Casey and Brian

Parents of Freddie (10), Bethie, Mary Frances (4), Gus (8 mos)

Bethie was diagnosed in-utero with heterotaxy syndrome and died at age 14 months

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| 1 | Title: *A prenatal diagnosis of heterotaxy: how palliative care helped parents continue the pregnancy and manage uncertainty.*Parents Casey and Brian describe learning at the 20-week ultrasound that their baby had heterotaxy with an unformed heart. "No one really offered what if you had her and met her. It was really-- this is how terrible things look. And it’s because no one wants you to go through the hardest thing you’ll ever go through. You should definitely have this baby and watch her die. You know, no one wants to say that to you." They decided to follow the baby's lead and continue the pregnancy; and found palliative care to help them through what they wanted. "They support you whatever your choice ends up being. They will be there for you, whatever path you choose."<https://youtu.be/j5sp63liNuo>**Casey:** So we found out about Bethy’s heart at my 20-week appointment. We just went in for regular 20-week ultrasound and we had a student ultrasound tech. I remember laying there thinking oh, my gosh, I’m falling asleep. This is so terrible. This is like a second kid, damn, so tired and I’m not even like paying attention [00:04:00:21]. And then afterwards realized no, it was taking a really long time. So she was taking a really long time getting images and then she left and brought back a more seasoned ultrasound tech who super time but zipped through more critically.Right, Brian? And got what she needed but then I just remembered she said something like, I’m sorry that I have to tell you this, but your daughter’s heart never finished or your child’s heart never finished forming because we actually weren’t going to find out the sex. And then at that same appointment we decided to -- we needed to know, we were having a girl or a boy. I remember Brian saying like we at least need some kind of good news here. So they told us we were having a daughter and then an on-call physician came in too I think to like, look through images maybe or look through images and payment [00:05:00:18] or something and I don’t think either of us remember exactly what they thought was wrong. But as it turned out it was way worse than what they thought. That’s we eventually found out. I would say that conversation with the surgeon was, at least for me, kind of the first indication that while it was bad situation already it would -- it was a bad situation that really wasn’t so clear solution to how to fix the problem that Bethy had at that time.**Casey:** There wasn’t really any good solution --. When we left the surgeon, Brian and I talked a while last night about this. Like, this is -- it just is what it is, but there was no one really offering what if you had her and met her. It was really-- this is how terrible things look. There aren’t great options, da-da-da. And it’s because you know no one wants you to go through the hardest thing you’ll ever go through. No one’s going to tell you, you know what, you should do the hardest thing you can possibly do. You should definitely have this baby and watch her die. You know, no one wants to say that to you. So that wasn’t even really even placed on the table for us. So we went home from the cardio thoracic surgeon and then talked through [00:10:00:07] -- I don’t remember who gave us these options. But if we were to terminate the pregnancy it would either be a DNE, I think or we could induce labor and meet her and lose her. Well, obviously that’s what we were going to do. We were going to induce labor and meet her and then quickly really -- so why not we just have her -- then why wouldn’t we just continue the pregnancy and meet her.And so I went to my OB with that information, talked her through our conversation and said so this is what we’ve actually come up with. She was like okay, I think there’s some #[10:44] but we’re like, how do we even do that. Like what does that even look like, we had no idea. And it’s you know, you just have no idea how you can actually do that. So I went and talked with her and she said, okay, [00:11:00:0o] I know there is some one at Lurie who can help with this. It was like within days I think that she figured it out it was Dr. Henner and that we met with Dr. Henner. And Alida [phonetic] one of the nurses who worked with her who ended up working on Bethy’s team the whole time we were in Chicago. We went and met with them, I think at Lurie and started talking through what we wanted for Bethy’s life and how they could help us make that happen.