

Joy and Bruce



parents of Corinne – Trisomy-18, 3 months old



Working with the Medical Team and Goals of Care

We are going to take one day at a time.

<https://youtu.be/z4H9ZPDygeA>

Bruce: /I have come to the conclusion that we are going to, take one day at a time. Enjoy every day and let nature take its course. She is going to determine her own path and whatever that path is we will be there to walk with her.

Joy: I have immense hope for her, I have faith in her that she is going to write her own story and she has set a lot of people back on her butts already. So she has shocked the hell out of a lot of people. I think including us to.

Bruce: I think you know, a lot of the doctors and stuff weren't expecting her to live past a month or a month and a half or so, and now everybody is kind of scrambling, trying to catch up to -- to get up to speed with what she needs and what we need and whatever.

Joy: When she was in the NICU they were all scrambling to send us home so that we could have time to enjoy her which, I guess I appreciate but at the same time it's kind of putting limits. You know, it's already writing her story and not letting her tell you what she is going to do. You know, I don't know how many times I have been asked if I wanted to sign a DNR. You know, and it's like well, first of all, no. Second of all, okay, so what if I did sign a DNR and it's only because she has trisomy-18. Just the diagnosis, not even looking at the problems associated with that. Just because of the diagnosis. But okay, so what if she, you know, chokes on a marble. That's something any kid could do. You know, so she at least needs that chance that you would give any other kid and I think that's been something that has happened to a lot of families with kids with this disorder or condition.

I want straightforward answers.

<https://youtu.be/AI6I-CACGLI>

Bruce: I am a no nonsense type of person when it comes to things like that. So I have told the doctors and the medical team in general when they were talking to us about different things, not to sugarcoat it. I want straightforward answer. I don't want to be cushioned and whatever. If the diagnosis or the prognosis or whatever is grim I want to know that. I want to know what I am dealing with so, I can motor through it and deal with it and hit it head on, instead of getting side-swiped.

You can say, "Hey, that's enough."

<https://youtu.be/okZs533nBjE>

Joy: one huge thing that took us a little bit -- a little while to learn with the doctors is you have to tell them what you want and you have to know what you want. And that means you have to do your research. And one thing that you know, I am really lucky to have is that I have a very extensive knowledge of anatomy. More pertaining to animals but it's really pretty much the same. So when I am talking to doctors about a malrotation of the intestines or the locations of a hole in the heart or what VSD stands for I can tell them, I can talk their language, I can play their little game and they can't stand there and talk to each other and think that I don't know exactly what they are talking about. That's helped a lot and just you know, something as simple we had to take her to the ER once and the emergency room has a very strict protocol. They have got to do test a, b, c, d and that's the way it's going to be. Well, this is -- this sounds so ridiculous now. But I didn't realize that you could say no, stop that's enough. And I boiled and boiled and boiled. They were trying to do this one blood test. I mean she was just over 5 pounds. They are pricking her heel over and over and over and they are never getting enough blood, I am like "Look, definition of insanity. You are not going to get enough blood, stop." And they did. And I was like, I didn't know that. You could say, "Hey, enough." That's helped a lot.

I am advocating for her to be looked at as an individual, not a diagnosis.

<https://youtu.be/kNlr1oyv7mE>

Joy: I guess what we are advocating for -- or what I am advocating for the most with is for her to be looked at as an individual. Not a diagnosis of trisomy-18. If you break your arm and you go to the hospital, there is a pretty routine protocol as to what they are going to do to fix that arm. I don't know what it is, I am going to pretend to know what it is. But with trisomy-18 all it is a diagnosis. You don't die from a diagnosis, you die from problems associated with that diagnosis. In all honesty, her problems are actually pretty minor compared to a lot of the ones that I have seen. She has two holes in her heart which would be of the most concern. But not an immediate concern, and then she has a malrotation of the intestines which again is a concern but not an immediate concern. Some people go their whole lives with malrotation and don't even know it until there is a problem if there is a problem.

So right now, those are the two biggest physical problems. We have not done an MRI. We don't know what medical or developmental limitations there may or may not be. So that's another thing to overcome but in terms of I guess to be very blunt life or death, right now there is nothing pointing towards the negative. There is with these kids also always a fear of breathing, stopping breathing randomly but there is also this thing called SIDS sudden infant death syndrome with all babies. So I guess, you know, we are trying to learn to not freak out over every little thing. And I think that's actually a pretty normal thing with being a parent is, you know, if the kid's sleeping too long. Oh my god, are they still breathing? So it's nice to hear that from other parents. I do that all the time what my kid.

