An Orange Socks Story – Stephanie and Andy: Acrania Anencephaly

Interview by: Gerald Nebeker, President of Orange Socks

Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I am your host, Dr. Gerald Nebeker. In this episode, I speak with Stephanie and Andy about their experience having a child with the terminal diagnosis of anencephaly. They have used their profound experience to benefit others by creating the nonprofit organization Carrying to Term. The information on their website, carryingtoterm.org, and their brochures placed in multiple medical clinics in 12 states, with more to come, have helped hundreds of expectant parents dealing with a terminal diagnosis. Their information and training has helped hundreds of physicians to better understand their patients' needs in dealing with this difficult circumstance. I was honored to speak with them, and I know you're going to benefit from hearing their story.

Gerald: Stephanie and Andy, thank you so much for taking the time to do an Orange Socks interview with me. I really appreciate your taking the time. Stephanie, tell me just a little bit about your story, when you found out you had a child with a terminal diagnosis and what it was like.

Stephanie: Andy and I were newlyweds. We had a dream wedding and honeymoon experience. We were living together, getting our home together, and we knew we wanted a family relatively quickly after getting married. We were at a really high point in life, and a few months later, we learned that I was pregnant. We were so excited that God had answered a prayer so quickly and easily for us. A few months later, when we were five months married, still very newlyweds, we received the diagnosis that started off as Acrania, where a part of Grace's skill was missing. Over time, that turned into a diagnosis of anencephaly. The diagnosis was presented to us, actually, at the end of the ultrasound. They had scanned her head, and up until that point, we had gone through the whole appointment thinking we had this perfect child, that everything was looking wonderful. Then they got to her head, and that's when the sonographer was a bit more silent, definitely noticed something was wrong and stopped the ultrasound. She said that she needed to step out of the room, and we were confused. We weren't sure what that meant exactly. I think at the time, Andy was a little more confident that something wasn't right, and in my heart, I was hoping it was just a doctor coming back in to confirm that everything was perfect.

Gerald: So, you got the news. What were your thoughts, Andy?

Andy: We were devastated. We cried immediately. There was a lot of being scared about what this journey was going to look like, a lack of knowledge about what it looks like to go through the next six months of our pregnancy, knowing that our daughter, who looked perfect on this ultrasound screen to us, she was flipping around and looked like our little ballerina. So, that's what we were saying, wasn't going to live much longer. One of the really hard things for us was that the doctor didn't know if Grace was going to live a month, or all six months, and they basically said that she's probably not going to make it to term. And if she made it to term, she's not going to make it through the birth canal because of her condition. And if she makes it through the birth canal, then it's probably going to be a couple breaths and she's going to pass away. There were all these times you're trying to live joyfully, and we tried to make as much joy out of being mom and dad to Grace that we could during that time that we had her, but there was also some fear in there that said, “This might be her last kick, that this might be the last time that we get to see her on the ultrasound screen.” There was a lot of that, so we really just tried to live in the moment and enjoy the time that we had with her. We weren’t going to be able to take Grace to the park, so we went to the park and we tried to do things we would do with a six-week-old or an eight-week-old, to try to be as much of a family as we could in that moment.

Gerald: That’s interesting. You created opportunities for Grace in utero that she wouldn’t be able to have after she was born. What type of advice, Stephanie, did the doctors give you at that time?

Stephanie: Our primary doctor wasn’t available at that time, so we had met with a doctor we didn’t know, and he was very compassionate. He extended his sincere apologies that he couldn’t give us the news that we had for that day. He said, “I would like you to go see a perinatologist to do a 4D scan, just to confirm that what we are seeing is correct. I want you to take the time to think about what you and Andy would like to do with remaining of your pregnancy, and whatever decision you make, we’ll support you in that.” After that appointment, we immediately met with the maternal fetal medicine specialist, the perinatologist, and at that appointment, the care was much different. She confirmed that this was acrania anencephaly, and she said we could induce early and try again, and in that moment, I wasn’t sure what induce early meant. I was very confused, because here I am processing this diagnosis, I said, “Induce early, does that mean as the pregnancy is going on, and we notice that something is happening, does that mean we could choose to go into labor early?” She said, “No, you could end the pregnancy now, if you’d like.” That’s when Andy chimed in, and said, “Steph, they’re encouraging us to terminate.” In that moment, we said, “Absolutely not.” I said, “We are not going to terminate.” Andy and I both repeated the exact same thing, just confirming, and we said there was no further reason for us to be here. We concluded that appointment and got out of there as quickly as we could. That compounded the devastation we were already feeling, because when we got the diagnosis, we had already loved our daughter. This diagnosis didn’t define her, and here we are having someone encourage us to end her life based on this diagnosis. We couldn’t personally comprehend that.

Gerald: That’s a very powerful statement, thank you. So, she was born, she lived through the rest of the pregnancy and was born. You named her Grace. How long did Grace live after she was born?