**Casey:** Honestly just offering it as an option, there is a team that exists, here’s who the head is and maybe like here are a couple of the ways that they could support you. And to be honest, they support you [00:14:00:07] whatever your choice ends up being. So just the knowledge that they’re there for you and for us it was they should really be like, once some physician or two physicians, if you need two to weigh on it, may come to the realization that this is a life limiting or life ending diagnosis, their team should be the very next thing that’s talked about because they’ll be there for you whatever path you choose. **Brian:** So that team can handle -- **Casey:** Anything.**Brian:** Dr. Henner was very upfront, you know, here are the options. There are -- there’s no easy option that all might be sad --everything right after you receive the diagnosis, like it’s all just fear and unknown and without her team it would have just remained fear and unkown. Because even if we were to somehow muddle through and make those choices ourselves, we would just, you know, like, we’re not physicians or nurses that we would be just cursing ourselves the whole time. What do we -- we’ve no experience in any of this. And so it really was having her there to plan out the details. So we didn’t have to do that. And the focus was on [00:18:00:05] living with Bethy while she lived. And loving her. And that was it. I mean, really that’s probably their ultimate goal is that that’s where a parent’s focus should be and their role is to enable that. |
| 2 | Title: *Decision-making over 14 months*: *Our goal was always for her to feel loved and be out of the hospital, at home, as much as possible.*Parents Casey and Brian talk about living into their daughter's life as she continued to live and grow beyond expectations following a prenatal diagnosis of heterotaxy. They elect a first cardiac surgery; and a second surgery. They reflect on what it means to be cardiac parents ... and prioritizing her life out of the hospital, not on the cardiac floor, and what that ultimately meant. "It's OK we didn't get the big miracle."<https://youtu.be/YXG4HJ9GtEA>**Casey:** So the goal from the very beginning I think was for her to feel loved, to be at home as much as possible and to have any pain that will come up controlled.Do you think that’s accurate, Brian?**Brian:** Yeah [00:19:00:14]. And the other two things we talked about last night were minimal time -- **Casey:** I couldn’t get my computer at the start. So -- **Brian:** Minimal time at the hospital and minimal painful interaction. So --**Casey:** Yes, yeah.**Brian:** We didn’t need -- we were just saying, okay, bring -- **Casey:** She was DNR from birth.**Brian:** Yeah, we do #[19:23] -- **Casey:** So that’s where we started. That’s where we started. The most important goals continued to be the same throughout her life, to be loved, to have as little time in the hospital as possible. And to be at home. But she in everyone’s best guess, we were going to have upto eight weeks with her. And that’s not what happened. She started growing and she continued living. And as you’ll later find out like, technically, [00:20:00:14] her heart made new pathways to keep her alive.And I think I remember Dr. Henner at one point saying, like we don’t often get to be wrong. But when we do, we really love it. So everyone was wrong in their predictions and she moved too to Colarado with us. We had to obviously switch palliative care, her hospice care teams. But she stayed in hospice when we moved here. And she just continued to live and grow. And our hospice nurse, here in Colorado, one day on one of her visits asked me, really gently with like no pressure. You know I know you’ve made all your choices but just in case, do you want to see a cardiologist at Colorado Children’s a get a second opinion, because she’s lived so much longer than anyone thought. And really [00:21:00:10] you know, we’ve only ever heard terrible news. So sure, like, let’s go do it, yeah. She’s still here.So we went and did that and heard the same thing. It was nothing different. It was just that this is the reason she’s still living but like there really aren’t good options that we’re able to offer you here. But there’s this one surgeon in California and it’s probably going to be a no. But would you want us to send her information in just in case. Really again, it’s not going to be anything new if he says no. So sure. So they sent it to him. He called us and said I’m 99 percent sure I can do it. Really cool. You know how do you argue with 99 percent. You really don’t. So we took her out to California for a surgery which was by all counts wildly successfulWe brought her home. She grew and she ate and she lived for a whole summer really well. And then we had to bring her back for second really [00:23:00:12] intense surgery. And technically it was successful but she just was not the same afterwards. And it was clearly not what her body wanted. And she died pretty soon after that.