Speak up

<https://youtu.be/I7P2Tjhezp0>

Joy: You can fire your professionals. That's, I think the most important piece of advice that I have. If you don't like the way somebody is doing something or you don't agree with it whether it be a doctor or a social worker or whoever, just you know, keep finding somebody else until you find somebody that you agree with because if you don't have a good team, then it's not worth it.

Bruce: I guess, I would say to other parents be a advocate, the night we took her to the emergency room, the ER has signs that say,

Joy: "Speak Up."

Bruce: "Speak Up." And you know, the doctor was saying oh well, try this. And then he would leave the room. And I spoke up. I hurried out and I said look, "You come in and watch her and do what we are doing and tell me there is nothing wrong with her. Instead of coming in and telling us to try something and then leaving the room." So speak up.

Joy: If Bruce had not gotten in that guy's face, she would have died, bottom-line. When you have that feeling that something's not right, or that you should do something you have to listen to that. Could you imagine the guilt if she had died that night because we hadn't been brave enough to speak up?

Bruce: Just speak up, don't be afraid of the professionals. They are going to put their pants on one leg at a time same as you and I do.



Spirituality and Religion

I am not religious ... But I have faith in people and positive thought

<https://youtu.be/DJzsDvXjY4>

Bruce: I am not a religious per se. I mean I believe that there is a higher power, I don't necessarily believe in organized religion and stuff but so, I just live one day at a time. And whatever happens, happens and I deal with what comes along.

Joy: No faith either. Again I don't believe in organized religion. I guess for me I haven't been able to just choose a religion that was decided by another group of people but I do have faith, I had faith in you know, nature. I have faith in people, I have faith, immense faith in the power of positive thoughts. I have seen the results of that many, many times with close friends and family who had whatever going on or health wise or emotional wise and the outcome because of people's thoughts. So whether that's in the form of prayers or just somebody saying I am thinking of you, I believe in that. And that's helped immensely.

Joy: It's helped me in just, I think the biggest way that it's helped me for people to say, oh, I am thinking of you, it's giving my daughter's life a purpose, I guess. It's validating her. That's why I, you know, I reached out to the local newspaper. They said, hey, you should do a story on her. That's why I am doing this. I think you know, for me it's important for her to touch as many as she can you know,

Don't talk to me about Karma.

<https://youtu.be/WjqDUjQYooo>

Joy: You know, I ask myself why me, all the time but it's my thought process and my dwelling over that, each time I ask myself is getting shorter and shorter which is a good thing. I get pissed off every time I look at Facebook and I see one of those stupid little posts about karma. I am sick of seeing this shit, no. You know, oh this person's did something terrible to me, they are going to get what's coming to them. Nobody does anything bad enough to merit having a daughter with this kind of prognosis. Don't talk to me about karma.

But I think in terms of asking myself why me, I think it's getting less and less and instead of why was I chosen to have a daughter with such a horrible diagnosis, it's why was I chosen to have this special child, you know, why -- why me, what did I do that was so wonderful that I deserve her. You know, and that's how you have to see it because she is a gift. I mean she is like the happiest baby in the world.



Seeking Normal & Making Memories

Instead of dreading things, we are cherishing them.

https://youtu.be/PI93E_iZxyo

Joy: But she is so much fun and you know, every milestone that she does reach is just going to be just that much more spectacular. Every day, you know, we are cherishing that much more because of her diagnosis. You know, we are able to stop and appreciate every diaper change. You know, and not, I don't know, instead of dreading it we are cherishing it, which I think is important and not many parents get to experience that. Get to slow down and enjoy the day to day stuff.

Joy: I think I have some kind of fear or dread every day. You know, I look over her and she is a little bit grey and my instant reaction is oh, my god. You know, is this it? But again that's getting shorter and shorter too and I am starting to come to terms with everything and this is also, this is my first child, this is what I know, you know, one of my friends had a baby two weeks after Cora was born and I look at her and I look at her hands are relaxed whereas Cora has tight fists all the time. She has got a her little rock star hands. My god.

