find that there was a significant flow of blood between the ventricles. Due to the nature of many small holes, it's difficult to tell what is what when the heart is stopped and there is no flow. They had to put her on and off bypass several times to safely close as many VSDs as they could. Dr. del Nido did this while following the electrical map they had previously created of her during the Super Glenn. The mapping technology pioneered by Boston Children's Hospital helped them navigate her electrophysiology, thereby avoiding the need to place a permanent pacemaker. Some of the VSDs were in places that could not be safely accessed during the surgery. They had to install a pulmonary band to offset the pressure caused by these VSDs so that the lungs would not get overwhelmed. It was explained to us that the hope was that the VSDs would close on their own over time, and as she outgrew the band, they could go in and pop it via catheter in a year or so. Most importantly, our little girl had two functioning ventricles and would be, with regards to her oxygen, "fully saturated!"

Post-Op

We walked into the ICU after the surgery, and as expected, there were dozens of machines and people working on her to make sure she stayed stable. Luna's surgery was really long, and her body was also adjusting to a new way of circulating blood that she had never experienced. These rooms are cold, and we noticed her legs were a little blue; there was also a sense of concern. Different people were walking in with a little Doppler machine, trying to find a pulse in her legs to no avail. We were reassured that this can happen after a long surgery, but that it typically comes back. As time passed and more and more people started to get excited when there was anything that sounded like a possible pulse in her legs, the gravity of the situation began to become more apparent. While nobody said it out loud, we knew what this could mean—and enough time had gone by with very little or no blood flow to her legs for serious cause for concern. Hours later, someone found the right angle and a pulse became audible; we took a sigh of relief and braced for the roller coaster we knew was coming.

Extubation

y now we learned that while surviving surgery where all goals are met is huge, the hours and days that follow are filled with as much or more anxiety. Luna wasn't ready to be extubated as quickly from the BiV as she was after her Glenn. The BiV was a long, complicated surgery, and she had to be sedated for longer. She was not a huge fan of being sedated and started to fight the medications, causing doctors to increase dosages. Despite how much we warned everyone that she produces a crazy amount of phlegm that finds its way deep into her lungs, everyone was surprised at the thickness of her secretions. We could see when her O_2 was going down, and we could tell a mucus plug was in her airway. This happened from time to time, so we asked for scheduled deep suctioning rather than a reactionary approach. There's a specific team that deals with this called the RT (Respiratory Team.). Luna had a habit of hiding her thick secretions, making deep suctioning difficult. This meant that the more experienced techs had to "really get in there." We knew she needed this to be safe, but it was painful to watch—she would look at us, wondering why we weren't helping her; it was absolutely terrible. Eventually, she was already starting to try to vomit the secretions. It got to a point where she wasn't going to stay under, and a plan was set in motion to extubate her.

This is always scary, but even more so this time around. Luna's personality was more apparent, and she had a pretty solid vocabulary. When your baby comes out of sedation, you never know how much of her will show up—especially after a longer period of time. Will she recognize us? If not, how much time will it take? How much of her progress will be lost and need to be regained? Immediately following extubation is one of the most dangerous moments; it is a process. For sure, she'll need oxygen support, but how much depends on her, and it's usually better to stage this process to avoid having to be re-intubated.

Luna was starting to wake up, and the breathing tube came out. The first thing she did was blow kisses at both of us. All we could think was, "Thank God, she's there—it's her!" Over the past week, the ICU team had heard dozens of stories about how special Luna is. We put a collage of pictures of her living her best life on the ICU glass door because we wanted everyone who came in to know who she is at her best. The goal was to bring back a biventricular version of her and nothing less. Nobody in the room was ready for what was going to happen next. She was aware and annoyed at the tube that was still in her airway, and the team needed to move quickly, or else her thrashing would dislodge the tube. We were talking to her and trying to calm her down, but she was still drugged, and we didn't know how much of what we were saying she was comprehending. The team came in and pulled the tube out. Luna made eye contact with us, took a breath, and started blowing us kisses. Everyone in the room immediately learned just how true the stories they had been hearing were. Our baby was back, this time with a bigger and better heart than before.

