JERRIS AND BOB MACAULEY

Lower Thirds

Jerris

Father of Faith

Faith had Osteosarcoma with multiple complications. She died at age 18

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| 1 | Title: “*Once you established trust with Faith, and respected her, she would do anything for you.”* The father of a young woman who was diagnosed with Osteosarcoma at age 5 and died at age 18 from complications from years of treatment, describes the courage and strength of his daughter and how she responded to people she felt she could trust.<https://youtu.be/2pF60mbkc5g>TC: 00:10Jerris: It was just a really complicated journey. And what was such an amazing thing to witness was this transformation from this cute but bratty little kid to this -- she literally transformed and she became this incredibly mature individual, and we heard that from all different care providers that at that point for five years old she was so connected to her treatment and what she wanted, what she didn't want, she was very clear on who she trusted, who she didn't trust, and we saw this fiery spirit of hers shift from fighting us on rules and behavior to quite literally fighting for her life. And she refused -- even at five years old she didn't want to work [0:01:00:07] with physical therapists. She didn't trust them. So she trusted me and so I would work with the physical therapist on her different procedures, learn what they wanted to do. They would supervise, but she would work only with me. And so I learned, quickly learned that with Faith once you establish trust and if you respected her, even at a very young age, she would do anything in the world for you. She could have major back surgery and I could have her up walking the very next day. And she would do it and she would cry and she would push, but that strength went from fighting rules to truly fighting for her life and then that continued to transcend for the next 13 or so years as she continued to be plagued with many, many major medical challenges as a result of her treatment. The cancer, we killed the cancer but the treatments between the chemo, the radiation, and 23 major surgeries end up killing her body. [0:02:00:05] And yet this beauty that we saw transition and transform as basically kind of an infant, it just carried on and continued to occur that through these surgeries, through these procedures, and through all the setbacks she had physically, it hit her so hard emotionally and yet her bravery, her strength just was compounded. Her maturity and understanding her life situation and how she interacted with providers would just continue to grow. And her kindness and compassion, she'd be sitting there in major pain and yet would actually grab the hand of a provider, a nurse, a doctor who was clearly upset and she would face moment of pain would actually grab them and say, are you okay? I'm sorry, I'm upsetting you, and that was Faith. [0:03:00:04] She was a special soul. There's just -- there's no other way around it. I heard it too many times from too many different people that had very brief interactions that she was just a very special, uniquely gifted individual and be able to feel empathy for others in her darkest moments. Her mom and I -- her family, the whole family, sorry, would see her. She had many physical challenges and yet she was still trying to live a normal life. It was amazing to see our torrential downpour of rains in Oregon. She would get out of her car when she was driving and her back hurt, her legs hurt, her hip hurt. She was always [0:04:00:05] out of balance because she had different strengths in her legs. And here it is pouring down rain and there's Faith walking across the parking lot and she is picking up worms and removing them from drowning in the water to put them in the dirt so they can continue to live. And she was always putting other people first regardless of her challenges. That's Faith. |
| 2 | Title: *Osteosarcoma in an adolescent and ‘Total Pain’: There were all these compounding issues.* The father of a young woman who was diagnosed with Osteosarcoma at age 5 and died at age 18 from complications from years of treatment, speaks honestly about the ways the treatments’ side effects impacted her sense of identity and how too many clinicians dismissed the physical and spiritual pain she was experiencing. Her palliative care doctor speaks of the obligation providers have to listen even when they can’t explain what’s going on. <https://youtu.be/OsPjczrScpk>TC: 13:50so these were just all compounding physical issues. And then imagine when we think about the challenges that our youth have today in body image [0:14:00:05] and that's both male and female, but let's just focus on female. And you have a young girl going through her adolescence going into her teen years with body image and especially today with all the social platforms around all these young girls her age that are posting videos around dancing and fitness and all of her siblings were all very strong, competitive athletes, and Faith tried, she tried so hard but she couldn't run well. So all these things were going on around life that she was trying to live, but yet emotionally she was being told all the time she couldn't do it because her body couldn't do it. Her will wanted to, highly intelligent, but her body could not keep up. So then as we were trying to treat all these different issues she would go to for different providers. And I remember one specifically, when Faith was talking about the pain she had at night and needing