And I was like, oh god, that baby's hands look so weird. You know, this is normal to me, this is what's perfection to me. You know, but yeah, I do -- I do dread the future and what will come but. Of course I originally get to it, you know, we have enough on the day to day that you know, planning ahead doesn't always make sense. And I am a planner.

Bruce: So you know what, I just -- I am a day to day type of person. I mean I can try to plan for things but life goes by so fast, it's hard to determine what's going to happen you know, two weeks from now. So I would just take things one day at a time. Enjoy every day, tomorrow brings what it brings.

Nobody has a guaranteed tomorrow

Bruce: Like I said, to me she is, you know, it's no different than having a normal baby. I am going to come and go and life is going to go on and when the time comes, it comes. And there is nothing I can do to stop it or anybody else. So --

Joy: Nobody has guaranteed tomorrow.

Bruce: Yeah.

Joy: You know, nobody, so in reality how is she any different? Just the fact that we actually stop and enjoy every minute, every second, versus somebody who gets into a car accident and didn't enjoy their life. You know, so in a sense that's actually kind of lucky in a weird twisted way.

Joy: This is a horrible comparison but last fall we lost two of our dogs within a month of each other. We had a three-year-old golden retriever and almost 14-year-old the other lab. And the golden retriever three-years-old, such a good dog, always hung around, great dog. It was on the side of the road, got hit by a car and died. The golden retriever slowly went downhill. We had the time --

Bruce: The lab

Joy: The lab slowly went downhill. We had the time to decide how we wanted to do things. The time to spend with him, make sure that there were no regrets. The golden retriever, I think the last thing I said to him was stop it. Whereas the lab you know, when we had him put down eventually you know, we are all there, we were all holding him and it was just, the way we felt or the way I felt I can only talk for myself is with the young dog, you know, it was so much more painful because it was unexpected and he was so young and it was just boom, literally and done. Whereas with the lab we, you know, he was put down the day before thanksgiving, last year, a year ago. And one of our reasons for doing that is, well, first of all he had a lot of health problems but the practical reasons we needed to make sure that we could dig a hole in the ground and you know, that's the reality of life.

It's kind of same thing with her. You know, we know that she is not going to live as long as most people will. We know that, that's pretty much a given, but we are able to enjoy what we have got. You know, whereas somebody else might lose their child from SIDS or from choking on something or whatever else and not have that enjoyment and not, you know, look back and say oh, damn I wish I had pictures of her picking the Christmas Tree.



CONTROL & SELF-CARE

I get control by being open about her condition.

<https://youtu.be/IA2TDkFK-Mc>

Joy: The way that I try to get control is through getting acknowledgement. You know, whether it be having the newspaper come or you know, talking to people about what's going on with her. You know, being open with her condition and that's how I get control. And not being, trying to not be afraid. I know that's hard, really hard to do but you can't enjoy anything if you are living in fear, and I don't know.

Like here is an example. I was adamant about taking her to cut a Christmas Tree because that's something I have done every year of my life with my parents and now with Bruce and his daughter. And so I bought her this ridiculous \$50 snowsuit that I can't afford and that she was only going to wear once. But she was going to go cut the damn Christmas Tree with us. And I was going to get pictures and you know, doing that make -- I mean, I took over a thousand pictures in my first month, you know, getting everything you can possibly get on film. You know, it may -- it may be 10 years till I can bring myself to look at the pictures but to have that, you know,

Being with my baby makes me feel better.

<https://youtu.be/3Hnj0MfUQs8>

Joy: But mostly, yeah, mostly just you know, being with my baby makes me feel better, you know. So, and that was another thing somebody said to me that I think was so, so important. I think it was one of the doctors. You know how everybody says, oh, you never wake a sleeping baby, let him sleep. Well, one of the nurses in the NICU said to me, she said, just in passing, you know, anytime you want to go and pick her up or go cuddle with her, just do it. She said it doesn't matter if she is sleeping, she will go back to sleep, she will sleep later. It's not going to hurt her and that's important. You know, if you are lying in bed at three in the morning and you can't sleep, and you want to go pick up your kid, go do it.



THE MARRIAGE

We have very different coping methods.

<https://youtu.be/yIY-iO75QWQ>

Joy: Oh, we don't talk. We don't have time to talk. He works all day and then comes home and I run around trying to get whatever I can get done but. I mean, yeah we did -- we talk about it sometimes and you know, we both do have a very different coping methods. Mine is to talk and his is to just kind of I don't know what yours is. Be quiet.