**Casey:** I think in the cardiac world in particular, you can get trapped. You can -- there can be a lot of pressure. Because I mean think like a cardiologist, a cardio thoracic surgeon, the whole team, their job is to save your child’s life. So if that means two years in the hospital, that means two years in the hospital. But that was actively not one of our goal. That was -- our goal was the opposite of that. We didn’t want her life --we didn’t want to save her just to have her live a life in the hospital. And I think it would have been much harder to stay true to that without Dr. Henner’s team saying, you deserve a say in these decisions. You know how best to love your child essentially [00:27:00:05]. Casey: the goal was just all -- it was always there. You know, it never really changed. So honestly, it was emotionally, I’m sure really hard that the first surgery went so well, and the second surgery didn’t. But it was also so obvious that she wasn’t happy and all we’d really wanted was that. So it’s okay that it didn’t go, you know, that we didn’t get the big miracle, didn’t actually matter. [00:34:00:07] |
| 3 | Title: *Our faith was already there waiting for us, which made a big difference*Parents Brian and Casey share how their faith helped them through their daughter's short life and imagining her now. "She was given to us. We were given a cheat sheet to God because we need our faith more than ever. It's how you keep going, happily, continuing with love." They also had a strong community.https://youtu.be/a2ymH2Hn\_DMour faith has been a part of who we are, both of us since birth we chose to continue making it a part of our life as you can or cannot do. As you get older we had already made that choice for ourselves before we got pregnant with Bethy. I think faith could be just as valuable even if you come to that decision throughout the process. But we had it already there waiting for us which makes a big difference. I think in terms of losing her ever since I was young say at one point I remember saying to Brian after Bethy died like, how do people do this who don’t have any faith. And he stopped for a minute and he was like, I think I don’t know. I think they might just be really [00:43:00:03] angry. And I don’t know whether that’s true or not but it made a lot of sense to me at that time. Like, there’s no reason for us to be angry. There’s no reason for us to have regret or be angry when we know that she’s whole and healthy now.And when you put everything we went through in the light of faith, we were chosen. She was chosen for us. She could have gone to anyone. And she was given to us. We were asked to -- we were given like a cheat sheet to God, when he asked us to have her. Because we need our faith more than ever. It’s like, of -- you know. So that’s it. It’s really like it’s everything. It was there the whole time through her life. It’s everything [00:44:00:06] since we’ve lost her. It’s how you keep going happily and continuing with love. And it’s what keeps her alive for us too.**Brian:** Yeah. I think the spirituality, I think our relationship and then we had a very strong support network amongst -- **Casey:** Yeah.**Brian:** -- to support us or too involved at the time. But I think those three things were the ways we got through. It was our faith helped tremendously and our communication with each other helped them on and if ever needed people outside of the two of us.**Casey:** We had what we needed which is very lucky. |
| 4 | Title: *We always knew what we wanted for her . . . and so we let her go.*Parents Casey and Brian share 'knowing' it was their daughter Bethie's time, despite the hospital trying to save her. "In the end, we stopped them."<https://youtu.be/jKA6oXPWPmU>she was just very unhappy and not herself and it was clear like something was going on and I had taken her to couple of appointments like with different physicians who tried in different departments to try to figure it out. And I had an appointment lined up with an allergist, an immunologist for the morning that she ended up dying. And she woke up and her diaper was dry from overnight and I realized I needed to take her to the ER and not to the allergist, immunologist appointment [00:53:00:18]. So I drove her there instead and brought her into the ER, tried to run her to the cardiac ICU and they -- had I talked with an actual member of the ICU physician or nursing team, I think they would have taken her but that wasn’t the case. So they sent us to the ER. And it was after like a short time in the ER room with the team working on her that it was pretty clear that this was it. And I remember calling Brian and telling him it seems like it’s her time. You need to come now. So he raced over so that he could be there too. And that was it. And they tried -- we had them -- they tried to save her. They’d saved her in the cardiac ICU at that hospital [00:54:00:10] once before, before her surgeries. And they tried in the ER but in the end we stopped them from taking even more extreme interventions.again, I think we just always knew what we wanted for her and what the goal was for her. And getting to that goal, like, ultimately and while fighting her goal. So we let her go.**Brian:** Yeah. |
