

Winnie Baez

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Good MOR... Soraya? Soraya? Oh Lord!!! Soraya! God please help, God please!!! Somebody!!!! Somebody please help!!! “Dios, no me hagas esto!!!!”

Soraya, My Four-Year-Old Daughter...

This is her story...

As a mother, the only thing you want for your children are to be safe and happy. Question is; what would happen if it was out of your hands?

What if you really couldn't do anything? What if it wasn't up to you?

I am Angela, Mother of Five lovely girls...

Who would've thought this would ever happen?

A life changing moment...

Puerto Rico...

On October 27, 2014 our lives changed forever.

That morning was one of the worst mornings of my life. Waking up to the same routine everyday taking care of your babies and making sure they were as comfortable as possible. That morning my routine as a normal mom was died...

7:00am

As I walked into my daughter's room I see my middle daughter with such an expression of worry in her face. When I look to my right I see my other daughter Soraya foaming, nose flaring, chest retracting, white as a paper. I screamed out loud reaching for my phone to call 911. I picked up Soraya not knowing what happened to her, calling her name to see if she would answer me. Nothing...

I called my husband and the only thing I screamed was “Soraya” on the phone, he dropped the phone and left his job.

I ran outside yelling for help as my little ones followed behind me crying. God! Save her! I screamed angrily looking up at the sky. Time and time was passing and no sound of the ambulance. At the time I had no knowledge of emergency resuscitation. The only one I kept asking for help was God. “God where are you!? Save her now what are you doing?”

Half hour later I hear the ambulance and a car rushing at the same time. The paramedics ran inside the house and took my Soraya to the ambulance. I rushed with all the babies at the same time and thankfully my husband Bruce came to the rescue. Bruce took all the babies back to the house while I left with Soraya in the ambulance. The only thing I

remember doing was screaming at people in the highway to hurry up. The paramedic was trying to calm me down by saying everything was going to be ok. I can honestly tell you the only thing I heard in my head was my baby crying. As soon as we arrived at the hospital they rushed Soraya into the emergency room.

As a mother the only thing you want to do is stay with your child always, but the staff didn't let me. Why? I screamed!!! No answer... the security guard pushed me back to the point he forcibly sat me down. Please!!! Let me see my baby!!! God please what is going on!? The security guards holding me back from the door. The only thing from that man's mouth was the words "calm down."

Calm down??? I exclaimed.

What do you mean calm down?

You won't let me see my daughter! A half hour passed, and I was still held back in that waiting room. Three police officers came in and asked questions, making me feel like such a criminal. I was feeling horrible and harassed. The thought of them wasting my time felt disgusting. As soon as they turned their back, I ran towards the emergency room door. The security guard grabbed me by the arm and sat me down.

"You cannot go in."

I prayed all the time sitting in that chair. The waiting room was filled with more than 50 people. My face was puffy, my eyes hurt from all the crying and tears flowing down my face. Covering my face I suddenly feel a warm hand touch my shoulder. "She will be fine, trust in him" they said. I looked up at this older looking man with a badge that read "God's angel."

I explained what was going on... The man walked over to the security guard and asked him to let me in and see my daughter. I do not know what possessed that guard to finally let me in. When they opened the doors I see more than 10 nurses and 5 Doctors surrounding room #2. The angel walked me toward the room and asked them to please let me stand beside her. One of the doctors walked out of the room and said he needed to talk to me. Without any sensitivity at all he said "Your daughter is in mechanical ventilation, we are doing our best right now." My knees dropped to the floor, shocked at what he just said. The angel helped me up and walked me towards the waiting room. My heart was destroyed... my baby is suffering I screamed. I called Bruce and explained what was happening. He was destroyed, not wanting to hang up.

9:45am

I heard my name being called in the intercom and ran towards the doors. The doctor's walked me over to a small room at the end of the

hall. I decided to keep standing as everyone sat down. "We finally stabilized her, but you need to be strong." My heart and mind filled with so many questions.

They finally let me see my Soraya,

As soon as they opened that door I fell to the floor with a silent scream of pain in my heart. My eyes filled with tears and my body weakened.

My Soraya was intubated, she had so many unexplained cables all over. I got up and rushed towards her. God, why... Why did you have to do this? My heart hurt so much I hated the world and everyone in it. I tried finding a way to hug Soraya but there were so many things on her I just didn't know what to do. The doctors finally came in the room and spoke about seizures, HIE and what not. I just couldn't believe anything that was going on, I was in denial.