assistance to sleep because she wasn't sleeping and he truly just diminish her and said, well, you probably just spend [0:15:00:04] too much time on your phone, here is a book to read and a book to read around sleep cleansing and how to prepare for bed and all this meanwhile she's writing and paint at night. And there's multiple situations where Faith would go to providers and even with what ended up taking her from us is heart failure and yet just a year before we had met with cardiologists and they were completely saying, oh, you're fine. The lightheadedness, you're fine, the queasy feelings, out of balance, you're okay, and continue to be basically put off, and she would do her part to try to do good self-care. She was extremely healthy on her eating, she would try to work out, and yet when she would go to different providers to get help quite often she was literally dismissed as it not being real. It's in her head. It’s psychological, [0:16:00:05] which probably at some point begin to become some of that as well, but it wasn't the core, it wasn't the root. And what we struggled with, both her mom and I and Faith was to get people to actually invest the time to go through the symptoms to get to the root causes of what was actually triggering some of her symptoms and her problems. And we just felt like so often we would get no call back from people for weeks and months and sometimes they just won't even call back or we would get past from provider to provider, oh well, it’s not really -- I should probably should go over here another three months waiting to get in. And this happened repetitively to the point where she -- especially she became 16, 17 we started seeing more of that teen spirit come out of basically eff them, they don't even believe me. She was getting more and more angry because people did not listen and would not care. And people would say -- the first thing people would always say with her you are so [0:17:00:08] complicated, and that would immediately make her feel like here I am a problem again. It made her mad, it made her mom and I mad because she wasn't complicated, she was Faith and her spirit was such that how can you dismiss this person who has actually been through so much more than most people will ever face in their life and she's still smiling, she's still trying, she's trying to live a normal life, and then you diminish her immediately as soon as she walks in the door. It was just so angry to see and experience. And you have to find this balance as her advocate that you need to continue to advocate and escalate in a way that you get the right attention without alienating the providers and then you're just passed along and ignored.**Bob Macauley:** So when I hear Jerris talk about being Faith’s advocate, her dad and her advocate, I've heard stories like this before [0:19:00:15] where people in my role have questioned and doubted and said stuff like, well, you shouldn't be in this much pain with the sort of unspoken end of the sentence being thus you are not as opposed to I just don't understand because it's a hard thing for physicians to say. And I think that’s one thing we do in palliative care, we recognize that pain is what a patient says it is, in the way they say it is. And also we thought a lot in palliative care about total pain, that it’s not just nerve endings and a physical part of your body, it's what your life is doing and what your soul is doing. And it does feel to me like Faith was getting hit from every single side. She was dealing with cancer, she was dealing with growing up in a culture of that [0:20:00:04] had expectations and fighting valiantly to achieve so many things despite all the obstacles she was facing. And then to go to people who were expected and should be supportive of her and should seek to understand her and should seek to help her and then questioning what the legitimacy of what her experience was both with regard to cancer and pain and other areas as well. That was a time when people should have rallied around her as opposed to giving her more things to overcome when we should be taking down the obstacles, not building them up. That infuriated me. And it wasn't because people weren't trying. I don't mean to cast aspersions. I just think that we as physicians sometimes that we can't explain something [0:21:00:05], it's hard for us to say I don't understand as opposed to attempting to say, well, that must not be the case because there's no explanation for it. |
| 3 | Title: *“We were trying to prepare her for becoming her own advocate. You need to be forthright.”*<https://youtu.be/iynuXco8gHk>The father of a young woman who was diagnosed with Osteosarcoma at age 5 and died at age 18 from complications from years of treatment, describes how he and his daughter became a team navigating relationships with her providers. TC: 27:30Jerris: She truly was just such a kind person that even when people made her mad she would express it to me or her mom but she wouldn't express it to them because she didn't -- she would say I don’t want to hurt their feelings, I don't want to be mean to them. So she would vent through us, but then she would show up. [0:28:00:04] She was golden. She was so kind. And there'd be a few situations where she would tell providers, I don't feel like you're listening to me, you're ignoring me, you're ignoring what I'm saying, I need you to hear me. And that was more as she got into her older teens that she learned to express her way. But we would coach her that way too, you need to