Hannah and Eric

Parents of Sage and older brother Gabriel. Sage was born with Arteriovenous Malformation (AVM) and died at age 3 months.

1	TITLE: *Telling our son's story* https://courageousparentsnetwork.org/videos/telling-our-sons-story/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM), had 5 brain surgeries, and died at age 3 months, begin the story of the start of his life, from pregnancy to his birth to the sudden emergency event. "That was the first kind of break that happened internally where we're sitting there and our baby is dying, that we know of now and nobody has even really seen this before. It humbled, to say the least." Transcript: **Eric:** To tell his story in detail and to share our feelings about it is that we need to, we need to do it and if sharing anything about ourselves and about our children can have any kind of impact on somebody who is in the position that we were in previously, then that's exactly what we need to do. **Hannah:** I'm Hannah Schermerhorn, Sage's mom and Sage was and is the most important person and force in our life. And he has changed everything for us. We had a fairly normal like lovely, healthy pregnancy with Sage and there really weren't any issues to complain of. There was one point when I was about seven months pregnant where I felt some strange moments in utero and I felt that they may have been indicative of something. But our doctor assured us that you know it was probably just my own anxiety and everything was healthy. I went into labor at about 36, it kind of began early and I gave birth two weeks later and he was large and he -- **Eric:** Yes. **Hannah:** -- the whole thing was really beautiful. It was really incredible. **Eric:** We were totally enamored and -- **Hannah:** Yeah. **Eric:** -- excited about the entire process.

Hannah: Yeah we --

Interviewer: Yeah totally love filled.

Hannah: It was -- it was wonderful and the labor aspect was really intense, it happened really fast, it was a little chaotic, but it went exactly as we wanted it to. But when Sage was born, we noticed that his head was a little bit larger, which I absolutely felt when I was giving birth to him. But he also -- he was a little dusky, he was a little purplish in his hue, there were some breathing issues but nobody seemed concerned. We stayed in the delivery room, I think an hour extra, while they monitored. Often in the next two days, he was having issues with his blood sugar, so we had a nurse come in and you know she would do like a stick in his foot and I remember being really upset that they were sticking him. You know I just wanted to keep him with me and anyway, so what happened was this incredibly kind of fortuitous event. Eric was home with our other son and a nurse was called in and didn't end up having a shift to be assigned to and was taking care of a student nurse, right?

Eric: This was our day of discharge.

Hannah: Yeah. We were about to be discharged and she knocked on my door and I said she could come in and just demonstrate some routine procedures and she saw that Sage looked dusky again and saw him, she didn't tell me immediately but she saw like a very, very small trace of a seizure happening. His eyes were flicking a little bit to the right. So she wanted to check his O2 saturation levels and they were in like the 40s. And she thought her instrument was malfunctioning. So she asked me to just scoop him up and walk down with her to the nurses bay and I laid him down and he had a full-blown seizure and he coded. So I remembered just -- they like pushed me into a rocking chair and I just sat and she called you know for doctors, the alarm sounded and within a few minutes, there are about nine, 10 people just kind of going crazy and Susan, that was the name of this nurse, completely saved his life. And she came and she said you know, "Hannah it's really serious, you need to get Eric back and we need to get him transferred, there is something really wrong with Sage." So we had him emergency transferred down to --

Eric: Tufts.

Hannah: -- Tufts, and before we were sent there, the doctor that was with him said that his heart was massively enlarged and told us that he was having seizures. So heart and brain were both affected which you

	know that’s literally the worst news that you can get. And that evening we sat down with the Head of the NICU Department at Tufts and they told us that Sage was born with a massive Arteriovenous Malformation which had completely consumed the left hemisphere of his brain. So all the tissues destroyed and hundreds and hundreds if not potentially thousands of arteries had grown and just kind of taken over the tissue. There were no capillaries, so all the blood that was going to this region was just wasted. So he was -- his heart had grown. **Eric:** The blood flow in that area was putting an enormous strain on his heart. **Hannah:** Right. **Eric:** And when I got back to the hospital right before he was transferred, I remember walking in and his x-ray was on a computer screen outside of the -- in the nursery where he was and it was from side-to-side sight across his entire chest and it was really shocking to see. **Hannah:** Yeah. **Eric:** And when we had the meeting with the Head of Neonatology, they -- the two people that we met with and they told us that they had never seen anything like what they saw in his scan and they were not sure if he was going to survive the night or really not sure about much. **Hannah:** Yeah, it was chaos. It was really insane just because nobody knew what they were really dealing with. They didn’t really know how he was alive. He was in a kind of active organ failure, he was having SVT episodes for his heart, it going up into like the 200 range, higher than that. And it was just this -- it was just this full-body devastation. And -- **Eric:** And escalating very quickly. **Hannah:** Yeah, it was wild. We just sat there, in this very dark room with these two people and they didn’t know, like they had really no idea and that I think was -- that was the first like kind of break, you know that happened internally where we’re sitting in Boston and our baby is dying, that we know of now and nobody has even really seen this before. It was humbling, to say the least.
2	TITLE*: We were trouble-shooting with the doctors and the nurses.* https://courageousparentsnetwork.org/videos/we-were-trouble-shooting-with-the-doctors-and-the-nurses/

Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM), had 5 brain surgeries, and died at age 3 months, talk about the early days of communication and intervention with their son's medical team, including the nurses. "Nobody had even really seen this before. It humbled, to say the least."

Transcript:
Hannah: We were troubleshooting you know with the nurses, with the doctors. They were completely frank with us because they didn't know how to treat him. And so you know we hounded neurosurgery, they declined to intervene and his heart was failing, they were having to do all of these different interventions but they -- none of it -- what they understood was to help Sage, we had to actually go and address the thing that was causing the problem which was his…

Eric: We had kind of become in closer contact and relationship with the lead cardiologist and the neurosurgery team and the head of neonatology because Sage's heart was under so much pressure from the increased blood flow with the AVM.

Hannah: Right.

Eric: And that seemed like the most manageable aspect in real-time. Of course while working with that and working with the decreased blood flow to all the parts of his body and there was this issue of, "Okay, we know he has this massive brain AVM, what can actually be done about that? What, even down the line, if we manage it some point down the road, what could actually be done?"

Hannah: Yeah.

Eric: So that was first, and we had conversations about different types of interventions that can be done for somebody with an AVM. The problem with Sage was that his AVM was so large and he was so small that the neurosurgery team there thought that any attempt would fail and was not at all worth the risk.

Hannah: He also was, you know he had had several strokes. There had been you know continued seizure activity, so it wasn't even just neurosurgery. We didn't know the effects the seizures were having and we knew that the vessels were incredibly delicate and seizure activity, hemorrhaging, it all -- everything was a danger. So there were these -- they were just there were so many different things that we had to hold and try to navigate. And one of the blessings that we really did have

	when we see it in retrospect, is the nurses that were alongside us, they helped us. They spoke with us, they let us kind of use them as soundboards, we discussed what the different medications were, what they were going to be doing, what the side effects were. What -- you know, what all of it meant because we also were keenly aware that for Sage to be even, to survive, that right hemisphere needed to be safe. His left hemisphere was destroyed, there was literally no saving it but the right hemisphere, everything was going to remap, that was kind of the hope. So it was also from a future perspective, how do we get him stable so that he can -- he can grow? So those neural-connections can be made so that he can get you know -- so he can really have a chance to be you know -- we also thought you know there was going to be some palsy and some issues on one side of his body but there were so many different things we were trying to manage and it was all interconnected. **Eric:** We had a very honest and difficult conversation with the head of cardiology and the neonatologist and they basically said you know, "We can manage the symptoms, we don't know for how long." I think they gave him about two weeks, minimum. **Hannah:** Yeah. **Eric:** But they said that basically doing that was not going to keep him alive because we can't address what's actually happening. So they recommended and really helped us facilitate the transfer. **Hannah:** Yeah they rallied. And we all, and it was you know, we were up all night, we were up all day and just constantly discussing this because there were also teams moving through, you know and the rounds that were taking place and the medications were changing and his status was changing. And they did their very best to help him and to help our family and they did, they prepared us and it was, I mean in retrospect, would happen there. Yes it did lead us to find Dr. Orbach at Children's and get Sage moved and at Children's, the next day Sage was -- there was an intervention. He had an eight hour brain embolization.
3	TITLE: *It's easy to get overwhelmed; so being an integral part of your child's care team allows you to have conversations and know why you're having them* https://courageousparentsnetwork.org/videos/its-easy-to-get-overwhelmed-so-being-an-integral-part-of-your-childs-care-team-allows-you-to-have-conversations-and-know-why-youre-having-them/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM), had 5 brain surgeries, and died at age 3 months,