The next day my mother was to arrive from Florida. All that time she didn't leave my side. At no time did I want to go back home either, I just didn't want to leave Soraya alone. That same night my other little one ended up in the emergency room with an emotional fever. She was the one whom had seen Soraya have that seizure. I was running from the third floor, back down to the ICU until my middle child was discharged. Thank God, she was doing fine afterwards.

Days were passing, and doctors couldn't give me any answers. I didn't quit asking them. I didn't miss a day without questioning. I was determined to find out.

November 17, 2014

Early Morning Three doctors walked in and asked to speak to me in the conference room. The faces they had told me they had something very important to tell me or ask me. "Mom, we are truly sorry for all the horrible treatments and the way we treated you, you deserve to know what your daughter has but we just don't know." My face dropped. I felt a small sense of peace in my heart. These doctors had made me feel as if I had hurt my baby. The feeling I felt was horrible, the most atrocious feeling any human being can feel. As they kept on speaking they started a new topic. "Mom, are you ready to save your daughter's life every day?"

My heart skipped a beat for a minute.

"Of Course," I responded. They all looked at each other and asked me if I had any questions.

I have so many uncountable questions, I was beginning to think it was a joke question.

"You do know your daughter will need plenty of medical equipment and

you will need to have a specific care for her.”

I know. I said.

As soon as I answered they decided to come out with the real topic of this conversation.

Tracheostomy and Gastrostomy.

What is that? I asked. The only thing they gave me was some pamphlets explaining what they wanted to do to my baby. I guess they thought I wouldn't read it through. I did. Of course I did.

That afternoon Bruce walks in. We had to leave our other babies with my grandmother for the time being. It was such a heartbreaker for me not being able to be with all my children. The only thing my husband did was hug me, not asking questions. I spoke to him about what was really going on. As scared as we were for our Soraya we decided to accept it, to save her life. Nothing was going to stop us now.

November 18, 2014

Today was the day our Soraya was going to get a Tracheostomy and a Gastrostomy...

Once again my heart sank as they were getting her prepared to transfer her to the operation room. I stopped them for a minute, I put my hand in her forehead and prayed. God, only you know what's best for her. Take care of her please. I beg you with all my heart. Thank you, Lord in your name... Amen!

I walked to the OR with my mother and waited for my Soraya to catch up. As soon as I see her crib entering the OR I see three angels at the end of her crib with long wings and beautiful white gowns. I thought I was dreaming... I looked at my mother and said: "Soraya will be fine." My mother smiled and said: "Yes she will."

We waited for an hour and saw my Soraya come out. I thanked God at that moment for taking care of her through it all. I looked at my baby wearing these brand-new devices. Lord, what is this? What are we going to do now? How are we going to take care of her?

That month must have been the longest month of my life. Family members were coming in and out of the hospital visiting. Many people from different churches came by to pray, sing, and visit. What great people! To wherever they are now I send them all the blessings from my heart.

December 1, 2014

Soraya was finally transferred to a normal hospital room. No more ICU. Thank you Lord. I was very happy to see my baby was feeling a little better. When we got transferred upstairs, she was doing better each

day with the trach and g-tube. Soraya was on plenty medication and a lot of care was needed such as suctioning, bathing and everything you can think of. She is 100% dependent and non-ambulatory. I bathed her everyday and was given the chance to start giving her the medication through her G-tube. Something was still not feeling right, I was very scared and worried at how I was going to handle all these medication on my own.

Sadly, Puerto Rico's health system was not doing so well to have a special needs child there.

I was raised in the Connecticut USA and I wanted my baby to be seen by doctors over there. Especially seeing all the care and medication she needed. I started emailing, calling and writing to many foundations in the United States. I must have contacted over 200 foundations. It was said I needed \$30,000 to cover an air ambulance for my baby to travel to Boston. I finally contacted the Children's Hospital in Boston, they asked me to gather the paperwork and money to get her transferred right away. I did. I asked the doctors to please refer my baby to that hospital. "NO." was their response. "What is in the United States that we don't already have here?" she asked.

"Many things," I responded.

The care my daughter is receiving here is not as I expected. My husband was the one that was buying all the diapers she needed in the hospital. We had to supply bedding and much more. I needed answers and referrals. I am losing time I thought.

February 3, 2015

Today was the 1st day my baby was finally ready to go home.