advocate for yourself as you're getting older. Her mom and I would try to prepare her, obviously, not knowing that we're going to lose her at 18, we're trying to prepare her for becoming her own advocate and we would share with her, you have to stand the ground, you can't always be nice. You don't need to be mean but you do need to be forthright, and she demonstrated that very well. What was -- I don’t know if this sounds right. But what was fun is Faith and I developed such a connection to where when she was kind of like done with a provider, whether it was a nurse or a doctor, she was just fed up all she had to do was give me a look and I knew and I would remove them, [0:29:00:07]. And there would be situations like I would walk into a room and I've been out for whatever reason and somebody was bothering her, pestering her, whatever and she didn't want it at that time, soon as I walked in there was just this one look, she would just look at me and I just knew I'd say, okay, you're done and move them. And it was just – it was fun in the way that we had been through so much together that there was just that unspoken connection that we just knew. But that's the way I tried doing it, that's the way I think she tried doing it. And I think that kind of stepping back from an outsider point of view, I think we helped each other through that journey. I definitely learned from her. |
| 4 | Title: *“It was a journey of contradictions.” Regrets and no regrets.* The father of a young woman who was diagnosed with Osteosarcoma at age 5 and died at age 18 from complications from years of treatment, speaks with such honesty about the tradeoffs they knowingly made for daughter Faith to live as long as possible. <https://youtu.be/LfnF1cdI4uM>TC: 37:40**Jerris Marr:** In terms of regret and looking back on Faith’s journey and her view on that I would offer both her mom and I and Faith, together the three of us and then one on one we all [0:38:00:06] talked about it multiple times through the 13 years that she experienced all this. And I think that the right place to start is with her mom and I because we made the initial decisions, we made all the decisions, and when we were first diagnosed with cancer because of the nature of the location of the osteosarcoma and what we were told as standard protocol for osteosarcoma back then in 2007, which still actually blows my mind as this was the common protocol even in 2007, it sounds so Civil War-ish, was normally because it affects legs or arms, typically big bones, the common standard protocol was to go to the next joint up, amputate, chemo radiate. And that just – and I'll never forget. In September of 2007 her mom and I are at the hospital and they're telling us this is the protocol, our [0:39:00:05] minds are like how do you wrap your head around that, that's still what we're doing. We're just cutting off limbs, right? And then, of course, they went on to explain, well, we can't do that because it's in her spine and they immediately started talking palliative hospice care at that point. That was the very first direction. And that's when I told them that's unacceptable. I don't believe in can't. And we're going to come back in a week and you're going to have options for us. And so her mom and I came back up, we started talking through these options, and of course, they gave us all the warnings and when we -- and there is multiple warnings along the way, there's multiple procedures, multiple situations that were caught -- one point I remember when we were in Boston, her mom and I had to give approval for the radiation and because of the location even though it was specialized radiation where it wasn't a whole body it was very specific and [0:40:00:05] it was still going to take a chance on sterilizing her, it was going to hit her ovaries, and we had to make that decision do we save -- try to save her and prolong the life but we're going to decrease the likelihood of her being a mom. And, of course, we're going to fight for her and worry about those other consequences later. So we made multiple decisions time and time again like that, and her mom and I -- through the years we would always sit back and say should we have done that? Should we have done that? But when you're faced with the alternative, if you don't, you know the answer is she's going to die, right. And so, I can say we live with regret every day. But if we wouldn't have taken those steps we wouldn't have gotten 18 years with her. [0:41:00:04] And looking back now little bit over a year of losing her we see the pictures and the videos and the memories we have, we wouldn't have had those. We wouldn't have known the person that she grew to be. We wouldn't have been touched and quite frankly educated in the world of being able to balance both extreme strength and kindness. And that's what I see from Faith, that's what I took from Faith is this person that is stronger than I'll ever be in life and yet also a billion times kinder than I can ever begin to try to be and how do you bring those both together? We would never have experienced that journey. We wouldn't have witnessed that if we wouldn't have made those hard decisions. We would have lost her sooner. Would we have prevented years of pain and discomfort? Yeah. But we -- I think -- and this is selfish to say, but I think the loss would have been greater than the cost because the journey with Faith was so beautiful. It really [0:42:00:15] was. And Faith, there is many times that she would talk with both her mom and I