

Hilaria's story: God's little princess

Born with a genetic disorder that went undiagnosed until she was 8 years old, Hilaria was a fighter. Most children with her disorder would have given up, but not Hilaria. We found her in another orphanage in the mountains of Panama when she was 9 months old and tied to the corner of a crib. We went to the orphanage for her brother Raul, but once we saw her and her underdeveloped condition, we got permission from the government to bring them both at the same time under the reasoning of keeping siblings together. Yet truthfully, she might not have made it had we not gotten her that day, as well.

There are many miracles to the story of Hilaria, but the first I'll share with you was the legal miracle. Our team of psychologist, social worker, and attorney had dug deep in her file. We started noticing things that needed to be investigated further. Due to the extensive training we give our teams, they were able to spot right away the problems and begin further investigation. When I say they went to investigate, I mean they went as far as you can go in the jungle. Our Panama City psychologist (a true city-girl!) traveled by horseback and dugout canoe with the indigenous guides. She went far into the indigenous village to perform a psychological evaluation of the birth mother and find who the father is. The grandfather was seeking custody and we did not feel that he was capable of handling the special needs of these children, so we wanted to go see for ourselves what was happening. Her evaluation proved that the mother had severe intellectual disability. She was absolutely incapable of remembering a seizure medicine schedule, much less anything else related to the care of a child. The mother could barely care for herself.

Our social worker then questioned several people in the village and we learned from Hilaria's aunt that, in fact, the father of the child was the grandfather. This man was trying to get custody of Hilaria only, not her brother, and one can only surmise as to why that was. He only wanted the girls in the family. We immediately wrote up our Heart's Cry psychological and social work report, which our attorney added to a Motion that was being prepared to send to the assigned judge in order to request termination of all parental rights in this case. We wanted to prevent the grandfather from custody or visitation rights. Just as the ink was drying on this report, we received the assigned Judicial Order giving custody of Hilaria to the grandfather! How could this be?! The next morning, our Heart's Cry attorney jumped on a plane with our report and flew to the mountains to meet with the judge in order to explain that the government had done zero to investigate the case and were just getting it off their desk by giving Hilaria back to the grandfather, who should be in jail. Praise Jesus, the Judge saw our attorney, read our Motion, approved our Heart's Cry report over the governments' social worker and psychologist reports of Panama, and reversed her own Order. Very few, if any, judges will ever reverse their orders! But she did. This was a legal miracle, the timing of it all. God laid it on our hearts to do the investigation at such perfect moments, in order to save her life from a predator.

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After a few years Hilaria's health started to decline pretty rapidly. The doctors could not figure out what was going on with her and it was driving us all crazy. We love her so much and couldn't believe how quickly she was declining. Her speech and lungs were affected and she had partial paralysis. By God's grace, our pediatrician that visits Casa Providencia once a week requested a blood test of a very rare genetic disorder called Alpha Mannosidosis. It was a medical miracle that we were able to determine this

is exactly what she had. At this point the hospitals had already misdiagnosed her multiple times, including one time we thought she had TB and had to put all Casa Providencia on lockdown!

But what to do about Alpha Mannosidosis? There was not one single case in Panama. Not a single physician knew how to treat it there. After investigating from other countries, we realized there was a possible treatment of one medication that could cost \$10,000 a month. We were requesting the government to go after this medication enzyme therapy in order to help her, but with changes of government there was no response, and time was ticking; her health was worsening.

On one of our visiting team trips, a nurse practitioner from DC decided she was not going to give up and wanted to help Hilaria. She got in touch with physicians in DC at National Children's Hospital who treated this disease, one of the few hospitals in the world that treat this rare genetic disease. Appointments were lined up at a discounted price with every Doctor that needed to investigate her specific condition as well as advise on how to treat going forward. Our next obstacle was, how to get Hilaria to DC? This is when more miracles began to pour in!

Our journey on getting Hilaria to America began with requesting permission from the judge in Panama to travel. We turned in all the documentation and waited and waited and pushed and pushed, but nothing. We prayed and prayed and finally got a hearing! At the hearing, the judge finally granted the motion after realizing this child may die under her watch, because the judge was literally denying her a way to go see a doctor. Once we had the permission to travel with Hilaria, the appointments were three weeks out. We also had to obtain her passport and visa in time, and how were we going to pay for it?

All of this was happening the week after our dear Eduardo, Director of Maintenance extraordinaire, passed away. We had seen how a hospital bill could jump from \$1000 to \$100,000 overnight and we had absolutely no funds available for Hilaria to go.