	talk about how critical it was to be integrated into the care team. They emphasize the support of nurses. Transcript: **Eric:** So our story in the NICU, I would say from the very beginning, was completely intertwined with just mystery and being kind of like at the forefront of this condition where there is not a lot unknown, there are all of these different components and you know we had to very quickly jump into that role. And Hannah and I often, even in pregnancy and because of our experience with our other child, we knew that no matter what happens with Sage, obviously there was no way we could have ever predicted what happened. But we knew that no matter what, that we would be ready, that we would do what we needed to do as parents. And unfortunately that meant just jumping in and really from the very get-go, trying to make sure that we can understand and facilitate communication and be a part of the team.… You are thrust into another world where there are specialists, there are people. And one thing I would like to add to this conversation shortly, is with all of the different team members and everybody that's giving you information and this kind of ties into the conversation that we had with the neurosurgeon also in facilitating our transfer. Being an integral part of your child's care team allows you to have those conversations and know why you are having them and I think that is really fatal. **Hannah:** Yeah. **Eric:** I think it's so easy to get overwhelmed and when you have specialists who view things in like a very narrow and specialised way because they need to, and that's what they are able to do and suggest to perform things they do, but to have the support of nurses who really encouraged us to take notes, reminded us of questions that we had in our private conversations, those things helped us. It doesn't make it easier but you have a better sense of why you've ended up in places you have and I think that gives you a little bit more platform to have the empowerment that you need to carry through those situations in such a fast way.
4	TITLE*: NICU: Bridging the Gap to the Medical staff. It was like being in communion with each other.* https://courageousparentsnetwork.org/videos/bridging-the-gap-to-the-medical-staff-it-was-like-being-in-communion-with-each-other/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM), had 5 brain surgeries, and died at age 3 months, note the gap between the parents and the medical team in the NICU and

	what they did to bridge that gap and make the connection. "Our child's life and death was occurring in a place that was also a work environment." They note the **importance of the nurses** and what they did – "It was like being in communion with each other." Transcript: **Eric**: It was made pretty clear that nurses and doctors and other providers really -- there is this level of separation. And I'm not exactly -- I think there are a number of things I can show you to that but we really facilitated bridging that gap and not in a forceful or aggressive manner but just by being present by asking questions, by really making sure that we were part of everything that was happening. People like the nurse that we wanted to be a part of the team, that we were there to help guide and understand Sage's care and I think that is what changed sort of the nature of everything that happened. And I think when there are families who for whatever reason whether it's fear -- I mean there are a number of reasons and they are very understandable why you might not have that type of connection. But when that's there I think if you come from that place and you are suddenly in a moment where a child is dying, if there is already a gap to be bridged, I think it just makes it that much harder for everybody , they can't provide for us. **Hannah:** Yeah. We were fortunate. We had a connection and there was always like one nurse who demonstrated a real incredible skill. You know I think the thing that's really funny is we found that the more time we spend in the hospital setting, we kind of began to pick up on the nuances of just the workplace environment, which is really kind of stunning because our child's life and death was occurring in a place that's also a workplace environment. And some nurses feel overlooked, some nurses feel insecure, some nurses are leaders you know some are, but there was always like in our first hospital there was Susan, she did things out of love. It was very obvious that she was a very, very kind connected, strong, smart woman and it was that intuitive piece that saved Sage's life the first time and it actually goes on to the second location and then there we met a nurse who wrote down, she printed out the pictures of every staff person on Sage's team, like a booklet with their name and their title and in addition to like the medications that he was on and we sat and we talked with her. You know and the thing is we were there -- like our son was before them, and Eric and I were completely open. There was nothing about it that was there to prove a point or to get ahead, it wasn't about a career. It was the most pure and it's just -- it's just the substance of life. Because this, the diagnosis -- nobody knew what was going to happen and how it was going to unfold and so we just -- we paid attention to

	everything and we asked a lot of questions and it was out of respect and there was a real kind of -- like there, it was almost like being in communion with each other for the sake of Sage's life and we lost. We lost the fight ultimately but there was still deep respect and love.
5	TITLE: *Being your child's advocate*: *It connects you to all things greater.* https://courageousparentsnetwork.org/videos/being-your-childs-advocate-it-connects-you-to-all-things-greater/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, share some of the small details of what they thought, saw, experienced with their tiny baby in the NICU, post-surgeries. It is a series of traumas - life-saving but complicated, with side-effects. Transcript: **Hannah:** We had just had a baby, we had just given birth. It's the most vulnerable place that you could be and it was also I think for Eric and I, just we were totally aligned, you know? We were in it and the Sage needed us. I think that's really the other thing too, he was so innocent and you don't -- nothing can prepare you for seeing a baby with you in the delivery room and then you know, you see them covered in IVs and you know scans. Like at one point after Sage was, the first embolization, we were standing there and they had this tiny little pulse monitor because they couldn't find a pulse in his leg, you know and it's after the procedure they told us because they had to go in through the femoral artery. **Eric:** To find that. **Hannah:** Yeah. **Eric:** Finding the veins through them. **Hannah:** It frightened them because the circulation might not return and just for the briefest second, well I mean hour, two hours however long, it was but at one point we were just standing there and you know like really like our -- is our child's leg going to be lost? **Eric:** Right. **Hannah:** His you know, his brain is so badly injured and by no action of his own, he was just born this way and it's just been a series of traumas, you know? And just standing there it's just such an unbelievable intersection of seeing what life-saving procedures really look like but

	also seeing how they do complicate and injure as well. And I think that that was something that Eric and I -- we were so conscious of. We wanted to know what the effects were going to be, we wanted to know how it's going to impact Sage because we weren't seeing it just from this medical perspective. We hadn't practiced this over and over. It was, we had to, you know? And he is our child. **Eric:** Being a parent in that way that there is an incomparable value to the parents who are also, as a part of the care-giving team. And that's because all of this was happening really in your first few days with your child which you know, as a mother you've carried for nine months. And as a father and as a family you are -- you are trying to imagine what it is going to be like, you are already coming up with different versions of reality before your child is even born. And to be there with Sage and be thrust into something so unpredictable and so chaotic and so in the moment, you have gratitude in those moments for the smallest things and I feel like it connects you to your child in a way that is -- I certainly won't be able to articulate. **Hannah:** Right, I think it connects you to all things greater. All things and I don't think that you can even really speak about them. **Eric:** Right. And you can't return to anything else. **Hannah:** No. No you can't.
6	TITLE: *Our son. Our effort; His edge of suffering; the Outcome* https://courageousparentsnetwork.org/videos/our-son-our-effort-his-edge-of-suffering-the-outcome/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk in detail about their medical decision-making and hopes in such an intensive situation. They speak about their tremendous efforts for their son and what informed their decisions, including their perception of his physical suffering. Transcript: **Eric:** I certainly feel that the effort and understanding that we had with Sage contributed to this massive, kind of, it felt like a force field of hope when he was in the hospital. Sage -- and again we didn't make decisions, there was thought, there is not time to process and in any kind of like a real emotional way that's going really penetrate I think. But we did strive to be as in control of those decisions as we could be and Sage proved to defy expectations in the most severe circumstances. For that reason, I don't -- it's hard to fully say yes or no because this was all

occurring at a time where Sage could have had a fatal brain hemorrhage at any moment. And so you are living with these different levels of risk and understanding of what the condition is. I think that we do -- we were left feeling that we did everything that we could, which as Hannah described earlier, that that is a gift that we have and not feeling the guilt or the confusion. Definitely removed some of the layers of weight but I think that this feeling that if you put your all into something that there is going to be a desirable outcome. I mean I feel that, in grief as well. I feel I am still in small ways, I catch myself constantly working really hard for things, to see if the outcome is going to be expected and it doesn't -- it doesn't work or soothe because it directly contradicts the most important event of our lives. And we carry what happened with Sage and our entire experience together and it's impossible to convey that fully to anyone who wasn't there witness it.

Hannah: I don't think that I feel that way about myself. I think what I struggled with was, not that I was trying so hard but that Sage was losing so much and that he was suffering so much, I think that was what was -- that's what I think kind of worked my perspective. You know what I mean? He lost movement, he began to lose sight, he began to lose hearing, he lost the ability to swallow, he and he just continued losing and it wasn't necessarily about the amount of effort we were exerting, it was just about how much, he as an infant, as our baby, had to lose. And I think that's what I struggled with a lot. I thought there was kind of an edge to suffering, well like an endpoint and especially for children.