and one on one and share that. There's times when she was down emotionally and she would say things that she wished that we never would have saved her, that she would have ended sooner because she was so tired of the pain, she was so tired of the journey. And she was truly afraid of growing up more and starting a life with somebody because she knew she could never have children and that wasn't because of fertility, her body couldn’t handle it. She knew that. At 15 she knew she couldn't carry a child. And she was scared about getting into a long-term relationship like a normal teenager should because she knew she couldn't offer them what they were seeking. And we all -- her mom and I just talked about this last week that we all knew she wasn't going to live a full life [0:43:00:06] but none of us really accepted that it would be this short of life either. And so we were all caught off guard, but I think Faith knew far better than we did. I think Faith really knew that she didn't think it was going to be 18 but I think she really knew that it wasn't going to be 30 either. And I think that as much as she at times regretted the journey because it was so painful and sad to her, she was sad. She was more sad than she was ever angry because she had this thirst for life and funny and witty and comical. I mean, she just wanted to live so much, and everybody she lived around and interacted with her she brought joy to them. So I think she was always caught in this battle of I wish I wouldn’t be going through it but yet I'm having these moments of fun along the way too. So I think for each of us [0:44:00:14] in our own ways it was a journey of contradictions. And even after losing her on one of my many kind of reflection points it struck me that I couldn't be mad at God, the universe or whatever that she was gone because she and I had sat multiple times in hospitals through recovery literally holding each other's hands as she prayed to be taken because she was so tired. And so how do you get mad at the universe or God or whatever for taking her when you sat with your child and praying with her that it would happen. Contradiction, the whole journey was an experience of contradiction. So it – and it doesn't change, that hasn't [0:45:00:08] changed a year later. I guess one thing that I finally settled on is after 14 months of reflection the journey both her mom and I went through watching your child go through all of this and then quite literally holding her as she died one would think that you would never do that again, right, because it's tremendously painful, but the joy of Faith, man, I'd sign up for 10 times over to get those 13 years again, those 18 years. I'd sign up again and again. It was such a gift to be her dad. She gave me far more than I could ever give her. |
| 5 | *Title: “We had a pinky promise that I would always be very honest with her. I sat on the bed and told her that she was dying.”*The father of a young woman who was diagnosed with Osteosarcoma at age 5 and died at age 18 from complications from years of treatment, speaks about how he fought to get his daughter home to die. https://youtu.be/6qAcyX75Ge4TC: 54:20**Jerris**: her mom and I were told now we have weeks, not months. And that's when the interaction with Bob and team increased and our goal moved from trying to extend her life to trying to keep her comfortable and get her home, and our mission that my feeling with the Bob. The partnership that he gave me was we were on hell-bent our mission she wasn't going to die in a hospital, wasn't going to happen. We had to get her home. And so we had to stabilizer and it took about a week. [0:55:00:05] And Bob worked with a team to help get her stabilized and get arrangements. And on Monday, January 25, 3:30 p.m. we rolled out of the hospital in the hospital -- in an ambulance, and we had to carry her in to the house. And then Bob and I stayed in contact via text and call until I lost her on February 20th.**Blyth Lord:** She got home. **Jerris Marr:** She got home. She got home. She was with her pets. She was in her bed. She was surrounded by her family, friends came by, and we -- she passed -- her birthday is February 7th, so she passed on the 20th, so 13 days later. So as a family we went back and forth, do we celebrate her birthday? Do we not celebrate her birthday? What do we do, because she knew she was dying. [0:56:00:04] When we got the news on January 16 that she had months, not years, the doctors asked, I think actually it might have been you, Bob, that asked do you want to tell her? Do you want us to tell her? And Faith and I always had a pact when she was little, we had a pinky promise that I would always be very honest with her and so it had to be me, it had to be her mom and I. So I sat on the bed and told her that she was dying. To do that as a parent. And so she knew she was going. And so by the time we got her home she knew and she -- and it was we’re just home for a short period of time, so we're weighing this notion of her birthday or not, and we knew she was also not fully aware of everything going on both because she was fading in the meds. And [0:57:00:05] her mom was very adamant we need to do this and it was -- I'm glad that she was. And we put together just a quick little family celebration and it was hard, but it was good to do. She knew she turned 18 and then we lost her a little bit later. |