After all this work, all this time, all this pushing and begging and fighting, we finally get a judge's order and Ari calls me to tell me OK - now can we pay Children's National? I was calling Matt to tell him the good news and the bad news: we have permission from the judge to travel, but no money to pay for it in the ministry. It happened to be one of our lowest giving months of the entire year. Zero extra to pay for this. I was going to have to tell Ari "No, she can't go..." after all that had finally been accomplished, and Ari was looking at Hilaria dying slowly in front of her eyes. So, I picked up the phone and called Matt to tell him all this, absolutely heartbroken and upset on every level. Matt "just so happened" to be leaving the post office box as our bookkeeper was unavailable that day to get the mail and check on donations coming in, so he had gone. As we were talking and I was relaying all this to him, Matt opened a check and he said, "Misty, we have a check here, designated for Hilaria, for more than what the doctor's bill is going to cost. And, it is from somebody I have no idea who this is and has never donated before!"

I just cried and cried. I could not believe the mercy of God at that moment. My faith is so weak. Even after all this time and after all the miracles we've seen since saying "Yes" to Jesus and moving to Panamá... our Savior did it again! Just in time, our good God, laid on the heart of this new partner in the ministry to pay the way for God's special princess to get to the one doctor she needed to see, and to pay for the expenses along the way!

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Later I learned the backstory of this new donor. He was sitting in church, weeks before this, and a child who had visited Casa Providencia from his church was sharing about the impact the trip had made on her life and also the story of Hilaria. She had to be quarantined because they needed medicine for her and couldn't get it because it was too expensive. This man had recently been zapped by the Holy Spirit, where the Holy Spirit told him he should sell one of his nicer possessions, a watch, to give to the needy. But to whom? He didn't know who at the moment, yet he was obedient and sold the watch. As he sat in church, he knew the Lord was saying, give it to Hilaria. So he sent the money through a charitable foundation which took several weeks to arrive at our PO Box, at just the exact moment when we were deciding whether or not this little child could travel to get the help she needed. **God's time is always perfect!** God literally blows me away every time. There's nothing wrong with nice things, but when God says do something with it, we have no idea the impact of that immediate obedience.

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Back to the travel decision moment, so I then called Ari, and we cried and praised Jesus! I shared with our prayer team and everyone rejoiced! We thought the hard part was over! But there were more miracles to come...

Ari went the next morning with the judge's order to get a passport for Hilaria and for her caretaker nurse. They got it right away and once they had the local passport, they immediately applied for a visa to travel to the US. The next available date was February of 2025 for a visa appointment! At this point the doctor's appointments were 2 1/2 weeks away, scheduled for the first week in October 2024. Ari promptly requested an emergency visa appointment, which the request to move the date up was then immediately denied. What? How could this happen? Nobody even looked at it. It was just automatically denied.

I picked up the phone and called the US Embassy and requested a reconsideration. Matt called a friend in DC, who started making calls like you wouldn't believe! By the end of the day, I had talked to 20 individuals from the offices of Congressman, to Senators, to the Hill, to the VP! *All working to help God's little princess, Hilaria.* I submitted paperwork to everyone to support the request for an emergency appointment. These individuals then started making calls to the Embassy in Panamá. Hilaria was given the next available appointment and was thereafter granted a 10 year visa! And with her condition we had no idea if she would make it to live 1 year and here she was given a 10 year visa!

Next thing we knew, they were on the plane, with tickets even donated by Copa Airlines! Copa had also heard about Hilaria and her story, and wanted to help in any way possible. She had royal treatment the whole way up.

Our family got to visit with her in the US. She stayed with my mom part of the time, and even got to ride a horse! And of course, saw the best doctors in the world for her condition. They deeply investigated her specific condition and how advanced it was. They even found another genetic disorder we didn't know about. Their recommended treatment plan was the reverse of what was being recommended before and we now know exactly what to do and how to treat her. Prior to this she was living in isolation as we were afraid any sickness would kill her, per Dr orders in Panamá. We were paying extra for individual caretakers and lots of unanticipated medical bills trying to figure this out. Now, we know how to

prophylactically treat it and allow her when healthy to be out of isolation, where she can be the amazing princess God made her to be! The one who rules the ballroom and brings so much joy to everyone!

If you have come to Casa Providencia, then you know Hilaria. She will pull you into the party! You cannot sit on the sidelines as she wants everyone included and engaged and having fun. If you try and sit on the side, she will come up to you, wave you into the middle and get you to start dancing and playing in whatever activity is going on. To know Hilaria is to love Hilaria!

Thank you for all your prayers over the special little princess and we ask you for continued prayers for her health. God literally has His hand on her and He loves these little children in ways we cannot even begin to imagine.

He also loves you just as much! Will you surrender your heart to Him today?

Thank you for walking with us,  
~Misty Hedspeth