Without getting too technical, there are different levels of oxygen support, different machines, and each of them has different intensities of settings. Teams will typically step the intensity down, then, if needed, step it back up to find the sweet spot that avoids re-intubation. In Luna's case, she was weak, had a lot of phlegm, and this scenario was becoming all too familiar to what we had been through during our last visit to Boston. After trying to support her with different intensities, it was determined that Luna had to be re-intubated. While this happens to a lot of kids in the CICU, it was never our experience, and we were terrified. But at least for now, intubated Luna was safe. She would be sedated again, given a chance to muster up some more energy, and then we would give it another go.

A couple of days passed and a plan was being hatched to extubate again. By now, she had been heavily sedated for over a week, fighting the meds and building a tolerance to them. We had no idea what this would mean for us in the coming weeks. Luna woke up again and was successfully extubated. The biggest threat now, aside from keeping an eye on how the residual VSDs would affect her, was her secretions. Too much blood flow from the VSDs would manifest as pulmonary edema, which is managed with diuretics, and while some drainage from chest tubes is to be expected, when it doesn't slow down considerably over time, it could be that the VSDs are allowing too much blood flow, or she could have chylothorax, or both. A test of the fluid being drained revealed the presence of chyle. A rare complication from thoracic surgery is chylothorax—a condition where fluid from the lymphatic system leaks into the space around the lungs. This fluid drains into the chest tubes, which means it takes much longer to remove them, translating to increased pain, since the chest tubes are the most painful part of this surgery. The best treatment for this is to stop all fat intake, which meant no milk for a while. Chylothorax can make things really bad really fast. All of this was happening at the same time, and Luna couldn't seem to catch a break. There was the threat of the VSDs, chylothorax, worse phlegm accumulation than that which almost killed her a year before, and now drug addiction.

Weaning

Yup, drug addiction. We had no idea what weaning was because her prior surgeries didn't require extended periods of heavy sedation drugs. Pulling these drugs from her system was a painstaking process that took about a month and required a very specific plan, including reintroducing some drugs to help her manage the process. In the middle of this, we moved out of the ICU and into the step-down unit. These withdrawals were very real, complete with sleepless nights of thrashing and yelling. The risk of her removing her chest tubes while dealing with this was dangerous. If there was ever a brief moment during all of this when Luna was not herself, it was during the weaning of these drugs. We were grateful for them and hated them at the same time. We found a new level of respect for people dealing with drug addiction.

Hair Loss and Walking

While still in the ICU, we noticed a bald spot on one side of Luna's head. It turns out this happens sometimes during long thoracic surgeries—it's called "pressure alopecia." They try to move her as much as possible during the surgery to avoid this, but when things get complicated, it happens. It had never happened to Luna before. This hair usually starts to grow back, but Luna's wasn't. With everything going on, this wasn't a priority, and we figured we'd address it when we got home. Several months had gone by since her surgery, and we were starting to feel like Luna might be in one of the rare cases where it doesn't grow back. Dunia started to make rosemary water and applied it to the bald spot. Within a few days, hair started growing.

Luna had never been in bed so long, but the chylothorax and chest tubes associated with that meant she couldn't go for a walk sooner. When we finally tried to stand her up, she couldn't hold up her weight. This was devastating. She was over-diuresed and weak. We worked with her on floor mats in the room to get her standing again; eventually, that turned into slow and short walks.

Music Therapy

The playroom had a guitar and some shakers. Renny is no guitarist and hadn't touched one in about 20 years, but he mustered up some chords he'd learned as a child, and Luna was in love with her nursery rhymes on demand. Music had always been present in Luna's life, her most requested songs to date being "La Vie en Rose," "You'd Be So Nice to Come To," and "Happy and You Know It." The guitar in the room was a game changer for everyone's spirits—mostly Dunia and the nurses, who were making fun of Renny's pathetic attempt at singing—but Luna got a lot out of the change in energy in the room. We can't stress how important music therapy is. Even if all you can find is a shaker, or if you need to make one yourself with some rice or beans in a container, much more than just listening, making music goes a long way! We missed the guitar when we were back in the ICU after her cath, and there was only one for all three floors, so we set up a quick meeting of the foundation and got unanimous approval to buy some instruments to donate to the hospital. Guitar Center in Boston stepped up with a solid discount, and we were able to buy three guitars and a bunch of hand instruments that we hope kids and their families are still taking advantage of.