Sage was only alive for three months and really in the timeline of everything, so he had every procedure he -- he went through, was absolutely life-saving. We had come to like the point where it needed to happen or he would die eminently, so we always opted for the procedures and it was a deeply thought out and very, very highly conscientious situation where we would be meeting with the NICU staff and we would have to kind of tell them what we understood and what we were agreeing to.

Eric: Right.

Hannah: And I think the thing that's kind of hard is we didn't let Sage suffer. His life was literally just under three months old, so when it was time and I mean we had that final meeting and we learned that the epilepsy was incurable and that there was no recourse for treatment, we decided we didn't want him to die having a seizure. We didn't want him to go in that manner, it was really horrific and really awful to endure but that right hemisphere had been attacked and it was destroyed which is what we learned. And again very unexpected and rare but to be honest

	with you, it was only a matter of days from that conversation to his passing. So we didn't live -- you know there are families who have children with complex medical needs who are alive for years and years and we didn't experience that. We had very intense suffering and you know our baby, it was hard, you know when a child is close to death, there is a lot of swelling. There is, you know his body wasn't -- it wasn't the body that I, you know gave birth to. It had changed dramatically and that was hard, beyond hard, to deal with. But it didn't go on for very long. And so for us, we couldn't have let it. And it's hard because I think that for families of children that have complex medical needs, it can go on. You can extend life, you can -- there are things that you can do and Eric and I never had to really grapple with that. And it's hard for me to even conceive, I mean we would have wanted Sage for as long as his life could have endured but unfortunately his life only endured for three months.
7	TITLE: *Being our child's advocate: "Every decision that was made medical was absolutely necessary. And then we knew when his body had endured enough."* https://courageousparentsnetwork.org/videos/being-our-childs-advocate-every-decision-that-was-made-medical-was-absolutely-necessary-and-then-we-knew-when-his-body-had-endured-enough/ Description: Parents of a baby son who was born with severe Arteriovenous Malformation (AVM) and died at age 3 months, talk about how they became core members of their child's team and helped promote communication amongst the team members as they opted for every procedure that might help, with the understanding that their son could die in the procedures. It was challenging but there was incredible hope. Transcript: **Eric:** We really had a relationship with the team, which again people are switching in and out pretty constantly. And so you are introducing yourself, catching people at speed, introducing them to Sage, trying to make these bonds very quickly and in some ways they naturally do in that environment. But we found ourselves sort of needing to prove our understanding of these very complex situations and also asking questions that promoted the inter-communication between different members of the teams and which doesn't automatically happen. **Hannah:** No. **Eric:** That was -- I think most people probably assume.

Hannah: Yeah.

Eric: So if you are hearing different information from different team members, you know they are viewing it from a very different lense, and there is value in all of that, but if you are hearing different information, you do have the ability and you need to take it to facilitate those people getting together explaining, you know why are you saying this and you are saying that, what does it actually mean? How do all of these things affect Sage in a total sense? And so we definitely had extensive talks with many, many people before these procedures and they were risky. I mean all of the procedures, there was a high chance that Sage was not going to come back.

Hannah: I think the thing is though, we knew objectively how dangerous the surgeries were, I mean we knew -- you look at his MRI scans and it's shocking and so we knew how bad the situation was but it was never -- we were never going to not opt for surgery. Like we were going to do everything we could as long as that was an option, that could make him better, you know what I mean? That could get him further, we absolutely opted for it and the thing that I think that was really difficult was we had planned out the next. So after his first embolization, the next one was scheduled for six months out and through a series of emergencies it ended up that he had to have his second embolization less than a month later. And then that one I think it was only -- it was another month potentially where he had to have this last kind of Hail Mary embolization where these arteries, what came to light, so basically he had to have these surgeries -- these embolizations. Every time he was embolized, his team -- Dr. Orbach and the neurointerventional radiologist at Children's saw more arteries get activated so that AVM is actually growing. AVMs are -- it's a vascular system but it's controlled by its own kind of hormone signaling. So it grows much faster than his body was growing and that's what exerted pressure on the brainstem which they had never seen. And that's why it became so, just kind of, even more high-risk and unpredictable. So the third embolization occurred because his brainstem was being impinged, it was being crushed. Sage's eye had turned inward, his eyes were bulging. He was in extreme distress and that was probably the hardest period of time for us as a family. And so we opted for this extremely dangerous surgery and Dr. Orbach's counterpart who was a neurosurgeon had even said during the meeting that you know he wouldn't have attempted it, if it was his choice, that Dr. Orbach was really kind of attempting something that he had never done before, that was new for the hospital and our -- actually the head of the NICU requested to go into the procedure to just kind of bear witness.

Eric: Right.

Hannah: And we had multiple meetings with you know with palliative care, with the NICU staff, with Dr. Orbach's team, with neurology, just having to kind of -- really what we understood and gave our approval with the understanding that he most likely would die during the intervention. And that was by far the most I think -- it was the most difficult but at the same time Eric and I didn't feel in that way that as parents we knew that he was going to die. So there was this momentum, there was this momentous piece and there was this incredible hope. And Dr. Orbach and his team were just as interested, it was something that was challenging, it was something unpredictable but everyone loved Sage. You know he wasn't just a patient, he was this incredible child and he was quirky and funny and sweet and alive, he was -- he was incredibly alive.

Eric: And we would have these glimpses and after his procedures where he would recover at like these incredible rates.

Hannah: Yeah.

Eric: And he would just wake up way ahead of schedule.

Hannah: They would -- yeah, they --

Eric: And be fully animated and we would immediately see that he would have increased function in his arm and he would be --

Hannah: He would hold tight.

Eric: -- Tracking with his eyes and making sounds and he would just look at you and -- it was amazing. It really was.

Hannah: Yeah. I mean we laughed.

Eric: And people would just look like that.

Hannah: And like people, we would all come and just you know and see Sage.

Eric: Yeah.

Hannah: And we -- everyone would laugh. I remember you know many people on his team just being smitten.

	Eric: Yeah. **Hannah:** Because it was just -- it was hard to even like you know. **Eric:** Fathom -- **Hannah:** Yeah, absolutely. **Eric:** -- what was happening. **Hannah:** So, no we, I think that Eric and I, every decision that was made medically was absolutely necessary. And I think one of the things that is really difficult to articulate also is that I never -- of course we had the conversation about what would happen if Sage died, multiple times throughout his life, and were told multiple times that Sage was about to die, and you know several times at the end of his life during seizure episodes, he did cde and it was horrific and sometimes it would take hours -- **Eric:** Many -- many times. **Hannah:** -- to get him back. And we lived through that so we knew -- we knew what it was and when it was absolutely time and Sage was physically no longer present in his body, you know the seizures were coming, they weren't -- we couldn't treat them, he was completely damaged and his body had absolutely endured more than it should have and I think that it was -- it was again we just knew. You know what I mean? We knew. **Eric:** And Sage let us know. **Hannah:** Totally.
8	TITLE: *The palliative care team would ask us, "How do you feel about what you just heard?"* https://courageousparentsnetwork.org/videos/the-palliative-care-team-would-ask-us-how-do-you-feel-about-what-you-just-heard/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk about how the palliative care team interacted with and supported them, and helped manage their son's pain and consider the future. "They really saw us as people and as parents. It was an awesome help to have them there." Transcript:

	Eric: Palliative care became a part of our team around the second embolization and they began as kind of this other group that would take extra time to sit with us and really get to know us and kind of talk to us. You know somebody to ask like, how do you feel about what you just heard? You know they would sort of come in after we met with a group or maybe they would have one or two members present when we were meeting with the neurology team and they would ask us you know if we had questions, how we felt about what was happening and we sort of bonded that way in a very natural and human way. And as that continued throughout all these procedures and when we came to the end, they were very helpful in us making sure that we felt that we were being heard and as we kind of shifted away from being so medically focused towards making sure that Sage was comfortable -- **Hannah:** Yeah. **Eric:** -- that we were still feeling part of the team and feeling like everybody kind of knew where we were coming from and what we wanted for Sage and making sure that they were all communicating even when we weren't present, trying to make that happen for him. **Hannah:** Part of it too Sage because of the change in his treatment plan and because he had multiple brain surgeries and he had five in total. Four of which occurred pretty close to each other, so he was on a good dose of painkillers, you know he was on Fentanyl for a while. And so PACT came in to help us manage the medications. And then for the day that Sage passed, they were present to make sure that we were okay and that Sage was not in pain. You know they played a very big role in making sure that it was peaceful because we felt like after everything that Sage had endured, we absolutely did not want him to die having a seizure. So we wanted that controlled. And they were there to help and respectfully, outside of our room but and that was kind of the presence they played but they you know I mean palliative care, it's a very unique and multifaceted group. They have doctors, they have nurses, they have social workers, so medically speaking we understood everything that was going on with Sage, we didn't need a lot of clarification. And but we didn't know what to expect in terms of planning for the future because that was impossible. So they helped kind of paint that picture and when it changed, when we got a new diagnosis or a new care plan or a new medication, we added that to the landscape that we were facing.