| 5 | Title: *“There are six of us, not five.”*Bereaved parents Casey and Brian share how they keep baby Bethie present and visible in their family home following her death. They talk about how big brother Freddie has some memories on his own and the stories the parents tell, and how the little sister shares about her sister, who died, with classmates. "Kids are the best, they ask good questions and nothing is off limits."<https://youtu.be/JixUyXK2LPQ>We have photos all over our house. You know Freddy lived with her, he was young. He was quite young still when she died but he does have a feel of his own memories with her which is really special. It’s mostly just we talk about her. We celebrate her birthday. She is a part of our family. Her name is on our Christmas cards and we love her in present tense. Not that we loved her, we continue to love her. [01:06:00:08] I always say like, you know, everyone means well all the time but her name is Bethy. Her name wasn’t Bethy in the past tense. It’s still is. She is always going to be part of our family. And she -- that’s really it for us. There aren’t a ton of special rituals. I mean we put up the birthday sign for her birthday too and we celebrate with something for her birthday even though she’s not here. But no other -- I don’t -- not that I can think of with particular rituals. Its just that she’s always a part of our family. There are six of us, not five.**Casey:** No, he was three-and-a-half. So he was little. So he has a unique memory though. So he does actually have a few memories of her that I don’t remember. There’s one that involves like, their grandma slicing strawberries for them and I don’t remember those things. So he definitely does remember her on her own but he certainly remembers her through stories and they watch like videos of the kids and things like that too. And kids are just the best. Like you know they ask really good questions and nothing’s off limits to them. So our daughter Mary Francis, the third, so Bethy’s younger sister, just recently have like -- really -- I think because of #[68:00] [01:08:00:15] at school so they brought in pictures of her and she was on the altar and we celebrated her. And they attend catholic school, our kids do. And a part of that is you know they get to talk about their sister if they want, whenever they want and they get to talk about where we believe she is and it’s -- nothing’s off limits which is really nice. But I think it’s because of his #[68:22] she got like really into talking about Bethy all of a sudden. So any time someone would chat with her she would bring up that she also has a sister who’d be eight years old or she also has a sister and then people say oh, who is your sister? And then you know she’s four, so she follows it up with Bethy, she died. And then silence is all #[68:44] like that’s the best thing about kids. She wanted to talk about her so she talks about her.  |
| 6 | Title: *“Advice to my past self at the 20-week ultrasound: It’s your decision at the end of the day.”*<https://youtu.be/9ZmRa93B6yk>Parents of a baby diagnosed in utero with a fatal condition encourage parents like them to listen to and consider the counsel of clinicians; and then make their own decision." We have no regrets. You're going to be Ok.TC: 1:10:10**Brian:** I think if were to talk to ourselves at that 20-weekultrasound a recommendation for which we knew was to take everyone’s opinion and guidance but at the end of the day form your own decision. It’s a decision for which you need to be comfortable making. So there were lot of people that will have opinions, even you know, people that are in the field or even people that you know had been through a lot in their own lives. But it’s really up to you and you I mean as a collective unit, if that’s there to make the decision together and really [01:11:00:11] #[70:59] that’s in the best interest for the parent or parents but more importantly for the child. So it’s really take it, digest it and then it’s your decision at the end of the day.we don’t live with any regrets. We made the choices that we felt were best and we’ve chosen to live with those choices. And I think we’ve lived with them pretty well. So honestly, what I would say to us is do what you’re doing, you’re going to be okay. |