Discharge?

Talk of discharge was in the air. We weren't done weaning yet, but there was a schedule, and while we were about a week away, medications were being optimized and we were ready to test her ability to swallow. Luna had weaned herself away from needing an NG tube as a newborn but had been on one during this time so far at the hospital. ENT came to the room and determined she had paralysis of one of her vocal cords. This was concerning but not too bad. We had dodged this bullet before, but we were aware that it's typically temporary, and in the meantime, she would just have a cool, raspy voice. The concern was how much this would affect her ability to safely swallow while it repaired itself. We would need to do another swallow study.

At first, Luna didn't want anything to do with the bottle after the surgery. We tried to do a swallow study, but she wouldn't drink the barium. We weren't dealing with a 7-month-old this time—she had her own Latina attitude, and forcing her to drink this stuff was not going to be easy. After several attempts, she finally barely passed with the thickest consistency she had ever managed. It was going to be almost impossible to get her to take in this puree of milk and cereal from the bottle. To make matters worse, she had already drunk water and was asking for it. We had to hide all water bottles in the room because plain water was no longer an option. Ice chips and a pink sponge on a stick became her favorite snack.

The difficulty in handling this thickness from the bottle meant that we had to keep the NG tube in for now—at least until she showed us that she could get enough volume to prevent dehydration. She was already starting to eat her hearty purees, so we knew she was getting nutrition, but she needed her milk. They performed an exit echo as part of the plan for discharge.

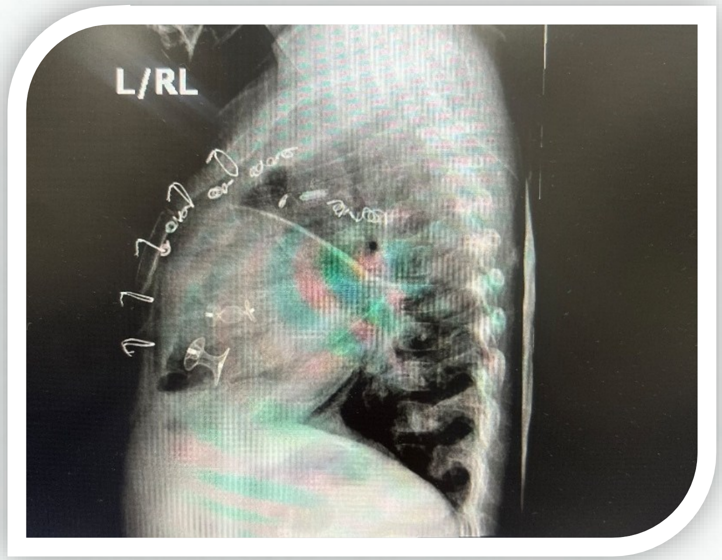
Residual VSDs

When you're a few days from being discharged and the surgeon, cardiologist, and attending all walk into the room at the same time, you know this can't be good. Dr. del Nido doesn't just come around at this stage. He was there to tell us that the echo showed too many large VSDs were causing fluid buildup in the lungs, which was speeding up her respiratory rate, and she was already being diuresed too heavily to manage it with medications alone.

Her best shot would be intervention via cath. We were told that the hope was to go in and see that nothing had to be done because the VSDs were indeed small enough to leave alone, but the metrics all pointed to some intervention being necessary. Via cath, they would enter the left ventricle and insert devices that open up like umbrellas on either side of these holes and seal them shut. It was a Thursday, and she was added to the schedule for a cath on Monday.

This was a more complicated intervention than we're used to because they would be navigating her electrophysiology. Even slight interference with the electrical signals in the heart could have serious implications.

Last Ones Out



We're used to being the only ones left in the waiting room, but this cath was taking longer than some surgeries, and it was safe to assume that interventions were necessary. Our cardiologist did come to join us in the waiting room and explained that some of the VSDs had been closed, but that there were some that were impossible to reach and that the measurements taken in the cath lab were promising—but only time would tell if this was something we could manage with medicine or if she was going to need another procedure. Future potential courses of action would be another open heart surgery to tighten the band on her pulmonary artery, which would offset the flow from the VSDs, or try to surgically close the VSDs. This is an extreme last resort because it involves cutting into the heart. We were mortified. Our best-case scenario was no more open heart surgeries. We hadn't even left Boston, and here we were talking about the possibility of another one already.