	Eric: And one thing I'd like to add as well is, I remember very distinctly and in many of our large meetings discussing Sage that the members of our palliative care team were eyes that I would go to when I was -- **Hannah:** Yeah. **Eric:** -- you know looking for somebody who I knew was you know had us -- who was there really -- **Hannah:** Yeah. **Eric:** -- kind of standing with us amongst the enormous group of medical professionals. You know it seemed like they were -- they really saw us as people and as parents and it was a massive help to have them there. **Hannah:** It was also I mean we needed that. We needed to be seen as his parents, we needed to be seen. We were living our life just like new parents to Sage in front of all these people, in a hospital.
9	TITLE: *Parents give tips on being in the NICU: Staying present, creating routines, holding your child as is possible; pumping* https://courageousparentsnetwork.org/videos/parents-give-tips-on-being-in-the-nicu-staying-present-creating-routines-holding-your-child-as-is-possible-pumping/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, describe the NICU as a beehive and offer their suggestions for how to navigate it and cope with the heightened sense of focus. Toys, books, music, routines as possible; and staying off social media; self-care; and the importance of pumping. Transcript: **Eric:** The NICU is a chaotic place by nature. It's like and I think we've talked about it being almost like a beehive and like in some sense it's like -- there are people just all over the place doing multiple, multiple things and I think it's important for parents to somehow recognise that they are allowed to ask questions, they are allowed to be as much a part of it as they want to be and that it is the job of the providers to help facilitate and support that. I think that for us, something that we've longed for since losing Sage, is that feeling of really heightened focus and sharpness that you have when you are having such a really serious and ever-changing experience. Things were so rapid with Sage and the risks were so high that you have to be fully heightened, ready to be at the level you need to be at to be on par with people who are in it every day. And it's okay as a parent in need to slow that down a little and to ask for

that kind of help from the providers. And I think it's also really important for parents to not spend all of your time taking notes and asking questions but also make time to hold and touch your child as much as you possibly can and try and somehow exist in those moments and really hold onto the gratitude in all that can come from that. I think that's -- that's a huge part of it. You are still the parent to your child. It's not at all what you thought it was going to be and you are not at home and you are in a place that is very far removed from probably anywhere that you thought you were going to be with your newborn but you're still mom or dad or family member or whoever it is that's there.

Hannah: Yeah.

Eric: And there is time to be that in a natural way, not just in a you know supporting role.

Hannah: Well it's -- I mean it's both. It's dual. You know I remember having a really hard time with the fact that I couldn't pick up my child when I wanted to. You know Sage didn't cry much. I think that he was too sick to cry but you know if I could tell that he was in distress, my instinct I wanted to just grab him and hold him and I couldn't do that. I was always -- we were always restricted and it is hard because there are nurses, there are people constantly touching him and caring for him, changing their diapers and so do what you can, like he said, to be involved. Eric and I always try to change his diapers. He didn't really wear clothing because he didn't -- you know it just didn't really work with his condition but --

Eric: He had hats.

Hannah: Yeah, he wore lots of hats. You know we provided him with toys and he had favourite toys. And we -- the thing that was really incredible you know in the NICU they provide like mobiles and just --

Eric: Sound machines.

Hannah: Sound machines, like things that actually you would put in a baby's crib and I think that's really lovely and I think it really helps. We always had music playing for Sage. Even if we weren't playing music ourselves and we had piano music that we were always playing for him. He had a favourite book that even the nurses recognised was his favourite book, like separate from us.

Eric: Yeah, they would ask us like, "He really likes this page."

Hannah: Yeah.

Eric: "Yeah, we know."

Hannah: Because he would respond. You know so I think that it's really important in the hospital setting to try and create as many routines as you would if you were home and holding your child is by far the most important and it's really healing too. I think every time I felt really despondent, just being able to hold Sage and to spend time with him and I think that's the thing that I really miss and when I was in the hospital with him I knew I was going to miss those moments and I really tried, as best as I could to hold on to them and but creating routines, I think, Eric and I did something that I really strongly standby which is we did not go on social media. We made an effort to --

Eric: Yeah.

Hannah: -- we weren't on our phones, we didn't talk to people. There was -- whatever communication needed to be shared with like our families and friends but we didn't want to be online. We weren't the type of people to be like actively sharing what was happening. It was far too serious. And it was just -- it was so ever-changing that Eric and I needed to just be consumed with what was going on.

Eric: Yeah, it's important to not be distracted and I think it can be really tempting to find small ways to try and soften the blow of what -- whatever was happening. And like Hannah said, you know we didn't have a lot of people in the hospital with us. We really we -- relayed information you know through a point person really but when things are happening that first and when it's so chaotic, it's really -- in order to be present in a way that's going to create the meaning that we've talked about that sort of facilitates all these moving parts coming into a you know a useful fruition, it's important really to be present but also to you know what, you need to take care of yourself in some ways too.

Hannah: Which was hard.

Eric: Yeah, that's impossible.

Hannah: For me personally pumping was extremely important and I did that up until the doctors told me not to any longer and that was an incredibly grounding and connective thing.

Eric: I think it was for both of us.

	Hannah: Yeah. **Eric:** Really. **Hannah:** I mean it was definitely losing that piece of it and it was a huge loss also but I felt like I was really contributing. If there was one thing I could do, if I couldn't be like a normal mother, at least I could keep doing that and try, so that was big. And I think yeah, Eric and I trying to do as many normal things as possible
10	TITLE: *Being in the NICU: Taking turns going home* https://courageousparentsnetwork.org/videos/being-in-the-nicu-taking-turns-going-home/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk about figuring out how to get home or step away from the NICU (the importance of the nurses) Transcript: **Eric:** We spent a lot of time in the family rooms and I'm trying to think, we had probably four or five different rooms. In the beginning we were there 100% of the time, things were so in the moment that there was just no way that we could leave. And our other son was being cared for by some of our family members. As Sage's condition really didn't kind of wax and wane like when he reached moments when he was sort of transitioning onto more like normal -- **Hannah:** He was stabilising. **Eric:** Yeah like working on feedings and when we were kind of getting into like the safer areas, then we would sort of break up our time and we would go home and you know because we were also trying to still be there with your other child somehow. **Hannah:** Also I think the nurses, so like we had one night nurse that I really loved and trusted. I mean all the nurses were wonderful but there are -- there are a few that you bond with. So when she was there with Sage, I felt infinitely better, and it was easier to go home or even fall asleep for a few hours as opposed to you know there would be some nurses where I wouldn't want to leave him and we didn't. You know so there were nights that we stayed up with him, I mean for the most part we didn't sleep and -- **Eric:** Yeah, we were really resting.

	Hannah: But we just -- we navigated it. If we had to go home, we went home. At the end of Sage's life, we were taking shifts. So I would go in like around four in the morning and then Eric would go in at night so we could be with our other son and just kind of manage. But because of Sage's condition just how extreme and how rare, there we didn't really get to kind of conceive our future plan -- we were working with palliative care but it was all just really back and forth. So we didn't -- there wasn't really like a huge amount of flow to what we were doing because we had, we just hadn't gotten there yet.
11	TITLE: *Our son's last day: "We knew we had done everything possible for him. It was right, despite how wrong it was."* https://courageousparentsnetwork.org/videos/our-sons-last-day-we-knew-we-had-done-everything-possible-for-him-it-was-right-despite-how-wrong-it-was/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, describe knowing that their son's body could not go on any longer, that they had done all they could for him, that it was time to let him go, and what that was like ... to shut off the monitors, remove equipment, play music for him, and hold him. "It made me feel a little crazy ... but it was the most loving thing we could have done. … We knew it was right, despite how wrong it was." Transcript: **Eric:** Sage's last day we -- we went home the night before. We had just had a really large meeting where we like collectively kind of had the discussion that you know it was time to really shift gears. There were no more interventions that could be done and we all had a really full understanding of what Sage was experiencing at that moment in time. And we had gone home, really just somehow began pondering how we would possibly know when it was time to redirect care and really -- well how would we know it was time for the end? And of course that's basically unanswerable and it's impossible to really have that conversation, I think, at least in our experience. And when we got to the hospital that day Sage was different. He had been kind of propped on a Boppy pillow and he had a BiPAP machine on and we had spoken to one of the nurses overnight, they were basically they were trying to decide whether or not to intubate and they wanted us to be there -- **Hannah:** Yeah, it's horrible. **Eric:** -- before they made the decision because they felt that if he had been incubated then he would not be coming off the respirator.