| 6 | *Title: The role that a dad can play in advocacy and care for the child. “We have to create an avenue for dads.”*The father of a young woman who was diagnosed with Osteosarcoma at age 5 and died at age 18 from complications from years of treatment, observes that his daughter’s care team assumed was the lead parent, when in fact it was him; and how clinicians need to be aware of and get beyond this automatic bias.https://youtu.be/VOyPlyH3xwwTC: 58:10**Jerris Marr:** Sure. I feel there's such a strong need for the industry and for fathers, for families to understand the role that a dad can play in advocacy and care for a child. It's a choice and it's not for everybody, right. Each person deals with these types of difficulties differently and some people just can't, and I get that. But what I found and the reason why I'm so passionate about it quite frankly is in our society it's going on for years that the mom is seen as the primary caregiver, and I understand how we arrived there, but in this day and age where we're trying to [0:59:00:09] demonstrate so much more around equity and equal roles and all those, the sharing of responsibilities there's a lot of dads, not all, but there's a lot of dads out there that are very active with their kids. And you'd have to talk to each of my kids to get their view on whether they felt that I was or not but despite working a very full time career I coached all my kids, I coached ten months out of a year for 15 years. I interact with them. I didn't miss #[59:26]. My job did not prevent me from being a very engaged dad and that continued, and transcended into the care part for Faith. As we went through over surgeries I always had my laptop out, I was tracking what the care was, what the meds were, what meds we gave to counteract the side effects of other meds. I was the constant. And I participated in rounds. And I think that that's so important for fathers to hear that you have a role in this and despite societal [1:00:00:15] norms around mom does that stuff and dads are just in the background, we need to create a safe place for dads in that way and we need to start shifting the industry from a healthcare provider point of view that when you're dealing with parents in the room and both parents are there, you talk to both parents. I can't tell you how often and you can imagine through 13 years, through her complex case hundreds, thousands of doctor's appointments and providers, male and female, would shift and focus on her mom. And in many situations not all, but in many situations I had more knowledge of the background, the history, and everything on Faith than her mom did just because the natural roles we both kind of took, and her mom would say I don't know, talk to him, I don't know, talk to him. I would step out of the room to go to the bathroom, go shower, whatever, and then I would come back in [1:01:00:07] and her mom would be telling me, okay, this provider #[1:01:03] because they need to talk to you about whatever we did. And it wasn't a control thing for me, it was a natural partnership between her mom and I of where we work and yet providers struggled to comprehend that. And I heard through the time, through all these years I can't tell you how many times people say you're such a unique person. This is not common. Most dads are kind of quiet in the back of the room. I can't tell you how many times I heard dads don’t even show up and then that just even blows my mind. I wouldn't have been anywhere else. And then what was interesting is because I was so involved I would have providers ask if I was in the business, if I was somehow in the healthcare industry because they still couldn't get their head wrapped around of I was just a dad, I was just a dad. And so, to me we have to do a better job of recognizing both parents, respecting [1:02:00:05] both parents in that way including them engaging the father as much as we engage the mother, and we have to create a safe environment for dads to actually show up and then we have to give them some tools and skills on how to do so, that you can't come in and react like I shared before with the emotion of a dad, you have to react with the emotion and the logic of a caregiver. So you can't come in thumping your chest and being the biggest person in the room. You have to come in with that spirit of partnership and collaboration and seeking to understand and work through things. But we have to teach parents that, but we definitely have to create an avenue for dads in that space. |
| 7 | Title: *The MD: “There’s a temptation by clinicians to do the problem-solving with dad and provide the emotional support to the mom.”**The dad: “We paint men into a corner of being non-emotional.”*A palliative care doctor acknowledges the understandable bias that clinicians have that in a mom-dad parent group, it is typically the mom who is most at the hospital bedside; and that parents respond differently to situations based on gender – mom is more emotion-directed; dad is more problem-directed – and that really what is called for is What does this individual need from me?https://youtu.be/kx4FZU4mggETC: 1:04:10**Bob Macauley:** So I think that we're used to dealing more with moms by virtue of oftentimes, although I think I always struggle with this because it's going to come out of the gross generalization. But just in terms of probabilities it's more likely that a mom is going to be in. If it's a mom and dad parent group, then it's more common in my experience for moms to be present more frequently in the hospital. So there's that piece. And I agree with all of what you said before about not making assumptions about