We went up to the ICU. Normally they would extubate right after a cath, but while we didn't get the exact play, we knew it was exciting in there—enough for several senior members of the cath team, as well as Dr. del Nido and Dr. Powell, to be involved. Given the sensitivity of the interventions and the fact that they don't typically like to leave extubation for the night team, she stayed intubated. We didn't leave the cath lab until after 11 p.m. Luna was in the ICU room, and she looked more like she had come out of an open heart surgery than that of a cath. We were terrified, and things quickly got worse. The electrophysiology team is not one we are accustomed to seeing. From what we gather, they review all the cases and are involved as needed in the background, but it's not a good day when they burst into the room at 1 a.m.

Luna was going into ventricular tachycardia, or VTach. This was a bad thing. Her heart rate was now over 200 beats per minute, and nobody was trying to play it cool anymore. The crash cart was in the room along with a whole team led by Dr. DeWitt, and we were completely helpless. Normally, we would stick around, but it was hectic enough that we retreated to the waiting room. If there was any chance she could code, we were at the point where neither of us could handle it. We walked a few feet away and prayed as hard as we could. After a little while, they had gotten control of her heart rate, and a massive bullet was dodged. They had a map of her electrophysiology, but the VSDs were where they were, and leaving, especially the larger ones, open was not an option. The devices themselves can irritate the tissue and affect the electrical signals, and this is probably what was going on. Some medications were given to control that, and she was successfully extubated and then closely monitored for a couple of days before we went back to the step-down unit.

Still Weaning

The pain management team was in charge of the weaning schedule—they were great. Boston sees enough cases that their own experience often sets the protocol for other hospitals around the globe. Luna got the benefit of that experience firsthand, and we are forever grateful for that. Having to go back to the cath lab and staying intubated overnight after the VTach incident was going to set us back a little with regards to our exit strategy, not just because of the narcotics, but because the intubation caused increased secretions. We also had the issue of her hydration and nutrition. We really wanted to avoid leaving the hospital with an NG tube. We hadn't dealt with that in two years, and it was going to be almost impossible to keep her from taking it out. We tried to encourage her as much as possible to pull the thick liquid from the bottle. We were also terrified that she'd aspirate and get pneumonia. The night before we were going to be discharged with an NG strategy, she yanked out the NG tube, and rather than replace it, the team gave us a shot at testing how much she would drink from the bottle. Luna stepped up to the challenge, and the NG tube stayed out.

Going Home

This is the first time we went home with uncertainty. We stayed in Boston for a few days because, truthfully, we lobbied hard for getting out of the hospital setting, but Luna was not herself. The new beta blocker she was taking after the VTach incident has side effects that make her somewhat lethargic. This would improve over time—and had already improved significantly—but she still had a lot of phlegm, and being weak meant the risk of choking on it was higher. Every time she coughed something up, we panicked.

Luna sounded junky. We were giving her regular nebulizer treatments to help break it up, but we didn't know if this was more from pulmonary edema caused by the VSDs or if she had aspirated because of the vocal cord and swallowing issue. Other indicators, like coughing while feeding and faster breathing, didn't give us clues either way. Leaving Boston was risky, but we boarded the plane anyway.

Back Home Again

About halfway home, Luna's demeanor completely changed. It's hard to describe, but it was like she was back—she started pulling her milk more easily and just talking like herself. There were three of us on the flight with her—Dunia, Renny, and Dunia's mom—and we all immediately noticed it at the same time. From that point on, to date, Luna has been bouncing off the walls. Something was missing once we were home, though; Dunia fixed that when she bought a guitar for Renny on his birthday.

After about a month, her secretions improved and we were able to stop the nebulizer treatments. She was still breathing a little fast, and eventually, it got fast enough to be a serious concern. She was at about 50 breaths per minute when we took her in for an echo and chest X-ray. Sure enough, pulmonary edema was forcing her to struggle to breathe. A possible solution was to give her more diuretics and hope we could find a balance between dehydration and suffocation. If that didn't work, there was the option of tightening the pulmonary band, which requires open heart surgery—if they tighten it too much, it means she doesn't get enough oxygen. Or, some kind of catheter procedure to close the VSDs, which they had already determined were too dangerous to close when she was last in there, at which time she went into VTach.