Bruce: I am not the one to talk about things. Yeah, I have been through a lot of tragedy in the past. I have lost two brothers, my mother, grandfather in the same years, my mother and stuff. I just you know, just keep around moving. I don't stop and slow down. Probably if I stopped and really thought about it, it would hit me like just running into a brick wall. But if I just keep moving, that's my way of coping. If I can go to work and stay busy I don't think about stuff. And I can enjoy what I have and worry about what I don't have later on.

Joy: You know, we were -- I was upset because it seemed to me like he just pulled it right along doing his normal things whereas I was like, my life changed. You know, I have, I have been home with the baby. I didn't expect to not be able to go back to work. Whereas he just continued going to work, you know, even when we were in the hospital. Partially because he had to, to pay bills and partially because that is his way of you know, dealing with everything but then I am stuck here all day. I am like dealing with this every second of every day. But I guess in terms of creating problems for us, not that so much. I mean, I am not going to lie, like we have issues. I am not going to stay here and be like oh, we get along so great because that would be a complete utter lie.

Where we started marriage counseling, our first visit I think we scared the woman away. She told us that we had pretty much every problem that a couple could have. Financial problems, people who have kids under 3 and teenagers, and we have both. Kids with medical problems or medical problem in the family. So at least that justifies, that at least we are not, you know, just fighting over nothing. But yeah, we do. We argue all the time.



DECISION MAKING & PALLIATIVE CARE

The quality of life is more important than the quantity of life.

Joy: I think, thank god, if there is a god. But the one thing that we have consistently agreed on and consistently been able to talk about together and come to a mutual conclusion has been Cora's healthcare. And that would be the one thing that I would pick first to agree on if I could only pick one thing. Because I don't know what we would do, if you know, I wanted to do every medical intervention possible, and he wanted to just let nature take its course, you know, or vice versa. That would be horrible.

Bruce: The biggest thing for both of us is that it's not about what I want or what Joy wants. It's about what's best for Cora. It's about what's, you know, her quality of life is more important than the quantity of life.



SIBLINGS

We don't hide anything from her.

<https://youtu.be/hcSsPfkXZS>

Joy: Olivia, even though she is just 13 and I came in her life when she was 9. We have always been completely blunt with her. If she asks a question, she gets an honest answer regardless of what the question is. She has been involved in all the meetings we have had here. She knows as much as we do. She sat here a few weeks back when Monica was here when we discussed our plan of where we would like for the baby to die at home or in the hospital.

So she -- she knows what's going on, and we don't hide anything from her. We don't try to sugar coat it or change the language. My reasoning for that is because I think that first of all she deserves to know and that's the way I have been with her with everything from the male horse in the backyards anatomy to Cora's condition and, you know, I think if you use mature language and are honest that kids respond to that more than the beat around the bush kind of language.

One of the people that we have to help with both Olivia and Cora, she is a child life specialist. She is kind of a pain in the butt but. She is one person that's always canceling or late and I just, I can't stand it. But anyway hopefully, she doesn't see this. She -- my goal for her is to take Cora and Olivia and show

Olivia what she can do to play with her. You know, because it's like when it's me or when it's Bruce with Olivia, it's like, oh, hold her this way, do this, you know. And sometimes I think that can be overbearing like do it this way. You know, it would be good for them to kind of go off. And I'd like Olivia to start having a little bit more responsibility with, you know, remembering that she has got an appointment this day and you know, so I think that would also be good for her. And it's one last thing I have to worry about.



Social Media

My greatest support is the Facebook group for Trisomy-18 mummies.

<https://youtu.be/lkhVyDcYrvk>

Joy: My greatest support is the Facebook group for Trisomy-18 Mommies. It's a bunch of women and it's just incredible. You can say whatever you want. You know, there is no judging. There is understanding that each child and each family is different. Some people choose to do lots of -- lots more intervention than others. They also have extensive medical knowledge. My family, my parents live in Iowa. So there is support over the phone. They are actually coming up for Christmas to spend Christmas with her. They don't want to see me, they want to see the baby. But you know, in terms of like I need somebody here, now, then there is not -- there is not really anybody. You know, we live in a small town. I don't have any family here. Bruce's family is crazy.