My husband and I were very scared to bring her home, we didn't know how to take care of her with all the medical equipment and medications she was using. No training, nothing. Hours before the discharge my husband had everything set at home with all the medical equipment they dropped off. Bruce looked up all the medical equipment manuals and put everything in place by himself. Back at the hospital I was getting everything of Soraya's ready. The doctors just said these words... "Mom, you're ready to go home, take care of her."

My face dropped as they spoke. My legs were shaky, my heart was racing, I just didn't feel good! The nurses came in and gave me a whole bunch of prescriptions for meds. I asked them if they would give me enough to go home with. One of them actually came through for us and said she wasn't supposed to do that but she helped us out to begin with Soraya's care until we got the prescriptions filled.

That afternoon Soraya and I finally arrived home. It felt weird going

back home with her. Coming back home, looking at how nice my husband and his sister had left it for us to come back. It felt good, finally home. my only thought was my babies can all come back. Or so we thought.

6:00pm

That evening, I will never forget it.

Bruce and I were studying different types of feeding pumps, tracheostomy care and much more online. We would help each other study and learn the care that Soraya needed. Suddenly, we hear her Pulse-oximeter machine go off with all the alarms.

As we ran back to her room Soraya starts throwing up by mouth, nose and trach!

Bruce and I rushed to help her by putting her on her side suctioning mouth, nose and trach. At the same time Bruce was calling 911...

Remember we didn't know how to stop what was happening to her. I screamed loudly: "God please don't take her!!!!" At that moment we see the numbers on her pulse-oximeter get back to 100 saturations from 50. The paramedics had arrived and took us back to the hospital. I come to find out that what happened to my Soraya was a withdrawal from one of the medications they tried weening her off from.

We spent another month in the hospital, and this time, I made sure we had everything we needed before a discharge. I was determined to keep forcing myself to learn more and more about my baby's conditions.

March 7, 2015

Today, another discharge day. By this time, I had already learned how to do trach tie care changes. Once again, we were worried bringing her back home due to what had happened last time. Bruce and I learned the little that we knew by studying and looking at nurses do their job. Arrival.

Back home we were doing great. We decided to keep going with the whole USA transfer. I finally contacted Boston hospital again, they asked me for referrals and many more documents. I spoke to them and explained what was going on. After hearing what I had to say they asked me for her medical record. I didn't have it. Supposedly we had to wait 14 days after the discharge date in order to obtain it. After the 14 day rule we decided to go back and request it. The hospital did not want to give us any medical records. We were without it for a month going back and forth with them. We got tired of their excuses and

decided to contact the news. We spoke to the reporter and asked to be in the 5 O' clock news demanding the medical record and explaining Soraya's situation. As mad as we were, we poured our hearts out in television and made the hospital respond to our petition. They did. Two days later they brought it to our house themselves.

That man.

A well suited 50 yr. old man walked through my door smelling like whisky holding my daughter's medical record.

"This will not happen again." He stated.

Hopefully not. we responded.

The news had helped us create a funding page to raise money for our daughter's trip. Problem was... the baby's insurance was not able to cover half of Soraya's medical needs. She needed caterers, gloves, gauzes, clothes, etc. etc. etc.

Bruce and I had to plan and quick...

May 20, 2015

I was looking through Puerto Rico's government offices that would help me cover Soraya's flight, not one day did I give up the information searching. I found an agency that is meant to help families in those situations. That week I decided to go to that office and orient myself. The lady was one of these elegant ladies.

"May I help you?" she asked.

I need to transfer my daughter out to the United States to a hospital in Boston. She looked at me oddly and said:

"What do you want me to do?"

Please help me, help my daughter.

"Do you have doctor referrals?"

No.

"Then I cannot help you."

Please, this is for my baby, I need your help and I know you can help me.

"Sorry, you need the right paperwork and it would take months."

I know you can help me... I will let you know right now that I will not give up! I exclaimed.

"Sorry, but you will be wasting your time." She answered.

I will come to your office each day and beg you to help me. I responded.

“Go right ahead.” She answered.

As I walked out of her office I had such a strong feeling in my heart. That feeling that I knew I was going to accomplish my goal.

I had walked back to that lady each time I could just to make sure she knew I was there. I was not giving up.

June 2015

Bruce and I were suffering each day trying to figure out what we were going to do for our Soraya. I was still walking back and forth to that lady’s office and I kept telling her I was not going to give up. She just kept ignoring the situation.

I walked through a circle of offices I had seen online and found a press office. As I walked in I received the weirdest looks. A tanned, slimmed woman called me into her office...

“What can I help you with today?” she asked.

Hello, my name is Angela and I am here seeking help to get my baby out to the United States.