We started with the meds, and immediately, within 24 hours, she was breathing better—but she was also severely dehydrated. We skipped a dose and started dialing back the meds to find a sweet spot where we could keep her in the 30 breaths per minute range. If we couldn't juggle breathing with dehydration, we'd be back on a plane to Boston quickly.

Luckily, we learned to read her signs. It would take a solid month before we had the right dosage, and even then, depending on how she presented and her breaths per minute, we would reduce, add, or even skip a dose. BTW, thank God for whoever invented the app called “Breaths Per Minute.” This app is a game changer—I wish we’d known about it earlier.

How Is She Now?

Luna was breathing in the high 20s and very low 30s breaths per minute, and after a few months, we started to see her dehydrate for no apparent reason. We had already started giving her water again in her restricted sippy cup, and she was having plenty of milk, so we knew this was cause for celebration. It had to be that the VSDs were closing, reducing the fluid buildup in her lungs—which meant we were overmedicating her. We adjusted her medications on our own to find the new sweet spot and eventually went in for an echo, cautiously optimistic. It was confirmed that her VSDs had started to reduce in size, which is what we've been praying for since her BiV.

What's Next?

We'll keep counting her breaths several times daily and keep reacting to any possible dehydration by adjusting meds. The priority is growth—the more she grows, the more efficient the band on her pulmonary artery becomes, and that internal pressure is supposed to help close the VSDs. We pay close attention to the quality and quantity of food, but also to avoiding setbacks. Getting a regular cold, or, God forbid, something more serious like norovirus or RSV, could put us in the CICU again and make her lose weight. At some point, she's going to outgrow her pulmonary band, and the restriction will cause her O_2 saturation to decline. She's going to turn a little blue—we're expecting this. At that time, we'll travel to Boston and break the band in the cath lab. She will no longer have anything foreign in her that wouldn't grow with her body and would need to be removed. This could be her last procedure. We also hope to be able to take her off the beta blocker under close supervision there. People ask us what they can pray for or what they can do. We ask that you pray for her growth and health, that you visualize the closure of her VSDs and a successful release of her band—and even more, that you visualize her as a happy grandmother surrounded by family. Also, if you've gotten this far, you're Luna's friend. Support the Luna's Friends Foundation in any way you can so that together we can help other families dealing with similar circumstances around the world. Visit www.lunasfriendsfoundation.com for donation information.

Facts and resources

Congenital Heart Disease (CHD) refers to structural abnormalities of the heart or the great vessels that are present at birth. These defects can affect the walls, valves, arteries, or veins of the heart and may range from mild conditions that require little or no treatment to complex malformations that need early surgical or catheter-based interventions.

Below are a list of common defects. While each of these defects occurs with its own frequency, many children with CHD may have more than one defect. In the most complex cases—like Luna's—the child has a combination of several abnormalities. Luna's combination is extraordinarily rare and represents one of the most challenging forms of CHD, occurring in far fewer cases than the more common isolated defects.

For parents, caregivers, and healthcare providers, understanding these definitions and statistics is crucial. If you are looking for more detailed information or the latest research, reputable sources we provide links at the bottom of this page. We're also providing a list of the Hospitals that are considered the leaders in CHD intervention in Babies. Keep in mind that depending on the route you take you may not need to leave your local hospital. In Miami, there is a great team and surgeon at Nicklaus Children's Hospital that has a phenomenal record on successful Norwood surgeries. While we were almost certain we would go to Boston for subsequent surgeries it made much more sense to have the first one locally allowing Dunia to deliver Luna at home, and endure our first prolonged hospital stay just 30 minutes from our house.

Prevalence

- ✓ **Overall CHD Prevalence:**
  CHD affects approximately **1% of live births** (about 8–10 per 1,000 births worldwide). In the United States, this is roughly **40,000 new cases each year**.
- ✓ **Complex Combinations:**
  Although many babies with CHD have a single defect, it is not uncommon for them to have a combination of issues. The complex combination described here

is exceptionally rare—less than 1% of CHD cases—with an overall occurrence estimated around **1 in 10,000 to 1 in 20,000 live births** or even fewer.