Hannah: He -- I mean it was a really hard thing to walk into.

Eric: He looked very different.

Hannah: He was --

Eric: He was swollen.

Hannah: -- very swollen and that Boppy pillow we had bought and because he had been doing better. So we were practicing, you know having him sit up and we walked in and yeah the CPAP was just you know kind of -- I mean it wasn't -- it is not a violent machine but it felt that way.

Eric: Like the one that he had, it covers the face, it's very intense looking and Sage just -- he didn't look like himself at all.

Hannah: Yeah.

Eric: The spirit energy wasn't there and he was -- something had happened overnight and he -- it was just clear -- I am not even sure if we spoke words about it.

Hannah: And I -- yeah we did. I mean I remember speaking them. I feel like I kind of had to, as his mom. You know what time mean? Like we needed to and we said it and it was in the morning and then it just very quickly changed and the nurses and they came in and you know for the first time the monitor was shut off, which was very jarring. I think that Eric and I had become very accustomed to looking up at it and checking his vitals.

Eric: Yeah.

Hannah: And they turned it to look at the window and I thought and I think about it still just how kind of symbolic that was. Like even the screen that had been tending to our son couldn't really look at what was happening to him and but we walked in and we knew -- just like we knew that like the surgeries that we were entrusting him to were going to help him you know we had been given the final analysis by -- I mean it was the whole team, the epileptologist, the nurse and even Dr. Orbach agreed. And --

Eric: Yeah.

Hannah: That you really be -- it wasn't a matter of saving him any longer, so when we had that definitively, we knew we had done everything for him. His body was being pushed far past what it should have for an infant and because that's what he was. You know he was still a newborn and so we played music.

Eric: We removed all of his equipment.

Hannah: We held him and we just let him go. We told him it was okay and we loved him and --

Eric: Yeah, we held him all day.

Hannah: Yeah.

Eric: And I played the song for him and you know and that was really, aside from the day he was born that was really the first time that we had been able to hold him without you know being worried that we were going to pull out an IV or having all these wires and needing multiple people to kind of help him --

Hannah: Yeah.

Eric: -- be in our arms. We sat together in a chair, I mean you know --

Hannah: Yeah we squeezed into an armchair.

Eric: -- all the way like this and he was there with us and we passed him back and forth and it took hours --

Hannah: Yeah.

Eric: **--** it took hours and I remember whispering to him that it was okay for him to go, that we loved him and yeah I mean we surrounded him with as much love as we could possibly muster.

Hannah: Yeah. And I think -- I think that he consciously, again it's hard, right? It's such a deeply unique experience and he was a baby and I think Eric and I really tried to make sure that he never felt fear from us. Throughout the entire experience, we wanted him to just know love. Even when we were holding him and so even in his death, I think one of the things that Eric and I discovered is that it didn't matter so much how they die as well and it's so hard to be present with it and to know what's happening and allow it. I think that was really and like -- it made me feel a little bit crazy while it was happening to be holding him and knowing

	what his body was doing, the body that I birthed only a few months prior. And -- **Eric:** And I think we loved -- **Hannah:** And we loved -- we loved him but I think the fact that he looked different, he had -- he had suffered and he had been through so much. And that was -- it was just, by far the most loving thing that I think Eric and I could have done was to understand in that moment. Nobody told us and it wasn't during a surgery, it wasn't apart from us. It was by our own understanding and intuition and it was right. And it's a gift that Eric and I know we gave him and we carry that with us, absolutely, and I think that's one of the things that, I think contributed to our healing immensely. You know what I mean? It's been, we knew, and we've we carry that, we know that it was right, despite how wrong it was.
12	TITLE: *Leaving the hospital after he died: It was unbearable.* https://courageousparentsnetwork.org/videos/leaving-the-hospital-after-he-died-it-was-unbearable/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk about how brutal it was to exit into the real world after he died; how isolated and alone they felt; only the people who had been with them in the NICU understood. "It is hard to know what our place is now." Transcript: **Hannah**: I remember we were in the elevator riding down and I had the baby seat in my hand and it was empty and I was just crying quietly and there was a mom in the elevator with me and she had twins and she just said to me, you know she kind of whispered like -- something like "It's okay," like you know like "your baby is going to come home soon." And she had no idea. I think Eric and I exited into a world that was just so foreign and so different and only the doctors and nurses knew and it was really, at first, unbearable to be around because even in the hospital -- even that mom couldn't conceive the fact that I was leaving because my baby was gone. You know it's just -- it goes against the narrative so profoundly. And when we left the hospital, Eric and I felt and we literally like we were in the room holding our son's body, we left him and then we were just out in the city streets and it was I wanted to walk in the traffic. You know what I mean? **Eric:** We both did --

	Hannah: Yeah. **Eric:** I mean you're leaving your child. You are leaving all of these people who really, we were so close to him in a way that it was just not like any other relationship you could form with somebody. **Hannah:** Right. And so -- **Eric:** You know there are these really there are these deep and quick bonds that you form in there, so much trust and so there are so many -- **Hannah:** Yeah. **Eric:** -- emotions wrapped into your relationship with people out of caring for your child and a lot of what Hannah has described and it came from Sage too. **Hannah:** Yeah, absolutely. **Eric:** It was -- it was more than just us being you know involved. **Hannah:** Yeah. **Eric:** Sage made these connections with people. People cared for him, totally separate from us. **Hannah:** Totally. Well I mean that, we are so happy for that. **Eric:** Yeah, it was amazing. **Hannah:** I mean he, he was -- he was his own evolved person. It's really wild to think about but -- that's again what I think adds to that conviction like we didn't leave the hospital -- I mean yeah the world feels pretty bankrupt sometimes and it's been hard to know what our place is as a mother and I felt like there is no ground to stand on and that's really hard.
13	TITLE: *Something broke inside of me when he died.* https://courageousparentsnetwork.org/videos/something-broke-inside-of-me-when-he-died/ Description: The bereaved parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk about how they think of, hold, and cope with their loss. "You have to be present in the room and experience your child actually dying to understand that

feeling but you do lose a very large part of your sense of self and safety and understanding of just who you are in the world and I think even lost in the sense of understanding what the world is because a lot of that has been thrown into question for us."

Transcript:
Hannah: Sage was, and is, the most important person and force in our life. And he has changed everything for us. And losing him has kind of even more so changed the trajectory of our life, so we're fairly new in our bereavement and we lost Sage three years ago but he -- his presence is felt and known pretty thoroughly by us and most of the people that knew him loved him.

I do very much think of it as a loss because there was something that intrinsically broke inside of me when he died. And even though his spirit, Eric and I can -- we can find it, we can perceive it, we are still alive and at times very much so feel lost. And you have to be present in the room and experience your child actually dying to understand that feeling but you do lose a very large part of your sense of self, and safety, and understanding of just who you are in the world. I think even lost in the sense of understanding what the world is because a lot of that has been thrown into question for us.

Eric: Absolutely.

Hannah: Yeah.

Eric: I mean it is a multi-faceted type of loss and I think being present for watching your child die and helping to facilitate that especially after being in a complex situation where you are facing and trying to absorb and process and mentally and spiritually accommodate different realities in the moment. When you've gone through that so many times, despite the complexity you are bonding closer with your child in a way that I don't think -- well most people don't experience, in that regard.

Hannah: Yeah.

Eric: And I think that when you reach the end, when you realise that you are in a position where you are going to be called upon to facilitate and kind of nurture your child onward and it is a -- it's a loss in all of those definitions of what it means to be a parent up until that point. It becomes something entirely new which is continuing to change and unfold and --

Hannah: Yeah.

