## Jacqui, Chris, Kevin

## Jacqui, Mother of Tommy (2 ½) and Claire (1). Claire has aspiration and sleep apnea. Christopher Hartnick, MD and Kevin Callans, RN Pediatric ENT at MGHfC/MEEI

1	TITLE: Apnea, Aspiration: The shock of learning my daughter is having trouble breathing and we don't know why.
	https://courageousparentsnetwork.org/videos/apnea-aspiration-suddenly-le arning-my-baby-is-having-trouble-breathing-and-we-dont-know-why/
	Description: A mother of an infant with serious apnea and aspiration describes the shock of learning that her baby is having trouble swallowing, and then breathing. "I wasn't prepared at all for what the swallow study would reveal and then the oximeter." It was the moment that everything changed. Her ENT nurse and pediatric surgeon talk about how sometimes providers don't have an answer for why, and how important it is that parents not feel guilt.
	Transcript: Jacqui: I'm married to my husband Jerry, and then we have Tommy who is two-and-a-half and we have Claire, who will be one at the end of this month. And Claire was born completely full-term, completely healthy pregnancy. There was no indication that there was anything wrong at all for the first couple of months. And then when she was about three months old we realised, you know, she's not gaining weight right and she was breastfeeding at the time and she just was starting to cough and vomit a lot and was really struggling to eat.
	So we had taken her to the paediatrician's office. The first couple of times they kind of just waved it off as she was fine and, you know, some babies just aren't as big as other babies and I'm comparing her to my son and all these different things. And then it became very clear that something is wrong.
	So then they our paediatrician had actually sent us to Children's Hospital first. We had a swallow study done there, which was the day that this was all thrown at us that I had I've never been so blindsided in my whole entire life. I wasn't prepared at all for what that swallow study could actually reveal to the point where I felt very I felt like I hadn't educated myself enough going into it or that someone hadn't maybe educated me enough into exactly what we were looking for when I went there.
	And then we did the swallow study. I was immediately pulled into another room and sat down with a bunch of doctors. I can tell it was not good. And basically they told me that she can no longer have anything by mouth and that she was getting a NG tube placed in her nose and that all of her feeds would

	run through this tube. So I was just in shock. I didn't really know what to think. I had to call my husband and tell him. And I was just and then we had to stay in the hospital for a couple of days to make sure that Claire tolerated the tube and for me to learn how to feed her now with this.
	So that's all overwhelming and scary enough, but then there is a whole piece that we do have a two-year-old at home that I'm supposed to also be taking care of and now I just left him and I'm not coming back today, which then became something that happened all the time, but that was like the moment where it all just changed. So then that first night at Children's Hospital, she was hooked up to the oximeter and that was when we discovered that, okay, not only can she not eat correctly, but her oxygen levels just keep falling and keep dipping and we don't know why, but now she's having trouble breathing.
	So that was October 8th. And it was, at that point, the worst day of my life. And I just I didn't know what was going on the day before. I thought I had a relatively healthy, okay child and then all of a sudden it was, okay, now we you know, what is going on, where do we go from here. It was just this massive, scary, horrible thing that you can't even begin to figure. You just don't even know how it's going to unfold or what's going on.
	Our diagnosis for Claire is that she has aspiration and also sleep apnea. We do not, we never found a conclusive reason as to why any of this happened.
	<b>Chris</b> : You would think at this day and age we would know everything and we're struck every day, we don't know everything. And it is super frustrating for parents because they want an answer. If we were parents we would want an answer too, and as doctors and nurses in healthcare, we want to give an answer and yet there is no answer.
	<b>Kevin</b> : When I first meet parents, I always try to tell them no matter what, nothing is your fault. Really nothing is their fault. Sometimes things are just positioned on families and it just happens, you know. And I think there is so much guilt associated with anything any time your child is sick particularly, a little baby, that if you can relieve them of feeling that pain and guilt, it allows them to absorb more information and move on.
2	TITLE: I was devastated Suddenly my baby needs a feeding tube. No more breast-feeding
	https://courageousparentsnetwork.org/videos/i-was-devastated-suddenly-m y-baby-needs-a-feeding-tube-no-more-breast-feeding/
	Description: A mother of an infant with serious aspiration issues describes her emotional reaction to learning her daughter can no longer receive food by mouth.