Stephanie: Grace lived for 10 hours and 32 minutes, and we were told that she might just take a breath and pass away. Our first priority after she was born was to baptize her. Our family was in the waiting room outside of our room, so within three minutes after she was born, a Chaplain came in who we had previously met with, and he did a beautiful baptism for her. The doctor went out of the room and shared with our family that she didn’t think that she had long. What we didn’t know at that time, was that she had told our family that maybe Grace would have an hour. And what ended up happening, was that we had 10 hours and 32 minutes with her. When she was born, she came out crying. We expected silence, so her cries were music to our ears, she sounded just as beautiful as any newborn crying. As she was placed on my chest, she settled into this very peaceful place, and she regulated her breathing on her own. We confirmed that she wasn’t in any kind of discomfort, and that’s where she stayed for the remaining of that time, with the exception of a couple of minutes when Andy held her. That was an incredible experience. We always talk about the spirituality and the power and those minutes together.

Gerald: Andy, what do you think the impact was on your life, personally, and your extended family, of those 10 hours and 32 minutes of Grace's life?

Andy: She had such an impact on our lives, our families' lives, and other people's lives. Steph shared our story on Instagram. We had people who came to us and said, "I was headed to Planned Parenthood to have an abortion and I saw what you guys are going through, something hit me." We think that's the spirit that said, "This baby is worth having." What many people see as an inconvenience, is sometimes inconvenient, but also very purposeful and powerful. We know that Grace touched many lives, even in her 10 hours and 32 minutes. I'd say she has probably had more impact in 10 hours and 32 minutes than most people have had in their entire lives. It's an amazing thing. Specifically, with our family, you can go one of two ways with God, that He is in control and that He does allow things to happen that will be used for good. Romans 8:28 says, "He does all things for good," and that really gave us conviction that that is the case. As a result of Grace, Steph and I both have extremely purposeful jobs, and purposeful ministries that we are embarking on, and I don't think we've ever been as fulfilled as we are now in what we are doing and our purpose. Grace gave us a purpose, for sure.

Gerald: That's great. Stephanie, if I were to come to you just having received a diagnosis that I had a child with anencephaly, what advice would you give me?

Stephanie: The first piece of advice I would give for families facing a diagnosis, is to really become fully informed about the diagnosis. Once you become informed, then you get to choose how you're going to live out your story. Embrace that there are opportunities to be intentional, to create memories. As humans, we are made of so many complexities. You need to consider your mind, your body and your spirit in this, and all of those things together make our fully informed decision. And continue to make intentional decisions throughout the pregnancy so that you don't have any regrets, so that you're creating memories as a family, so that during labor and delivery, you have special keepsakes and things that you can hold on to so you can really cherish that time together.

Gerald: Andy, this was a tough time that you had. You opted not to abort the pregnancy, to terminate, but to have a child. Any regrets?

Andy: There are really no regrets in that journey. There are things that happened after Grace passed, in the midst of grief, that I probably would have done a little bit differently as a husband and as a father. Very few people get to experience that level of grief, having seen their daughter take her last breath, and with that grief, I believe that the enemy loves to seek out those people and exploit that grief. There were some things, as a husband, that I probably would have done differently with a grieving wife, but those are probably the only things that I would have done differently. Replaying that year after Grace passed away when we were in the depths of grief, but other than that, I think we would have done the exact same thing, the exact same way.

Stephanie: To add to that, I would say in our experience, when we were facing death each day, that forced us to really ask ourselves, “How much love can we give Grace, how much love can we give each other?” We talked about how joyful our pregnancy was with Grace, that once we embraced our story, we had an amazing community of support. We really felt called to share our story, and we did that with conviction. We experienced so much joy because of that. Going back to the question about what we would share with parents, I would also be really honest with them in saying, “To prepare for the time that you have with your baby, you don’t know how to prepare for what happens when they are no longer with you.” So, I think prenatal counseling and understanding the grief that happens with a diagnosis and following is so important. We really leaned into healing and doing some intentional healing and things like that as a couple, because as Andy just shared, that was really difficult on us, trying to navigate that. After being surrounded by such a wonderful community, suddenly it was just him and me alone, and that was a really lonely place for us. We got through it and continue to embrace those triggers and pain that still come as a result of not having Grace here.

Gerald: What I think is wonderful is that you’ve extended that knowledge to others through the creation of an organization. Do you want to talk about that?

Stephanie: We launched Carrying to Term.

Gerald: Okay.

Stephanie: Which can be found online at carryingtoterm.org, launched in June of 2016 about Grace’s legacy. It is an online space that provides support and online resources and tools to the medical community, parents, and their friends and relatives.

Gerald: Great, it’s a wonderful site, and I would recommend it to anybody. What a wonderful resource you’ve created for those communities.

Gerald: I am grateful for Stephanie and Andy for sharing their story, and I encourage you to find out more information about their organization, Carrying to Term. Please, go to their website today at carryingtoterm.org and make a donation to help them help others who are trying to cope with a terminal diagnosis in their unborn child.

Thanks for listening to this episode. Orange Socks is an initiative of Rise Incorporated, a nonprofit organization dedicated to supporting and advocating for people with disabilities. Follow Orange Socks on Facebook and Instagram, and visit our website, orangesocks.org for more stories and to find national and local resources to help parents of children with disabilities.