	Eric: -- define itself constantly but it is also a loss of self and a loss of purpose and hope and all of these sort of things that you need to redefine as well. **Hannah:** Like Eric said, a lot has been cut away. We also recognise what is really beautiful and special and it's not -- I don't know, you can't really -- you can't really attribute it to anything it just is that way. And knowing what death looks like and living it so intimately and feeling like a part of our lives has been fully consumed by it. To recognise that there is beauty and that there is love and forgiveness and goodness,it comes from somewhere.
14	TITLE: *Our son and this experience still push us to rise and be the most actualized versions of ourselves possible.* https://courageousparentsnetwork.org/videos/our-son-and-this-experience-still-push-us-to-rise-and-be-the-most-actualized-versions-of-ourselves-possible/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk about the calling (and pressure) they feel to honor and continue their son's legacy and grow as parents. "It was the most fulfilled we could have been, and not having that has been difficult, so we find new ways." Transcript: **Hannah**: Our period of time was -- it just -- it burned incredibly bright and then it -- it did end and I think that one of the things that Eric and I, we know, is that it was so fast and so long that it gives us a million different angles to kind of analyse and survey. But it's impact has been great and I don't think that -- I think there is always just something new to look at and to observe and it's -- so it's unique but it's devastating in its own way but every loss is unique and devastating. You know every child that dies is unique and their loss is devastating. So Eric and I just, I don't know, I think we -- the impact of it is just still -- it's so, kind of, burned into our eyelids, you know what I mean? **Eric:** Sure. **Hannah:** And -- **Eric:** I mean I would say that a way that it's maybe not a loss, sort of like another side to this -- **Hannah:** Yeah.

	Eric: That we are still his parents and Sage still and kind of pushes us to rise and be like most actualized versions of ourselves that we could possibly be. **Hannah:** Right. Well we have that marker. That's like one of the other things we talk about is in the moment when Sage was born, when we learned that he was sick and everything we had to get him through, we rose to these new heights that I think it was just the purest and like the most fulfilled we could have been. **Eric:** Yeah. **Hannah:** You know so having something so you know worthwhile to fight for, something that we loved so dearly and so desperately, there was no choice in it. It was just like this natural event. And so not having that has been certainly, I think in the beginning especially, was very difficult and so you find new ways
15	TITLE: *"You do learn these incredibly profound lessons and I think that we have a responsibility to share that."* https://courageousparentsnetwork.org/videos/you-do-learn-these-incredibly-profound-lessons-and-i-think-that-we-have-a-responsibility-to-share-that/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk about the sense of responsibility and energy they feel to share what they learned with others. Transcript: **Hannah:** We were so present and we just saw -- we saw the entire situation entirely and fully for what it was and that's why Sage lived as long as he did. **Eric:** And we had to guide him in a lot of instances as well. **Hannah:** Right and I think that in retrospect, it left us, there was no guilt, there was no regret and I think those were two things we didn't have to carry and never have to carry. And I think that part of the reason why Eric and I do feel so strongly about speaking about it and sharing Sage's story is, one, when you do have a child who is extremely rare, you know Sage's story is then, it's influencing the way that doctors are treating AVM patients and just because Sage, he was this beautiful anomaly and that's what we are kind of left with. So we have to discuss it

	because that’s what’s happening and but also because you do learn these incredibly profound lessons that you wouldn’t have learned otherwise, and I think that we have a responsibility to share that and we don’t bear the burden of guilt or regret. And so there is nothing wrong that you can find. You know I mean? Like the very nature of your child’s death is wrong and I feel that, we feel that. **Eric:** Every day **Hannh:** As a mother, I mean I had given birth, like I needed him. I needed my child in a way that’s hard to speak about but I don’t have him. And I’ll never have him, and that is something that Eric and I can’t sit still with. We couldn’t just sit still in the hospital, we were active. We did everything we could, and what we found is that after your child dies, that continues. It’s even harder to stay still.
16	TITLE: *“It’s a deep wisdom you come away with at the cost of extreme suffering.”* https://courageousparentsnetwork.org/videos/its-a-deep-wisdom-you-come-away-with-at-the-cost-of-extreme-suffering/ Description: Bereaved parents of a baby who died at age 3 months (from AVM) talk honestly but gently about the profound lessons they've learned from their experience, their grief, and how they struggle with all of that. "For families like ours, who’ve watched your child die, it just opens up a world that’s intricately and infinitely more complicated than we could have anticipated and we knew we were embarking on that when Sage got the diagnosis." It comes down to the question of "What do you do?" Transcript: **Eric:** I think our ability to not have regret comes from us making decisions from love and not out of fear, despite the circumstances. **Hannah:** It’s hard though because what we are able to walk away with, we still feel in some ways we know how futile it is to try and fight things you can’t control, you know? So some of these lessons that you learn from you know it’s like a deep wisdom you come away with at the cost of extreme suffering but you can’t teach it to anyone really. You struggle to understand it I think probably for the rest of your life. And in some ways like if anything we’re just we are more and more aware of how hard life is and how unfair and all but if you add it to we want to put in there, in some ways like it doesn’t get easier by any means and I don’t want to sound you know terribly negative but it doesn’t get easier. You still have to live your life, you still have to pay your bills, you still have to

	work and take care of your children and each other and yourself which was definitely hard at first. When the thing that you love, which you should love, -- you know your child is by far the most important and pure thing and children, no one can negate that or debate that and for families like ours, who've watched your child die, it just opens up a world that's intricately and infinitely more complicated than we could have anticipated, and we knew we were embarking on that when Sage got the diagnosis. And we knew when he was dying that we were already on our way and that it was even more unpredictable and unknown but I can't say that we've landed on a shore, by any means we are still you know we are out there. But we know you know we have the wisdom, we know a lot but again it comes back to that question of what do you do, you know? I think that Eric and I like to do things, we want to -- we are aware of the fact that every human being should be concerned with the suffering of others and should be grateful for what we are given because life is precious and beautiful. And that's I think the startling thing is I thought that at first that I would come away with this and just see only ugly things and it's really the opposite. I mean Sage's beauty and his life has taught us beauty and that's what makes it so hard. So then you are aware of all of the problems that exist in it. In some ways like there is a part of me that feels incapacitated by all that knowledge, but at the same time, I'm not -- I am not the person that I was before Sage. You know Sage's death it, in some ways I think it's freed both of us quite a bit but it has also damaged us quite a bit, because how could it not. And we are present with that every day and it's, yeah you were kind of tending to your own wounds to an extent, so that's kind of where we live I think. And coming up with new ways of finding and expressing beauty and helping other people and trying to feel as fulfilled as possible because we have more to fill, certainly.
17	TITLE: *Bereavement: This is very isolating. You don't wake up and forget. We are holding on to what we know.* https://courageousparentsnetwork.org/videos/bereavement-this-is-very-isolating-you-dont-wake-up-and-forget-we-are-holding-on-to-what-we-know/ Description: Bereaved parents of a 3-month old who died in the NICU speak eloquently about grieving - "In terms of how society works, what the norms are, you view things as you put in the work, you yield the reward. And for families like us, we don't and it's such a conundrum, it's such a deeply unsettling thing that makes no sense that children suffer, that they die, that people just cast it out of thought. And we don't have that luxury because we are still living with the impact of it. You don't wake up and forget."

	Transcript: Hannah: We fought hard for our son -- we, our love, I think but what we succeeded in was we showed the staff how much we loved Sage and they loved him because of the example that we set. We gave others an understanding of who we are by loving Sage and that is -- it is powerful and it lasts far beyond death. And I think the thing is like whatever we feel is true because it did happen, and we know that. And we lost in the end, right? Like in terms of how, you know, society or what the norms are, you view things as you put in the work, you yield the reward. And for families like us, we don't. It's such a conundrum, it's such a deeply unsettling thing that makes no sense that children suffer, that they die, that people just cast it out of thought and we don't have that luxury because we are still living with the impact of it. You can't interpret the loss of your child as if you've done something wrong. It's not karma, it's not anything that they deserved or you did wrong. The human body is fragile and life is very fragile and I think that Eric and I have struggled to kind of know what's what. You know parenting Gabriel and having there, be it so many gray areas and not a lot of people can really guide us and it's been hard. It's been very isolating but at the same time it grows a truth so deep inside of you that like it shouts out louder than anything that anyone else could say to you. And it comes from parenting, and it comes from love and it comes from giving yourself to something greater. And I don't wish any of what's happened to us on anyone and I think that it -- it's a forever devastation. You can't rebuild on those foundations, you can absolutely find more beauty and you can absolutely move forward with tenacity and conviction, but you don't rebuild. You know what I mean? I think people kind of misunderstand like you don't wake up and forget in the morning that your child died when you were holding them and you felt their life slip away.
18	TITLE: *To pediatric providers: "There is no way to make child death easier but there is a way to help parents feel more supported."* https://courageousparentsnetwork.org/videos/to-pediatric-providers-there-is-no-way-to-make-child-death-easier-but-there-is-a-way-to-help-parents-feel-more-supported/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, speak honestly about how difficult grief is -- "We've been just like crawling on our hands and knees, trying to get back up to like walking position. It's a lot to carry all the time." -- and how people need to be taught how to talk about grief, child loss. There is so much we can learn from each other by having the conversation.