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	Transcript: Jacqui: So our decision to put Claire on a feeding tube originally really wasn't a decision at all, that was one of those split decisions. But when we were at Children's, it was just she's going to have an NG tube. There was no because it was like an instant thing that needed to happen and no one knew why this was happening or how long she was going to need it. So it was just like this is happening right now whether you like it or not.
	And just as a mother who I was breastfeeding. I had breast fed my son for a full year to just be like in that second be told that you can't do this anymore, like, that's it, was very you know, just a very overwhelming, sad thing. Anyways, I mean, women have trouble when they try to give up breastfeeding anyways, more trouble than like babies do sometimes just from an emotional standpoint.
	So to be standing in a hospital and just be told, okay, no, now like you're done with that, you can't do that anymore and now she's going to be not having anything by mouth. I mean, I was devastated. I was absolutely devastated. I couldn't understand how this was happening to us, like, this isn't something that happens to us, like this, you know, like, this she's a healthy baby, she's been breastfeeding fine, I don't understand what's happening.
3	TITLE: I had never met anyone whose child had a G-tube. I felt so isolated but I had to make the decision for my daughter.
	https://courageousparentsnetwork.org/videos/i-had-never-met-anyone-who se-child-had-a-g-tube-i-felt-so-isolated-but-i-had-to-decide/
	Description: A mother of an infant with serious apnea and aspiration talks about how reluctant she and her husband initially were to give their daughter a feeding tube. She describes the process that led to their decision to get the G-tube and how they have adapted. "We got to the point where we had to do something different."
	Transcript: Jacqui: You guys had started to suggest that maybe we switch to a G-tube. And for my husband and I, we just still were so unclear of why these things were happening and if there could be some sort of quick fix in all of this that we didn't want to go ahead and give her the surgery and, you know, for the hole in her tiny little perfect body if we didn't have to.
	So we wanted to try to ride it out and see if we could keep the NG tube because it was so temporary, as frustrating and difficult as it was to deal with daily, you know, it was something we were willing to do if we thought we could like

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	almost save her from the G-tube because in our head that's what it was at the time.
	Now in hindsight, that was foolish and I wish we switched sooner, but we kind of struggled on for another month and she wasn't really getting any better. And with Claire's condition with her respiratory issues too, it was not helpful at all that she had another tube in her tiny little airway taking up space and it was also stinting her stomach open and she had reflux as she was with the aspiration piece. So in reality we finally just got to the point I remember being in here and Dr. Hartnick came in and it was like, well, we're kind of to the point where we have to do something different, we have to try something different and see if it works.
	So at that point we decided to go ahead and do the G-tube. I think we just felt going into it, I mean, I had never met anyone with a child who had had a G-tube. I have never talked about it. I mean, we have so many friends with babies and extended massive Irish families with all these kids and all these people and nobody else had ever dealt with any of this, so I had no one to call and say, hey, what did you do when it's that feeling of you know, you feel isolated, you feel like is this the right decision. And it's also like you're I was Claire's voice. She can't tell me what she wants, is this what she needs now, do I have to make that decision for her.
	And at that point it was difficult, but we were to the point where she had had the NG tube for three, four months, which is a long time to have an NG tube and things were not getting better, if anything they were only getting worse. So at that point we decided to do the G-tube. And I honestly will say to any parents who are facing that decision, it's so much easier on the other side of now having it and she still has it and we use it six times a day. It's built up in your head to be so much worse than it really is.
	The surgery itself wasn't a big deal at all. She didn't even like notice. The next day she was completely fine, sitting up, like, just sitting in the bed. She wasn't fazed by it at all. And as far as the actual feeding, once you learn how to do it, it's really not you know, as a parent you're going to learn to do whatever you have to for your kid to take care of them and if it yeah, at the beginning it was so outside of my comfort zone. And I couldn't believe that this is how I have to feed my child and now that's just what we do every day.
4	TITLE: Decision-making re Trach: <i>CPAP and doing everything possible not to get a trach for our daughter</i> .
	https://courageousparentsnetwork.org/videos/decision-making-re-trach-cpa p-and-doing-everything-possible-not-to-get-a-trach-for-our-daughter/

Description: A mother of an infant with serious apnea and aspiration describes her daughter's terrible sleep apnea which required help breathing and their determination to avoid the trach if possible. "How could I put another hole in my beautiful baby girl if we can make it work with the CPAP and it isn't absolutely necessary?"