Common Types of Congenital Heart Defects

For context, here are some of the more common types of CHD, along with their approximate frequencies among CHD cases:

- ✓ **Ventricular Septal Defect (VSD):**
  - ➢ **Frequency:** About **30–40%** of CHD cases.
  - ➢ **Overview:** A hole in the wall (septum) separating the two lower chambers (ventricles) of the heart.
- ✓ **Atrial Septal Defect (ASD):**
  - ➢ **Frequency:** Approximately **10–15%** of CHD cases.
  - ➢ **Overview:** An opening in the wall that separates the two upper chambers (atria).
- ✓ **Patent Ductus Arteriosus (PDA):**
  - ➢ **Frequency:** Roughly **5–10%** of CHD cases.
  - ➢ **Overview:** A condition where the ductus arteriosus (a vessel connecting the aorta and pulmonary artery during fetal development) fails to close after birth.
- ✓ **Tetralogy of Fallot (TOF):**
  - ➢ **Frequency:** Around **5–8%** of CHD cases.
  - ➢ **Overview:** A combination of four heart defects that together affect blood flow through the heart.
- ✓ **Transposition of the Great Arteries (TGA):**
  - ➢ **Frequency:** Approximately **5%** of CHD cases.
  - ➢ **Overview:** A condition in which the positions of the aorta and pulmonary artery are reversed, leading to problems with oxygenated blood circulation.
- ✓ **Coarctation of the Aorta:**
  - ➢ **Frequency:** Occurs in about **5–8%** of CHD cases.

  - **Overview:** A narrowing of the aorta that can cause high blood pressure and restricted blood flow to the body.
- ✓ **Hypoplastic Left Heart Syndrome (HLHS):**
  - **Frequency:** Seen in roughly **1–3%** of CHD cases.
  - **Overview:** A severe defect where the left side of the heart is underdeveloped, typically requiring multiple surgeries soon after birth.
- ✓ **Double Outlet Right Ventricle (DORV):**
  - **Frequency:** Estimated to account for approximately **1–3%** of CHD cases.
  - **Overview:** A condition where both the aorta and the pulmonary artery arise predominantly or entirely from the right ventricle, often resulting in mixed oxygenated and deoxygenated blood.

Links:

https://www.heart.org/en/health-topics/congenital-heart-defects

https://www.childrenshospital.org/conditions/congenital-heart-defects

https://www.chop.edu/centers-programs/fetal-heart-program

https://www.heart.org/en/health-topics/congenital-heart-defects/about-congenital-heart-defects

https://pubmed.ncbi.nlm.nih.gov/?term=congenital+heart+disease

https://www.cordblood.com/blog/new-hope-congenital-heart-defect-patients-through-power-newborn-stem-cells

Click here to learn about freezing stem cells:
https://learn.cordblood.com/referral.html?contactid=0013l000020n7NFAAY

Top Hospitals for CHD Intervention in Babies

- ✓ **Boston Children’s Hospital (Boston, MA)**
  Boston Children’s is internationally renowned for its comprehensive Pediatric Heart Center, offering state-of-the-art surgical and interventional treatments for a wide range of congenital heart defects.
  Boston Children’s Hospital – Pediatric Heart Center
- ✓ **Children’s Hospital of Philadelphia (CHOP) (Philadelphia, PA)**
  CHOP is widely recognized for its leading-edge congenital heart programs,

providing innovative treatments and advanced surgical care for complex CHD cases in infants.
CHOP – Congenital Heart Center

- ✓ **Texas Children's Hospital (Houston, TX)**
  As one of the largest pediatric hospitals in the world, Texas Children's Hospital has a long-standing reputation for excellence in pediatric cardiac care, including complex congenital heart surgery and interventional procedures.
  Texas Children's Hospital – Heart Center

- ✓ **Cincinnati Children's Hospital Medical Center (Cincinnati, OH)**
  Cincinnati Children's is recognized for its innovative approaches and multidisciplinary teams that specialize in managing and treating complex congenital heart defects in infants.
  Cincinnati Children's Hospital

- ✓ **Children's Hospital Los Angeles (CHLA) (Los Angeles, CA)**
  CHLA provides comprehensive cardiac care for children, with a dedicated team focused on complex heart conditions and groundbreaking research in pediatric cardiology.
  CHLA – Cardiology & Heart Surgery