	Transcript: **Hannah:** The doors don't just swing open, you know it's not like your life just flows forward. I think that's the thing too that was really surprising was Eric and I felt that we've been just like crawling on our hands and knees, trying to get back up to like walking position. You know it's not -- it doesn't -- it's not easy and you do have to grapple with a myriad of emotions but also just like the reality of your day, you know? Which can be infinitely as daunting and yeah there is definitely anxiety, you know? You can't really control any of that stuff, so you just have to carry all of it. And it's a lot to carry all the time. **Eric:** I think that our goal in terms of being able to help is having a unique perspective of what this experience is like. You know, being parents who have been through it, we've been through everything that occurred through Sage's life, in facilitating and in helping him die. I think that there is so much that occurs at that moment that needs to be talked about and discussed and taught throughout healthcare and just in society in general. I think that, you know, people don't, no one talks about it and nobody really understands, and even for us you know to talk to you or anybody else who has had your own experience there is still -- there are differences there. There is so much -- there is so much that we can learn from each other in having that conversation. And I think that healthcare providers generally, I think they need to have that with them even from the very beginning of their training. They need to have an awareness that this does happen, that families are going to experience this and that there is really, everyone is going to process and handle that differently. You know there is no way to really make it easier, but there is a way to make people feel supported and help people feel like they are capable of doing it and help people know that they are doing what needs to be done as a parent.
19	TITLE: *When our child is about to pass away, we know we are about to plunge over that cliff* https://courageousparentsnetwork.org/videos/when-our-child-is-about-to-pass-away-we-know-we-are-about-to-plunge-over-that-cliff/ Description: Bereaved parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months speak gently about knowing they need to keep going. "You still need to live." Transcript: **Hannah:** When our child is about to pass away, we know that you are about to plunge over that cliff. You have no idea what to expect. You don't know what each day from that point forward is going to feel like

	but you still have to live. I mean that's really the truth, right? Like all of us parents, we still have to live. We still have a responsibility and if you hold life sacred, you want to do it well, and death teaches you that life is sacred. So therefore you must do it well. **Eric:** Right. **Hannah:** And I think that's the legacy that Sage left us and we hope that we are living it because speaking about it, those opportunities don't come often but it also, in some ways like it is how you live and it is the acts of compassion and kindness that you put forth and -- **Eric:** Right, even in the smallest ways. **Hannah:** Absolutely.
20	TITLE: *Parents worry about the impact of child death on the staff* https://courageousparentsnetwork.org/videos/parents-worry-about-the-impact-of-child-death-on-the-staff/ Description:NICU parents whose baby son has died express their wish that providers had been better able to sit with them in their grief, and they also acknowledge that the hospital environment and intensity makes it very very hard on providers. Transcript: **Eric:** And I think the providers are, they are up against a lot, you know? I mean in retrospect I mean when you learn about how the hospital operates and you think about Sage's team members who were with us but also with you know some number of other families, and because they know they haven't had the proper or extensive enough training to really be able to understand, because it's not a part of how they are taught to be caregivers. They are up against a lot to try and be that fully for all of their patients. **Hannah:** Yeah. **Eric:** And I think -- yeah I think it is true. I think in some regards it's too hard, and you know we also think about the fact that when we left the hospital there was another patient in Sage's room probably the next day. And some of those nurses and doctors were with us where just right back into it with a new patient. **Hannah:** Yeah.

	Eric: So they are also not -- there is no way that they have enough time to process everything that they are going through. And there needs to be -- that somehow needs to change.
21	Title: *Hospitals need to be more active in how they support bereaved parents. "We are a gold mine of energy and love if given a chance."* https://courageousparentsnetwork.org/videos/hospitals-need-to-be-more-active-in-how-they-support-bereaved-parents-we-are-a-gold-mine-of-energy-and-love-if-given-a-chance/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, encourage medical institutions to do more where the community does little. "We are a gold mine of energy and love if given a chance. We all want to parent our kids more. There is so much truth that we have." They encourage providers to learn how to talk about death both before and after the child dies -- that is a gap that can be filled. Transcript: **Hannah**: For families of children with medical and complex needs, it's too much to expect the community to shoulder the role of caring for these families. I think that the medical institution needs to be active in how they support bereaved families after a child dies. I don't think that society is evolved enough yet to even really begin to do that and the reason why is because, as you know, we are a gold mine of energy and love and action, if given the chance, right? Like we all want to parent our kids still and there is so much truth that we have that we know but it's hard to, at least for us, you know it's been hard for us to find any place to kind of share it or break through you know? And so I think exactly, so I think that's why we are here and I also think that you know we found that a lot of the providers didn't know how to talk about death, and Eric and I feel that it is an incredibly sacred and important thing and it's not just going to occur at the end of someone's life, aged 70, 80, 90, 100. You know Sage lived his full life expectancy by three months; he had lived a full lifetime of treatment essentially. It was just sped up to a comedy, his rapidly deteriorating condition and we recognise that. I don't think that Eric and I, I mean of course to an extent we mourn what could have been, you know and I wonder what Sage would be like if he was here and I ache for him every day but I fully recognise and accept his death. And that's come at a lot of very deep and private introspection which I think every parent needs to do, but I also think that our situation would have been easier had we had some community support to fall on, especially with Gabriel and -- **Eric:** Yeah.

	Hannah: -- there is just, it doesn't really exist yet. And that's kind of what we found with Sage, right? Sage's condition was at the forefront, medicine wasn't fully able and we accept that, right? That's the limitation of being human, but we also -- we do see that as like if there is a hole that can be patched, I think it's that. I think that institutions need to take a much deeper look on how people that are dying are cared for specifically children and also caring for the families, exactly.
22	TITLE: *Sibling illness and death: Parents on how they support their older son who has autism* https://courageousparentsnetwork.org/videos/sibling-illness-and-death-parents-on-how-they-support-their-older-son-who-has-autism/ Description: Parents of a baby son who was born with Arteriovenous Malformation (AVM) and died at age 3 months, talk about they supported their older son who has autism - during the NICU hospitalization and through bereavement - utilizing child-life, keeping a schedule, processing death and loss. "Being Gabriel's parents prepared us immensely to be Sage's parents and it has aided us in understanding grief. I do feel like we've aged an extraordinary amount." Transcript: **Eric**: So, Gabriel has autism. So we spent the majority of pregnancy really preparing him, which he took to beyond our expectations I think. Gabe was really prepared to be a brother and we really, really as a family you know nurtured that and really made sure that he was ready, which he was. He was really excited, but all those preparations were really for us to be out of the home for about a day. You know the plan was we were going to go, have Sage, I would come back the next day and bring him in to meet his brother, we would you know, wait a day or two and then we all would come home. And that was really -- that took months and months of preparation to get that plan and have him feel okay. And in the immediate you know when everything began to first unravel and we were learning about Sage's condition, Gabe was with Hannah's brother who actually was, you know, cared for Gabriel throughout most of Sage's life. And you know we face-timed with Gabe constantly and he actually did come to visit Sage quite a few times in the hospital and you know which just speaks and meant save his bravery but -- **Hannah:** He was very anxious. **Eric:** And there is no way to really explain what was happening.

Hannah: Yeah.

Eric: And his -- he would always ask when's Sage coming home.

Hannah: Yeah.

Eric: And our answer was usually, "Soon or we're not sure." Like you know there is no way to -- if we were able to be with him fully or have him with us in the hospital I think we would have wanted to give more information but because we couldn't be there to help him with whatever information we would be giving, it just didn't seem right at all.

Hannah: Yeah.

Eric: And he was really nervous and I think our goal was to really -- to just make sure that Gabriel was with people that were going to be able to support him.

Hannah: Yeah.

Eric: In the best ways because Gabe lives a life that is based on routines and --

Hannah: Yeah, it's really ironic.

Eric: And Hannah and I --

Hannah: It's -- I mean it's like stunningly ironic.

Eric: Yeah.

Hannah: And very sad but, and Gabriel, he does very much focus on what's expected and has a very hard time inferring or anticipating change which is -- you know it's kind of like the hallmark of autism so it adds a layer to it that is incredibly hard to explain. Gabriel was very well cared for while Sage was in the hospital but you know when Gabriel would come, we utilised child life help and we did music therapy, we did a lot. We -- you know Children's has wonderful services for family members.