## Transcript:

**Jacqui**: Claire was working so hard to breathe at night that she wasn't growing properly. So even when she had the feeding tube and we were giving her the calories that she needed, she was still struggling to breathe. And sometimes like her heart rate would be very high. It would be as if she was running a marathon and she'd be sweating and she would be sleeping.

So that was a whole, you know, other piece to this that we really -- I never had even thought about or knew anything about. So from there we discovered that when we were in the hospital one of the times that she CPAP seemed to -- she seemed to respond well to it, and that it was enough support to not only get her through the night, but make it so in long-term she could grow again and develop appropriately as a baby.

So a piece of it for a little while that became a question and the trach was brought up to us a few times when this past winter it was like she just kept getting respiratory issues, like cold after cold after cold, and we kept coming back into the hospital and we spend some time in the ICU. So Dr. Hartnick and his team basically, you know, it was brought up that if she had a trach, we wouldn't have this constant fear that she can't breathe right.

And I think that for my husband and I that was something -- when we first heard the word trach, I was again -- second day I was caught up so off-guard and had no idea really that was coming or that that was a possibility of something that would even be considered for what she had going on. So we decided, you know, we will try to do anything in our power for her not to get a trach. Different families feel differently and have different opinions.

I think part of it may have to do with the fact that we have Tommy at home, our two-year-old, trying to figure out how we could possibly manage all of that and not to say it like that, obviously we would do whatever was best for Claire, we really struggled with the fact that during the day when she was awake, she was completely fine. So I was like, how do I go ahead and do something so invasive and so intense to my beautiful baby girl and then put another hole in her body if it's not absolutely 100 percent necessary.

So then the idea was that, you know, if the CPAP are supporting her well enough that we don't have to go there and then it was kind of brought up like it might be kind of difficult because then you're tied to this machine and this

	thing outside of her is what is supporting her and all those types of things. And in my head I would do anything I possibly could, I would I mean, I would walk around holding that machine all day long if I had to for it to mean that she didn't need a trache and that's just how we personally felt about it.
	And if we got to the point where it wasn't supporting her and if Dr. Hartnick said we had no choice, obviously we would have done it if that was what was in her best interest. But at that point we just felt like if we can just get her through this winter, get her through these colds with the CPAP and some oxygen when she needs it. And in hindsight, I'm so happy that we did make the decision that we did and she's really doing so much better now. And we've managed to support her through that without going that ultimate invasive step.
5	Step.   TITLE: Googling images of babies with trachs – Can I imagine that for my child?
	https://courageousparentsnetwork.org/videos/googling-images-of-babies-wi th-trachs-can-i-imagine-that-for-my-child/
	Description: A mother shares her reaction to the word "trach" and what she imagined as she considered it for her daughter. "To a medical person, they see these things all the time and it's not a big deal, but to a parent, when it's first happening, it's devastating. I didn't know anything about any of these things and now it's happening to my little girl and I'm the one who has to learn everything and make the best decisions."
	Transcript: Jacqui: Trach just sounds so much worse and more invasive. And you know, it was literally like I didn't really understand I knew that it was in her throat, but you know, I was literally sitting in the hospital room on the other side of this place Google imaging babies with trachs.
	And that's like the first thing I ever saw of it and I just I'm like, that's not Claire because in my head through all of this no matter what's wrong with her, she's still this perfect little thing and we're just getting her through all of this. And you know, it's just how to wrap your head around, but again, if we had to go there, we would have. And any parent who's trying to make that decision, like, you will learn and you will adapt.
	And even though those first Google images are horrifying to see even with the G-tube, what does it look like, how big really is it, you know, what does that actually mean, or the first day when they went to shove the NG tube down her and then it's taped to her face to my three-month-old's perfect little face. And, you know, just as a parent I think that's a piece of it that like to a medical person they see these things all the time and it's not a big deal, but to a parent when it's first happening it's devastating. You don't know like, I didn't know

