

Love Doesn't Count Chromosomes – A Trisomy 18 Journey
By: Christie Gibbons

I have typed and deleted, typed and deleted while tears run down my face trying to find the right words to share our Trisomy 18 journey. I have wanted to share Mackenzie's story, our story for a while now but I never knew how to prepare my heart to re-live those moments but then again, who am I kidding, I have re-lived those moments over and over again for almost 2 years now.

My second pregnancy started like my first, very normal until I got a call from my obgyn, telling me they found cysts on the baby's brain but don't worry, they are common, and they go away. So off to see a Maternal Fetal Specialist (MFS) who also reassures me, and I quote "they always, always, always, go away". I go back around 18 weeks for a check up to see if the cysts are gone, nope, still there but they are smaller. She said once the body realizes they are there, they will disappear. While at that appointment, the MFS notices that the baby is measuring small and it's chalked up to having a marginal umbilical cord insertion. I end up having to go back every week for the next 20 weeks to get the baby measured and the baby gets 8 out of 8 on the biophysical profile every single week for 20 weeks. In that time the cysts do disappear but now I am holding on to extra fluid. My MFS suggests that I shouldn't deliver past 39 weeks, so I get scheduled for an induction on February 11, 2019. On my very last appointment with my MFS she tells me that everything looks great, I don't need to deliver at a special hospital and the baby weighs around 4 lb. 12 oz. We have prepared ourselves and our home for a little bitty baby. We bought premie clothes, setup the bassinet, bought what I thought were the tiniest diapers I have ever seen and so ready to welcome another addition to our family.

The morning of February 11, 2019, we take our daughter Adeline who is 14 months old to day care and our wonderful friend Penny, who happens to be her teacher will be caring for Adeline while we have our baby. As we drop Adeline off and start walking away, Penny so excitedly yells at us "you are going to have a baby today!" I re-live this moment a lot. I am all hooked up to Pitocin, I have my epidural and I am anxiously awaiting the arrival of my new baby girl or boy when a nurse comes in and informs us (my husband Christopher and I) that they baby is stressing out a bit so they are going to turn the Pitocin off for a little bit. After about an hour they start it up again and everything seems fine, my water breaks or is leaking, which is normal and I sit and wait. The good doctor arrives and is decked out in a full suit! We joke around a bit about his outfit and he says he's going to put scrubs over his slick outfit. Around 8:30 he checks for dilation, puts scrub bottoms on and then everything happens so very fast. Dr. Stokes is now at the foot of my bed, the bed is being transformed for delivery and everyone is ready to go when massive amounts of water come gushing out and soaked my nurse. Dr. Stokes is forcing me to dilate because something is clearly wrong with the baby. I am currently unaware that anything was wrong because I am concentrating on pushing, not listening to the babies monitor, Christopher was a bit suspicious but didn't say anything and continues to watch our daughter being brought into the world. Mackenzie Johnnie Gibbons was born at 8:45 pm on February 11, 2019 weighing 4 pounds 4 ounces and 17" long and she wasn't breathing. They quickly took her from Dr. Stokes and started working on her. I was scared and worried but in

the back of my mind I was thinking, Ethan, my brother's little guy's lung collapsed when he was born and he was okay. She is finally breathing on her own and I get to hold my sweet baby girl. Now that Mackenzie is good and in Mommas arms, Christopher leaves to have a cigarette. As I am holding, snuggling and kissing my baby girl, she starts turning blue, I hit the call button and scream for help! There is nothing worse than being helpless and watching your baby not breathing. The nurses come running and the code blue alarm is sounded. Since we are currently the only ones on the delivery floor, my husband comes running back to the room while they are working on Mackenzie. They get her breathing again and put her on a monitor. I get to hold her briefly before they take her to the "special care" nursery. Once again, I am scared and worried but once they get her stabilized because she so tiny, she will be fine. I get up multiple times that night to visit her in the nursery. She's so tiny, absolutely adorable and is doing well without any further episodes. That news is so good to here.

The next morning after we have visited Mackenzie several times, the hospitals pediatrician comes to our room to talk about how Mackenzie is doing. He informs us that there are 3 soft markers: small chin, low set ears and overlapping fingers for Trisomy 18. He hasn't pushed the issue yet but just casually mentions them. I have an idea what Trisomy 18 is but not my baby, we are taking her home tomorrow. Christopher and I talk about and aren't in panic mode yet because if those are the only things wrong, no big deal, right? We continue to visit Mackenzie throughout the day and even get to hold her. There is nothing like snuggling and loving your new baby. The next morning, traditionally the day we are supposed to take Mackenzie home, Christopher and I walk down to the nursery and are bombarded by the pediatrician who is certain Mackenzie has Trisomy 18 and starts listing off all the other soft markers he finds after looking Mackenzie over again until I literally have to tell him while I am sobbing to stop talking and collapse into the nearest chair. No mother ever wants to hear that their baby is going to be different or have special needs or will more than likely die. This can't be happening to us!! I pull myself together because I want to spend as much time as I can with Mackenzie. We are in the nursery passing her back and forth as our arms get tired and loving every moment we have. The pediatrician comes in to tell us that someone from Universities Hospitals Rainbow Babies hospital will be coming to take a sonogram of her heart later today and he wants to get blood drawn for genetic testing. Once all the testing and sonograms are done, we go back in to spend time with Mackenzie waiting the results from the cardiologists. The pediatrician may not have any bedside manners, but he did come back to the hospital to talk to us about the cardiologists findings that evening instead of making us wait. He basically told us that if she didn't get surgery in the next 5 days she would suffocate to death. No parent should ever have to be given that news, ever! He also said that UH Rainbows and Babies hospital is willing to do the surgery. We couldn't just let her die, we had to give her a chance! While waiting for the arrangements to be made for her to be transported, I called my brother Phillip, ask him to share the news with the rest of my family and to ask for help in taking care of Adeline. While waiting for the arrangements to be made for her to be transported, I called my brother Phillip, ask him to share the news with the rest of my family and to ask for help in taking care of Adeline. Later that evening they transported my little girl to the NICU and I wasn't allowed to go with her in the ambulance but I watched them as they strapped her in to the tiniest incubator and then she