Eric: Yeah.

Hannah: Which we utilised and Gabriel and I think he connected with it as much as he could but that has been extraordinarily difficult. There are really not a lot of people that can really relate to autism and bereavement. Eric and I have found that that's just kind of an unbridgeable chasm.

Gabriel is really high functioning but he is very anxious and has a very hard time expressing what his body feels like. And adding in death to the equation has just totally upended his world. And how he processes things, it's kind of an enigma, certain things kind of arise and you can't -- they are sometimes unexpected, sometimes it just takes him a very long time, but there has been a ton of change. There has been a ton of emotion around him. You know and he -- he is this amazing kid whose baby brother died and you know a lot of people can't talk about it, and so there is like this thing that's happened -- there is not a lot of you know reflection of that in his world, and it confuses him, like it confuses us but it's hard. To be honest with you though, I and this is something that Eric and I, it's another reason why I think we've been given the chance to speak is because we understand when Gabriel was diagnosed with autism, you have to approach it differently. Your expectations for what, for how they operate, for what their mind is capable of, for what they are capable of, and what their needs are, it's different. It's just inherently different and you have to be clued in. So having Gabriel, we felt really prepared us for Sage, we felt like it all made sense when Sage got diagnosed because we had been through everything with Gabriel and all of it was just like, "Yes, okay, we are going to."

Eric: We already had a different view of the world.

Hannah: We have like a taste of it, right? And we did -- we had a very different view of the world. So I think in some ways, being Gabriel's parents -- being Gabriel's mother prepared us immensely to be Sage's patents and it has aided us and in understanding grief. I do think it's made it at times a lot more isolating because the need is always there, you know you can't -- there aren't really breaks that come from being a parent to a kiddo with autism, so I do feel like we've aged an extraordinary amount in the past three years. And it's hard, you can't -- it's always there, lingering. There is a lot of anxiety and fear. Gabriel isn't ready to understand all of what death is. He hasn't really asked a ton of questions. I do think it does scare him --

Eric: Yeah.

Hannah: -- quite a bit.

Eric: I think it's really infiltrated everything. I think that Sage's death combined with just mom and dad being in the hospital and away from him.

	Hannah: Yeah. **Eric:** Having this prolonged time of abrupt change with no real set endpoint and not a lot of information, I think really wiped out a lot of the foundations that he had obviously worked very hard to construct. And you know which -- **Hannah:** I mean all of us have been working to construct it, so I think our whole family foundation -- **Eric:** Yeah. **Hannah:** -- really got hit pretty hard but Gabriel is resilient.
23	TITLE: *Eric & Hannah: Being Sage's parents then and now. Sage's story.* https://courageousparentsnetwork.org/videos/eric-hannah-being-sages-parents-then-and-now-sages-story/ Description: Hannah and Eric, parents of baby Sage who was born with Arteriovenous Malformation (AVM), had 5 brain surgeries, and died at age 3 months, share Sage's story and how they are finding their way after this death. Transcript: **Eric:** This is one of our favourite pictures of Sage. And this is actually towards the end of his life. **Hannah:** Yeah. **Eric:** This is after his final procedure that he would have which was to put in this -- this shunt here, but he was really, he had this period of time a few weeks before he died where he was just extraordinarily animated and we -- you know we like to say that he was like seeing angels or he just had this -- there was this magical quality that took over in that period of time. **Hannah:** There’s something victorious about this photograph. **Eric:** If sharing anything about ourselves and about our children can have an impact on somebody who is in the position that we were in previously, then that is exactly what we need to do.

Hannah: I'm Hannah Schermerhorn, Sage's mom. Sage was, and is, the most important person and force in our life, he has changed everything for us. When Sage was born we noticed that his head was a little bit larger, and we also noticed that he was a little dusty. He was a little purplish in his hue. There were some breathing issues, but nobody seemed concerned. We were about to be discharged and he had a full blown seizure and he coded. So I just, they pushed me into a rocking chair and I just sat, and she called for doctors and you know, the alarm sounded, and within a few minutes, there were about nine, 10 people just kind of going crazy and Susan, that was the name of this nurse, completely saved his life. And she came and she said you know, "Hannah it's really serious."

That evening we sat down with the Head of the NICU Department and they told us that Sage was born with a massive Arteriovenous Malformation which had completely consumed the left hemisphere of his brain. So all the tissues destroyed and hundreds and hundreds if not potentially thousands of arteries had grown and just kind of taken over the tissue. There were no capillaries, so all the blood that was going to this region was just wasted.

Eric: We had a very honest and difficult conversation with the head of cardiology and the neonatologist and they basically said you know, "We can manage the symptoms, we don't know for how long." I think they gave him about two weeks, minimum.

Hannah: At Children's he had an eight hour brain embolization. Because, the diagnosis -- nobody knew what was going to happen and how it was going to unfold. I think what I struggled with was, not that I was trying so hard but that Sage was losing so much and that he was suffering so much. He lost movement, he began to lose sight, he began to lose hearing, he lost the ability to swallow, he and he just continued losing and it wasn't necessarily about the amount of effort we were exerting, it was just about how much, he as an infant, as our baby, had to lose. And I think that's what I struggled with a lot. I thought there was kind of an edge to suffering.

Sage had 5 brain surgeries in 3 months

Hannah: It wasn't the body that I, you know gave birth to. It had changed dramatically and that was hard, beyond hard, to deal with. But it didn't go on for very long.

It wasn't a matter of saving him any longer, so when we had that definitively, we knew we had done everything for him. His body was being pushed far past what it should have for an infant and because that's what he was. You know he was still a newborn and so we played music.

Eric: We removed all of his equipment.

Hannah: We held him and we just let him go. We told him it was okay and we loved him and --

Eric: Yeah, we held him all day.

Hannah: Yeah.

Eric: And I played the song for him and you know and that was really, aside from the day he was born that was really the first time that we had been able to hold him without you know being worried that we were going to pull out an IV or having all these wires and needing multiple people to kind of help him --

Hannah: Yeah.

Eric: -- be in our arms. We sat together in a chair, I mean you know --

Hannah: Yeah we squeezed into an armchair.

Eric: -- all the way like this and he was there with us and we passed him back and forth and it took hours --

Hannah: Yeah.

Eric: -- it took hours and I remember whispering to him that it was okay for him to go, that we loved him and yeah I mean we surrounded him with as much love as we could possibly muster.

Hannah: It was just, by far the most loving thing that I think Eric and I could have done was to understand in that moment. Nobody told us and it wasn't during a surgery, it wasn't apart from us. It was by our own understanding and intuition and it was right. And it's a gift that Eric and I know we gave him and we carry that with us, absolutely, and I think that's one of the things that, I think, contributed to our healing immensely. You know what I mean? It's been, we knew, and we carry that, we know that it was right, despite how wrong it was.

I do very much think of it as a loss because there was something that intrinsically broke inside of me when he died. And even though his spirit, Eric and I can -- we can find it, we can perceive it, we are still alive and at times very much so feel lost. And you have to be present in the room and experience your child actually dying to understand that feeling but you do lose a very large part of your sense of self, and safety, and understanding of just who you are in the world. I think even lost in the sense of understanding what the world is because a lot of that has been thrown into question for us.

I mean I had given birth, like I needed him. I needed my child in a way that's hard to speak about but I don't have him. And I'll never have him and that is something that Eric and I can't sit still with. We couldn't just sit still in the hospital, we were active. We did everything we could, and what we found is that after your child dies, that continues. It's even harder to stay still.

I can't say that we've landed on a shore, by any means we are still you know we are out there. But again, it comes back to that question of what do you do, you know? I think that Eric and I like, we want to do things, we want to, we are aware of the fact that every human being should be concerned with the suffering of others, and should be grateful for what we are given because life is precious and beautiful. And that's I think the startling thing is I thought that at first that I would come away with this and just see only ugly things and it's really the opposite. I mean Sage's beauty and his life has taught us beauty and that's what makes it so hard. I am not the person that I was before Sage. You know Sage's death it, in some ways I think it's freed both of us quite a bit but it has also damaged us quite a bit, because how could it not.

You still have to live. I mean that's really the truth, right? Like all of us parents, we still have to live. We still have a responsibility and if you hold life sacred, you want to do it well, and death teaches you that life is sacred. So therefore you must do it well.

Eric: Right.

Hannah: And I think that's the legacy that Sage left us and we hope that we are living it.