	anything about any of these things and now it's happening to my little girl and I'm the one who has to learn everything, learn it quickly, and do my best to take care of her and make the right decisions.
	<b>Chris</b> : You have visceral reactions to I still remember you when we yeah, the first discussion we had of the tracheostomy, your description of how you felt Jerry would feel about that and it was like a line in his hand, no.
	Jacqui: Yeah.
	<b>Chris</b> : I think it was just and you know, visceral reactions are real, right.
	Jacqui: Yeah, yeah.
	<b>Chris</b> : When it was just that you guys could not go there and you would have gotten there, I know you would
	Jacqui: No, we would have if we had to.
6	TITLE: Decision-Making: the gift of time to figure out what your child needs and what you can handle.
	https://courageousparentsnetwork.org/videos/decision-making-the-gift-of-ti me-to-figure-out-what-your-child-needs-and-what-you-can-handle-cpap-vs-tr ach/
	Description: A mother of an infant with serious apnea and aspiration, and an ENT pediatric surgeon talk about they are working hard with CPAP and making time to see if they can get through without a trach.
	Transcript: <b>Chris</b> : And then even walking you through what CPAP means, you are like, a typical hero mom you're not describing what it's like to be a child to be on CPAP. It's not so easy to have your child on CPAP at first. And you have to get used to that and work at night and the mask and shift and you're up some of the night.
	Jacqui: Oh, we still don't sleep.
	Chris: Yes, right, you got to say then.
	Jacqui: I haven't slept for the past eight months, but it's worth it.
	<b>Chris</b> : Right, right. Those are the small little things, but it's worth it. But those are the that's the heart you know, and that's where the time comes

	in. I mean, if you had tried it for a month and it wasn't working and Claire was turning blue and all those obstacles, you totally would have gone there.
	Jacqui: Yeah, yeah.
	<b>Chris</b> : It's just a question of just you have when you have time you have to make use of that time.
	<b>Jacqui</b> : I think it's people like family situations too. Like, we've been very blessed that I was able to stay home from teaching anyways, even once I had my son who is two. You know, if I had to work right now, I don't even understand how any of this would look. I mean, it's been completely lined up, so as we said, I mean, I'm both of their mom and I'm Claire's nurse and it's a very full-time job, 24X7 job that, I don't know, and I feel like any mom would do it if they could, but if they also have to support their family, I really don't know what that looks like and how you make that work.
	So we also that's a piece of it for us where, you know, we are tied to this machine and we are tied to these things and we were able to even make it so to try to keep Claire as healthy as possible. I mean, she very, very rarely left the house at all this winter. No one came to our house, because to protect her from the germs. Whenever we take Tommy anywhere we really get him home and strip him down and throw him in the bathtub, like, it's been like try to keep everything as sanitary as possible. Obviously you can't avoid germs, she still manages to get sick. But I think we've just been put in a situation where we could try to give her that time and that safe nest and that sport where she can get through this and we're very lucky that we have that opportunity.
7	TITLE: Shared Decision-Making: Parent and Provider (Trach)
	https://courageousparentsnetwork.org/videos/shared-decision-making-pare nt-and-provider-trach/
	Description: An ENT pediatric surgeon and an ENT nurse talk about how in most US hospitals, it is the practice to give parents space and time to consider what they want for their child, rather than Provider dictate. The mom who had to make a decision re a trach for her daughter note how she appreciated how the decision was framed and supported.
	Transcript: <b>Chris:</b> It's really important if you really think that something is in the best interest of a child, you say it and the parents have to we work through it together. And it is interesting, you know, Kevin and I do a lot of missions abroad taking care of kids who have airway problems and breathing problems where they don't have resources like we have.