was gone. We went home to give Adeline some hugs, kisses and snuggles, throw some stuff into a bag, make arrangements for Adeline's care and then we were off to another hospital.

We spent the next 20 days meeting with Mackenzie's care team, cardiologists, geneticists, palliative care doctors and nurses, hours and hours researching options on out how to save our little girl from dying. I can honestly say I remember very little details from the NICU stay besides the big moments like the day she arrived and how long it for them to hook her little body up to the medication, monitors and what seemed like forever before we got to see her that night. We couldn't hold her for a couple days until she was able to regulate her body temperature better, so she had to stay in her incubator. I remember the wonderful nurses she had and when they finally let us hold her and change her diaper, which are even smaller than the ones I bought! I remember reading her books, playing music and singing for her while I held her. I remember calling the hospital multiple times a night to see how she was doing and the music they played while I was on hold, still haunts me today. I remember the little noises she used to make and how the only time she was unhappy was when she was wet or hungry. I remember her little fingers wrapped around mine. She looked absolutely adorable sucking on the tiniest pacifier. I remember the day Now I Lay Me Down To Sleep came and took pictures of us as a family for keepsakes. I remember when we had molds of her hands and feet made with the art therapist. I remember when the music therapist came and recorded Mackenzie's heartbeat so we would always have it to listen too. I haven't yet got up the courage. I remember seeing a picture of a heart up in Mackenzie room listing everything that is wrong with her heart; Coarctation of the Aorta, Patent ductus arteriosus (PDA), Atrial septal defect (ASD), Ventricular septal defect (VSD), Unicuspid aortic valve and multiple other holes in her heart. I remember when the cardiologists told us the surgeons would not do surgery to save her life because she had full Trisomy 18 and was basically a "bad bet" and when a "Trisomy friendly" hospital gave us the same answer. We didn't know Mackenzie had anything wrong with her other than she was going to be small. After spending hours in the hospital looking over my medical charts and things that were told and not told to me, all the pieces started adding up. There is absolutely no reason we shouldn't have known that our baby had Trisomy 18, other than the MFS not doing her job. We spent our days with Mackenzie and our evenings with Adeline. I always felt guilty leaving Mackenzie because our time might be limited to go spend it with Adeline and then guilty for leaving Adeline because she has to be so confused with all these new people taking care of her and she didn't understand, either way we couldn't win. I remember the day they tried getting a pic line into Mackenzie so she could continue to get Prostaglandins (the drug keeping all of her valves from closing and killing her). I prayed that God would make that decision for us so we didn't have to. Mackenzie spent less and less time awake, she looked paler by each day and we decided it was time to take her home with Hospice Care.

After much talk and a lot of arrangements made, we brought Mackenzie home on March 5th. Our family was all together! I spent the next 48 hours awake and holding Mackenzie, rarely putting her down because I didn't want to miss a moment with her. On the morning of Sunday, March 10, 2019 after I fed Mackenzie through her NG tube, a little of her formula leaked out of her mouth and it looked and sounded like she was struggling a bit to breathe. I absolutely refused to let Mackenzie suffer in any way, so I gave her a little bit of Morphine as prescribed

by the palliative care doctor and I then call our Hospice nurse. The nurse arrives about 30 minutes later and checks Mackenzie over and sat with us. No one tells you when a baby dies, that their body doesn't know how to give up. There is absolutely nothing worse in the world than having to watch your child die in your arms. Mackenzie passed away at 12:20 pm on Sunday, March 10th between Christopher and I.

I wish there was a happier ending to my story but there are stories of babies that have done well with medical interventions and thriving. Any Trisomy diagnosis should be just that, a diagnosis, not a prognosis. I know in my head that Mackenzie's heart was complex and not repairable, but my heart will forever be broken. For those moms and dads who have to walk this path in the future, my heart breaks for you but you will find the strength to get through moment by moment. For those family members who don't know what to say, pray for strength because the parents really need it, don't be afraid to mention their child's name and its okay to talk about them. You aren't going to remind us to miss our child, we think about them all the time. For those moms and dads or family members who want to reach out because of a diagnosis or just looking for a little support, my email address is gibbonsc248@yahoo.com.