why that is or casting aspersions or making false assumptions eventually that the dad is not involved or the dad is not aware. So I think there is that piece. I think there are other pieces too. One is, and again, gross generalization coming. In my experience, [1:05:00:15] moms and dads often generally react differently to certain situations that -- I can't count the number of times people have said something like, dad is kind of quiet, he doesn't say much and the unspoken assumption is there's not much going on there. And I'm like, no, there is a whole lot going on there, but maybe he is just not revealing it for all the world to see in real time. Another piece too is that there is a lot of work that has been done in our field about what it means to be a good parent, asking parents what does it mean for you to be a good parent, and generally speaking, again, another generalization. They are two big groups of – I’ve thought about this. One is being a good parent is making good medical decisions on behalf of my child and the other is being a good parent is making sure my child feels loved. Those are not mutually exclusive. It's not either or there's some balance there. [1:06:00:04] But studies have also shown that that mothers tend to be in the second group and fathers tend to be in the first group, like not always. And so I think there's a temptation to sort of do the problem solving with dad and provide the emotional support to the mom. The other thing too is, and this is speaking as a male physician. I think that it is a little bit more complicated when you're dealing like, let’s say, kind of with guys. Like I'm a tall guy, I'm aware of my presence in a room, I'm aware of gender and power imbalances. And so there are female members of my team who are much more likely to go and give a mom a big hug than I am because I don't know how that's going to be received even if I feel called to that. And I think that it can be hard to know what to do with that, like what does this person need? [1:07:00:05] Do they need answers? Do they need a hug? Do they need time? Do they need someone just to give them a place in silence to honor what's going on with their family? I think that adds a whole new wrinkle and complexity that sometimes it's harder to understand what to do.**Jerris Marr:** If I could even building upon that. I agree with everything Bob said. The issue of advocacy as a father is just one component of a larger issue that in society we still paint men into a corner of being non-emotional, non-feeling, you're not allowed to, it's not safe. And while I think the tide is beginning to change in that somewhat that we're still not allowed to be who we are and feel and express what we're actually feeling. And so, again, through real experience of my journey in clinical situations whether we got bad news or we're going through a hard moment in a hospital room, [1:08:00:09] providers would turn to mom and say, how are you doing, okay, a hand on the shoulder and turn and walk out the door with no acknowledging me even being there, or that I'm sitting there crying, or that I'm feeling the same pain or fear that mom is, that oh, mom, are you okay and then just walk out the door and not even acknowledge me and what I may be going through. And unfortunately, her mom and I have a good relationship where we understood the dynamics. We worked well together through all of that and her mom is a wonderful mom. And so we just created a natural connection in how we navigated all of that and handled stuff, but it's an empty feeling to be feeling the same or similar fear and sadness the other parent is and yet not even being acknowledged at all. It's wrong. It's just wrong because [1:09:00:05] I guarantee you can have the – I’ve met Bobby, he's a big boy, but I guarantee if he's sitting there and his child or even I believe he felt this true Faith, the sadness that you feel, and just because you're big of stature and you're a man doesn't mean that you don't feel it. It's the wrong assumption and we need to start acknowledging that more. We need to start allowing space for men to be feeling safe to express that as well. |
| 8 | Title: *A palliative care MD: “We need to try to understand what the motivation is on the parent’s side; and we need to be real with ourselves and not shy away from pain.”*A palliative care doctor encourages clinicians to really lean in to what the child and parents are experiencing and need; and then to acknowledge how hard that can be and take care of themselves afterwards. A dad observes that bringing compassion is critical to providing care. https://youtu.be/kfGK4AG76NkTC: 1:23:20**Bob Macauley:** So I think if I were to give some advice to people who don't do this for a living but are dedicated and compassionate and want to provide the best possible care to their patients, I think couple of things come to mind. One is trying to understand not just what the surface expression of something is but what the motivation is, especially on a parent side. So a parent who is taking us a little bit by surprise. So instead of being sort of more kind of receiving and deferential, but is a little more assertive and this is what I need for my kid especially if they [1:24:00:14] have the stature that Jerris has physically, don't just let it to the surface. Look at what's driving this person, what's in their heart, why are they saying what they're saying, maybe they're frustrated because they don't feel understood, maybe they are adamant because they made a promise to