	Jacqui: Right.
	<b>Chris</b> : And parents have to work or live and I'm always struck by how the doctors and the healthcare professionals are much more like it's not none of these conversations take place like you need a trache, you need a G-tube, this is what you need. And what's amazing is the parents go with it because they want their child to survive.
	Jacqui: Yeah.
	<b>Chris</b> : And you know, I think so and there isn't either their continued access or e-mail or dialogue, you know, all of the conversations that you can have that make you feel like you know, this is a terrible hard decision, but we're doing it together and it's slow and I think it's that time aspect that gives you time.
	<b>Jacqui</b> : Yeah. And I will say just from the beginning with Dr. Hartnick as he was you were our second opinion in all of this. And from the second that we did find you, I always felt like you were very honest and very straightforward, yet if there was time you try to leave it on the table for us to make the decision.
	Kevin: Yeah, yeah.
	<b>Jacqui</b> : But I felt like I trusted you enough that you would let me know, like, okay, but no, she really needs this or she doesn't.
	Chris: Right.
	Jacqui: And we really that meant a lot to us too.
	<b>Kevin</b> : I second with Dr. Hartnick because he is really good about saying it. I mean, if there is no choice, there is no choice. But if there is a choice allowing families to kind of come along and kind of make their own decisions and share it together, there really is you know, in some situations there really is no bad decision, you know, it's just a process. Maybe it'll work for a while, maybe it won't, come back to revisit it and hopefully the parents feel that, you know, that they're supported, you know, we're still around to help make these decisions as they move forward.
8	TITLE: A mom on asking for and accepting support from her community. "We're parents, not super-heroes."
	https://courageousparentsnetwork.org/videos/a-mom-on-asking-for-and-acc epting-support-from-her-community-were-parents-not-super-heroes/

	Description: A mom of an infant with serious apnea and aspiration on asking for and accepting support from her community. "We're parents, not super-heroes."
	Transcript: Jacqui: Don't be afraid to ask because times when we were in the hospital, everyone kept saying like what can we do, what can we do. Even a group of actually my husband's group of high school friends, they for months now they created a schedule where at least once a week they someone brings us dinner, just so it's one last thing that we have to worry about. So you know, I think in all of this it's asking for help, it's accepting help.
	People actually want to do something for you. And such a little thing can make a big difference. It's one night that, okay, we don't have to worry about cooking something and it can just mean that much more because even with a child on a feeding tube it's so time consuming, it takes so much time. You feel like she's just always eating and she's always hooked up to it and then she's done and it's quick. Like, drive wherever you're going and then plug her back in again, like, it feels like it's just constant, it really does. So it leaves very little wiggle room for other things to happen.
9	So I just think again, to get back to what I was saying though that, like, accept the help, appreciate the people that you have, they really do want to help and it doesn't mean you're weak. I mean, I went through a little phase where I was like, why can't I do this all, why can't I do it all and you just can't. We're not you know, you're parents, you're not superheroes. TITLE: <i>A mom on every night with the CPAP (rather than a Trach): parents learn what they can tolerate.</i>
	https://courageousparentsnetwork.org/videos/a-mom-on-every-night-with-t he-cpap-not-trach-parents-learn-what-they-can-tolerate/
	Description: A mom of an infant with serious sleep apnea, on every night with the CPAP all the worries: "Watching my kid's oxygen levels all night long is a form of torture but I'm just going to do it." The pediatric ENT surgeon observes that parents learn what they can tolerate.
	Transcript: Jacqui: The actual CPAP mask doesn't fit Claire's head. Her head is too small, it still doesn't fit her head. So she still uses a RAM cannula with the prongs up her nostrils, which then is always also you know, it's not fully sealed, is it giving her these are just things I've had go in my head, is it giving her everything she really needs and those types of worries and then she can just if she wants to scratch her nose, she can just knock it out.

I sleep in a twin bed next to her in her room. And I'm probably up at least once an hour to make sure that it's still in her nose or to just check on her or, you know, check the --so she's on an oximeter at home too that tells us her oxygen levels, which I think that machine is probably my worst enemy. And the day that we don't need it anymore, I'm going to throw a huge party. But just to sit there and watch your kids oxygen levels all night long I think is a pure form of torture.

I mean, like, I sit there and I look at it and it's at 95 and if it goes to 94 I want to cry and if it goes back up -- I mean, a lot of times it dips lower than that and then comes back up, but it's always like -- it's just a big head game at that point and it's like you could just -- I mean, I can stay up and just stare at it. And you know, it's very -- it's comforting the fact that I know, but sometimes it's almost like you know too much, like, you know what I mean, like you just -- so that's still a piece that is difficult and makes the night times very, very hard still.