“What do you want me to do?” she asked.

I just want to get my baby out of here, I want to know if by any chance you know of any help that is available.

She opened her eyes big and started mocking the situation.

“There is no money here, I don’t even know why you’re here.”

I am not asking you for money, I am asking you for information on how I can transfer her to Boston. She has HIE and is non-ambulatory.

“I honestly don’t know why you’re wasting your time, your daughter’s brain cells are already dead.”

My heart sank.

I took a deep breath and stood up.

Thank you, I answered. I got up slowly and walked out of her office with my head held up high.

“I will never quit,” I thought to myself.

June 10, 2015

What a day, my other two girls are leaving with their father in Florida, also Soraya’s biological father. I feel so hurt they’re leaving and I still couldn’t resolve anything for Soraya.

After this day I spent my days crying because I wanted my girls altogether. I want my family back!

Back home it was only Bruce, myself, and the other three girls. My

nine-year-old would look into my eyes and sing songs to me. She felt something was wrong. She smiled and gave me the most comforting hug ever.

June 12, 2015

12:00pm

After a long day, I sat in the porch as Bruce was taking care of Soraya in the room. He would give me breaks here and there.

How I love that man... such a great father to Soraya, such a wonderful role model to all his daughters.

Best of all, the best friend I never had, the one I can now call my husband.

Daydream over...

My phone rings...

Hello?

"Hello Angela, this is Roxie from the CF office."

Yes! Yes! Is everything ok?

"Well I have good news and I have bad news."

Any news is fine right now Roxie.

"Ok, good news is I can have your daughter transferred to Philadelphia hospital for Children's, flight will be 100% covered"

What!? I screamed... but.

"Now the bad news is... you would have to find me a residential address for me to transfer your daughter... I need an answer by 1pm today."

Roxie, I don't know anyone in Philadelphia.

"One hour." She responded.

I got up from my chair and started walking around back and forth. I asked God to show me the light at that moment. Please help me Lord. I looked through my phone and found some numbers from aunts and uncles. I decided to call a Pastor from my father's side. The Pastor gave me a number to another Pastor and that Pastor to another until I finally spoke to Pastor Rose.

Hello Pastor Rose, my name is Angela. I need your help.

I need to find a place for my daughter and I in Philadelphia in order for her to receive better care in a good hospital.

"Hello Angela, my wife will speak to you in a minute."

Ok, thank you. I responded.

.....

"Angela, hello this is Eve I am the Pastor Rose's wife."

Hello Eve. I am hoping your husband spoke to you about my situation?

"Yes, and we have a room for you here in our home for you and your baby, just let me know what you need in it." She asked.

Seriously?!!!

Thank You!!! Oh my God thank you! I screamed.

As soon as I hung up with the Pastor's wife, Roxie calls back.

"Your answer please?"

I have the address for you Roxie.

"Great, you will be leaving today at 6:00pm, and Angela?"

Yes?

"There is always a light at the end of the tunnel, Good luck you're a great mother." She responded

(My eyes watered...) Thank You Roxie!

I remember running towards the room where Soraya and Bruce were.

Bruce! Soraya and I are leaving at 6:00pm today!

Bruce's face enlightened, he started crying of happiness not being able to speak he held his head up and said, "Let's Pray." We both kneeled in front of Soraya's crib and thanked the Lord for everything he had done for us that day.

6:00pm

The time has come!

Time for Soraya and I to get transferred! Bruce and I were so happy to see everything come into place.

I hugged, kissed and blessed the girls that had to stay with Bruce.

Bruce and I hugged and kissed. I left all my belongings and brought only what belonged to Soraya.

No time for anything I thought.

I took all three big binders and every paper I had stored for my Soraya.

We finally arrived at the airport, they prepared Soraya for the 6-hour flight towards Philadelphia. We had stopped at Fort Lauderdale for a break and a change in pilots. As soon as the pilots changed and all was well we kept going on our journey. I was always looking at Soraya throughout the whole trip scared something would happen to her.

2:00am

Philadelphia, PA

Arriving at the Pastor's house was one of the most emotional moments. The only thing I saw as soon as I got out of the ambulance was a nice looking couple holding hands. I considered them my angels. They helped us in the house and brought us up to this nice air-conditioned room ready for my Soraya. I organized all the medical equipment and

laid Soraya down on the bed to rest. What a day.

Eve helped me with everything that I needed, she even had a nice cup of coffee for me. She noticed I arrived with a fever due to the stress of the flight. She decided to make me a shrimp soup in less than half hour. I was up all night with Soraya making sure she was fine with meds and everything she needed.