their kid that they need to make sure that they keep, they’re looking at where their heart is as opposed to what the sort of surface expression is something I think that's important. Another is to be honest and real with ourselves and not shy away from pain. I think this is a very natural human thing, like, we shy away from pain. If your hand gets close to a flame you pull it back, it hurts, we don't want that. That experience that I had the first time I met Faith where [1:25:00:05] she ended up talking on a very deep level about some incredibly personal experiences was the most palpably painful conversation I can remember having with a patient. And so what we did is we didn't run away, we didn't change the topic, we sat with that and honored it, and then we also tried to take care of each other. My first step after leaving that room was to get our team, especially our two learners into a room privately and say, are you guys okay? Because, like I've been at this long enough that I think I have a few resources to cope. And I was like, I looked at them, they were shell shocked. They were ready for something but they weren't ready for that. And so we need to make sure that we create [1:26:00:06] that space to honor that because if we had walked out of that room and said, okay, let's put some #[1:26:08] we’ll see the next patient. I think sometimes people in my business, we sweep so many things under the rug, the rugs are practically levitating. There's so much that's gotten swept under them. Now we got to stop that or else we're not going to be able to really be present for people. **Jerris Marr:** Just hearing Bob and thinking about it from a different point of view of what I would ask of providers. Everything Bob said is so spot on, but I think from the classroom to the practices, I think if we can get providers to do a better job, and we're generalizing here, but a better job of balancing a couple of things here. And you thought your question to Bob was around are you really providing good care or good medicine if not doing those things? Well, to me, there's medical practice [1:29:00:14] and then there's care, and we say medical care but we do medical practice. We need providers to really emphasize and amplify the care part of it, right. It's, oh, we provide just clinical services and that's what you're going to get is less caring, less connected service. You're getting your oil changed, right. It's not that. We need to remember the human in this and the family dynamics. So it's medical care. And then it's -- the other thing I would ask is to not only listen but hear. People, they'll sit there and they listen to the patient, they listen to the parents, but they're not hearing because they're so busy formulating their opinion but they're not actually hearing to your point earlier when you are sharing that what's the driver behind a sense of urgency, or why is somebody so scared, or why are they so frustrated. Dig beyond the immediate interaction to understand what is really being said. [1:30:00:15] And then the last thing I would add is in terms of balances, balance the clinical with the compassion. If we could get providers to really start looking at, yeah, here's the medical thing that I know we should do through textbooks, through training, and through practical application. Here's the clinical approach we need to take. Now let me pause for a minute and actually demonstrate some compassion to here. Why is this upsetting this person so much, why are they pushing so hard on this, why are they withdrawn, right. And that's the compassion side. In this business I think you are failing in your job if you're not doing both. |
| 9 | Title: *A dad to fellow parents: “Be present, have a voice, trust but validate.”*https://youtu.be/4abqwt6yvBgTC: 1:31:50**Jerris Marr:** What would I encourage parents to do. I think when I've spoken to other parents that are either beginning their journey or [1:32:00:05] well into it or sadly at the end, I think it's so important. The simplest way is be present. Be present, have a voice, trust but validate. I'm not a doctor, but there's so much information available to us anymore that you can research and ask questions and that's what I mean by being present. Don't just sit in the back of the room and let the providers come in and work with your child and you just are there just to hear it, right. Ask the questions, dive in, ask how their child is feeling even at a youngest age. Faith was four years old and yet both her mom and I say, well, how do you feel about that? What questions do you have? Make them a part of the process so that they begin to, one, learn, but you're removing some of the burden that comes with everything being done to them, they've lost [1:33:00:06] all control. And so we worked really hard to try to give her control back where we could. So be present and help your child and yourself navigate the whole journey by asking questions, seeking to understand, finding your voice. And I think probably the last thing is acknowledge your emotions. You're going to be -- I don't care dad or mom, you're going to be scared, you're going to be, it's terrifying. You're going to be frustrated, you're going to be sad, you're going to be angry. Those are all very real. They're valid, and you're going to experience them at different times, allow yourself the space and the grace to feel them and then be wise enough and strong enough to pull yourself out of them so you don't get lost within them, so you can go back to being present. |