And even though now, like, she's proven that she is safe and she is okay even when she does have these obstructions from her sleep apnoea, however, as a mom, every time that machine beeps, even though it's the like 1000th time, I still go until -- I think it's like PTSD, I go and do this panic of like, oh my God, we're going to be back to like in the ICU where we were before. And I think that's something that's just going to take me time to heal from all of this, like, the trauma of watching her not be able to breathe correctly.

It's just -- I mean, to me it's my worst nightmare and it keeps happening over and over every single night. So that part is very, very difficult. And you know, I just -- I wake every day and I'm happy that the sun is out again and we just -we'll deal with it again the next night, but to make sure that she gets through it and that she's okay.

**Chris**: But you know we talk about crystal balls but you know you're doing it.

Jacqui: Yeah, we are doing it.

**Chris**: You know, if you had a crystal ball and you know -- then you couldn't -you wouldn't be able to tolerate it then we would have thought about something else. But it was -- I mean, every night you do it and you're tolerating it and it's working or if you had a crystal ball and you knew that she wouldn't tolerate it, right, that would have been a different story, but you don't have those crystal balls, but you know, I certainly remember you guys both wanted that fighting chance.

Jacqui: Yeah, yeah.

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	<b>Chris</b> : And you took it by the horns and that's probably and then you gave it
	your best shot.
	<b>Jacqui</b> : Right. Well, that's one of the things too, that I think as a parent, like, you get this like I don't know, this deep inner like I just I have to do it for her. Like, I still wouldn't be doing this for myself. I would just go in the other room and go to sleep. You know what I mean, but you just like you have to, you have no choice and that's why we're given the choices of being so tied to the CPAP machine, what that means at home. I didn't have a doubt in mind regardless of how tired I got, like, I'm just going to do it. If it works well enough for her, I'm just going to do it. And there wasn't doubt in my mind that I wouldn't make it work. It wasn't going to be because of me that she you know what I mean, like, if I had anything any power within me to make it so she didn't need the trach and we could support her with that then that's what we were going to do, so we stuck to that.
10	TITLE: Decision Making about the trach: Would talking to another parent be helpful?
	https://courageousparentsnetwork.org/videos/decision-making-about-the-tr ach-would-talking-to-another-parent-be-helpful/
	Description: A mother of an infant with serious apnea, an ENT pediatric surgeon and ENT nurse talk about how when considering a trach for their child, some parents want to talk to other parents while others do not. Even as she did feel isolated, this mom wasn't ready to talk with another parent.
	Transcript: <b>Chris</b> : We spent a lot of time for the decisions of when talking about trachs or not, I mean, I think we ask it was offered do you want to speak to do parents want to speak to another parent. And I think and I'm struck by sometimes they really, really do and sometimes they really, really don't.
	Kevin: They really don't, yeah.
	<b>Chris</b> : They're not I remember I don't remember you feeling that that's something you wanted to do.
	<b>Jacqui</b> : So I said I remember saying I would be open to it. I think in that time, to be honest, the fact that we didn't know why any of this was happening, I honestly felt like I had no one who could relate to what like, my specific situation. And to be honest, I also I think like talking to a parent of someone who had a trach would have made it like a more real thing for me and I was not ready to go there. Like, I wasn't ready to actually have that conversation until you told me that this is happening.