The next night, I feel my Soraya warm to the touch. I took her temp and found that she had a fever. We called 911 and made it to the nearest hospital.

1st Hospital stay

At the hospital I see that doctors are asking many questions and trying to figure out their new patient. Thank God I had all the medical records for Soraya.

The doctors started making changes to Soraya's care and even changed the type of Trach and G-tube. The equipment Soraya was using was literally from 10 years ago according to these doctors. There was a positive change already. They were very surprised at how much I knew of Soraya's care. At the breaks I would call Bruce and update him on everything. He was very happy!!! At the time I started seeking different types of help and applied for them. I was approved and kept moving up little by little. Social workers and case managers were very happy to see how I managed. While Soraya was still admitted I stayed at the McDuff's house. What a great help. I was feeling rested and ready to take on another day. A week later Bruce and little Glen came over to Philadelphia and stayed at the McDuff's house too. Soraya was admitted for over two months before we were discharged. We finally found a place to stay with a friend and I will always thank them for sheltering my family. Soraya could not be discharged anywhere but to a facility where we had to complete our training. It took us 6 months to finish our training, not missing a day. We would walk two hours to get there. It was well worth it. Bruce and I finally met our goal of doing a 24 hour shift in order to conclude our training. Thank God Bruce's parents were there to help us out with little Glen. His parents stayed for two weeks and made sure we were fine for them to return to Puerto Rico. We were ready, we had finally saved enough to rent a house, big and perfect enough to bring our Soraya home from that facility. There was a catch though... for us to bring Soraya home we had to get the house inspected and have the electricity checked. It took us more time because the house didn't pass. Good thing was that they managed to fix it. Our next goal was to fight with this facility to let go of our child.

They didn't care, they wanted to keep her there. Why? I guess they considered my baby a dollar sign. We made sure we finished our training, the 24-hour shift and everything we had to do. What was the excuse now?

They had none... they had to let her go home... if not, I was going to sleep there until they did.

December 9, 2015

Soraya came home...

Nursing, medication orders, medical equipment orders and much more... check.

Goal accomplished...

2 years later...

Today...

December 5, 2017

Today is the day I finish telling you my daughter's story...

I am here typing it next to her medical bed in a hospital, she is such a strong girl. As much as everyone admires my husband and I, we admire how far SHE has come.

Our family has gone through a lot yes, but this day I am happy to say my girls are together once again.

We will protect them with all our heart and use the sharpest claws you can imagine.

We will keep them happy.

People have asked questions and have also assumed.

Only God knows what he has in store for us and why he wanted us to take care of one of his angels. Ladies and Gentlemen, this is such an honor for me, to be able to take care of an angel and do God's work each day.

Yes, we do get physically and mentally tired.

Yes, we would like to do more things.

Yes, it is scary at times.

Yes, we must keep learning more every day.

Yes, we feel lonely at times.

Yes, we know how hard it is.

Yes, we go in and out of hospitals.

Yes, we do get annoyed when people don't understand the situation.

Yes, we work hard to keep our family happy and satisfied.

Yes, we must run every time our child De-saturates.

Yes, we have rules and papers hanging everywhere.

Yes, we fight and make sure our child receives the services she needs.
Yes, we have medical bags ready for each member of the family.
Yes, we must plan a trip to a supermarket.
Yes, we appreciate life and we learned what it means to never take anything for granted.
Yes, to everything you ask.

We are special needs parents, but we are also normal parents of 4 other healthy girls.

All of them have different needs and us as parents we need to be there for them, no matter how hard it can be.

Every day I read about how we can always make things better. I must have changed Soraya's logs like 200 times. I love what I do because it is helping our baby. God has bigger plans for us and we need to get ready for when they start.

The best feeling in the world is looking at your child in the eyes and see how they glitter looking back at you. Our children look up to us, it is our job to make that transition work for them.

If there is a day you feel like you have failed, think back to what you are reading and think that if we did it... you can do it too.

Hope each one of you reading this find your way and live life.

Forgive and forget...

Never let hate run your life.

We have the best thing the Lord has blessed us with.

Let's take care of one selves and keep going.

Accomplish your goals.

You can do it...

Now off to study more on Soraya's care.

We learn something new each and every day...

Parents:

Do not give up, no matter what people say.

Remember, nobody will think of you and your necessities, only you can fight for your family.

Thank you, Lord.

Winnie Linnette Baez Velazquez