	And aside from that I was like, kind of just like, we're not going to we're just not going to go there. I was just already so overwhelmed in what we were already doing and dealing with, you know, we spent a lot of nights in this hospital. I was saying earlier how I slept many nights over there. Yeah, because my mom would come and stay in the room with Claire, so I could get away from all those beeping we're talking about and the alarms, but it's a great view of the city.
	<b>Kevin</b> : But as I recall, you were researching them all time, you were alive.
	<b>Jacqui</b> : Oh, no, and I was, I'm not saying it I mean, like we said it I'm a teacher, like, I wanted to be educated on it at that point, but I also you know, talking to a person who was really going through it, like, talking to somebody else I just don't think I was I wasn't there yet. But it is one of those things, like, now I would love and this is why I'm here today, I would love to be a resource to somebody if I can help in any way because you do feel isolated and you do feel like, you know, and it's like if someone is ready to talk then it's a good thing to be able to share your story and what you went through.
11	TITLE: A mom to fellow moms: "No matter how blindsided you feel, you will get through it. You are strong enough."
	https://courageousparentsnetwork.org/videos/a-mom-no-matter-how-blinds ided-you-feel-you-will-get-through-it-you-are-strong-enough/
	Description: A mom to fellow parents: No matter how blindsided you feel, you will adapt and get through itTake time to make decisions that are right for your child, your family. You know your child best.
	Transcript: Jacqui: I think the only thing I could say to families is that, that feeling of being blindsided and that feeling of, like, this doesn't happen to us, like, this only happens to other people, I think feeling like it's okay to feel like that or feel like you know, and it doesn't it doesn't really get you anywhere, but I think you need the time to process what's actually happening to your child and you go through, you know, in a weird sense like a grieving period even though she's completely fine and in front of me, but this is not what we expected. This is not what I thought the first year of my baby girl's life is going to look like.
	And I think you need to allow yourself to have those feelings and go through that and then say like, okay, now it's time to, like, you can't think about that, you just have to keep going and you just have to stay positive and work with the doctors and work with the nurses and work with everyone who is here to help you and your families to just, you know, help them and get them through. I understand that we're in a situation that we're lucky with her diagnosis or lack thereof that the end result is hopefully that she will be much better.

	So I try to ride with that as much as I can on the days where it's a little bit more tiresome and we struggle at home a little bit. But I think to just to say to parents that if you have the time, take the time to really make the right decision for your child, not what somebody else did or not someone else's opinion or you know.
12	And that at the end of the day, as wonderful as the doctors and everyone is, I mean, you really do it it sounds silly, but you know your child best and you know I mean, I feel like a part of me is so I'm Claire, I'm her voice, that's why I'm sitting here today because she wants us to share her story if we can help in any way possible. But I think just trust your gut and know that no matter how scary it is or what is expected of you and no matter how much you weren't expecting any of this that you will get through it and you're strong enough and that's that. TITLE: <i>A mom to medical providers: "For you, you do it all day long. For us, our</i>
	world just got turned upside down." https://courageousparentsnetwork.org/videos/a-mom-to-medical-providers-
	<u>for-you-you-do-it-all-day-long-for-us-our-world-just-got-turned-upside-down</u> ∠
	Description: A mom to medical providers: "For you, you do it all day long. For us, our world just got turned upside down."
	Transcript: Jacqui: I think just sometimes overall in general, because this is what you do every day, that no matter how nicely someone tries to present this information, like, I wouldn't want to be you telling people telling parents these things about their children and I don't really think there is necessarily like there is not a good way to do it. I feel like the way you were always very direct and honest with us was very, very helpful.
	And I think at times when it seemed like maybe we like pushed back a little or asked a lot of questions or things like that, you know, I think it's just I think it comes down to, which I think all healthcare people try to be sensitive to the situation, but it's one of those things where you do it all day long and for us this is our whole world, this is our whole life and just kind of always keeping that in the back of your head that, you know, this is our world is completely turned upside down right now and we never thought we were going to be here.
	And, you know, if you can just in any way soften the blow I guess of what's going on, you know, really try to give all the information upfront of what does this actually mean. Because just the first few times where the word trach was

dropped, I just felt I still did feel very off-guard and very, like, whoa, like I said, then I'm like Google imaging, like, what is this, what does this actually mean to us right now. So I think just, you know, just being sensitive to that.
<b>Interviewer:</b> I just had this image I just had this image of like you're in the room, the doctor and the nurse are in the room and then somebody opens the door and lets a dragon in. And the dragon is not paying any attention to you, but now there is a dragon in the room and you're like, there is a dragon in the room and it's not talking and it's not coming towards you and in that moment it's leaving you alone, but there is a dragon in the room.
Jacqui: Yeah, it's there, yeah.
<b>Interviewer:</b> And who the f*ck let the dragon in.
Jacqui: Right, right.
Interviewer: I do not like the dragon.
Chris: Yeah, yeah.
Jacqui: Yeah, no, that's a good way to put it.