An Orange Socks Story – Deborah and Kent: Traumatic Brain Injury

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I was honored that Deborah and Kent agreed to an Orange Socks interview. While I have known them for many years and cherished them as friends, I did not know the details of the incident that resulted in their daughter, Heather's, traumatic brain injury. Their story is hard because they experienced first-hand a parental nightmare, the drowning of a child. Deborah and Kent recognized many miracles that occurred that eventful day, and believe there was divine intervention that led a stranger to help save their daughter, and many blessings have occurred thereafter.

Deborah: On September 8, 1984, I was upstairs working, Kent was downstairs watching TV, taking a break from yard work, and our oldest daughter who was four years old came running into the house and said to Kent, "We are never going to see Heather again." Heather was almost two at the time, and we had a three-year-old son, Jeff, in between. Kent shouted, "What are you talking about?" I heard Kent yell, and I came running downstairs because I could tell there was panic in his voice. Natalie, our four-year-old, said, "Well, Heather fell into a ditch, and she got sucked into a culvert." We ran to where it was, and we were surprised that at four years old, Natalie knew exactly where it had happened and showed us the spot. They apparently were walking down the street toward the 7-11, unbeknownst to us as they weren't supposed to leave the yard, but they were following some neighbor children, and Heather had gotten fascinated by the water that was running in a ditch alongside the road, and she went over to explore it. Natalie didn't realize the danger, and the next thing we know is that she fell in and got sucked into the culvert and disappeared. We obviously panicked and looked up and down the culvert. The culvert was under a driveway then opened up for a space, then it went under the street, so there was a long part under the street. We looked under the other end of the street to see if there was anything we could see in the water. We couldn't find her anywhere, and we weren't calm, so I think the neighbors heard us panicking and started coming out. The people in the house in front of where she fell in came out, and somebody called the police. Again, we were just panicking, looking all over for where she could be. At some point, the police arrived, and they made me go behind a bush as I was not allowed to watch what was going on, so you'll probably have to explain what happened while I was behind the bush because they apparently thought I was hysterical. I didn't think I was hysterical, of course I was upset, but I wasn't out of my mind.

Kent: Just to clarify, when Natalie first informed us that Heather had fallen in the water, I got in the canal, and the water was up to my chest. I felt all around the canal for the full length of this home. I couldn't find her obviously, so I ran back home on a couple of occasions to get two-by-fours and umbrellas and whatever I could find in the garage to try to see if I could poke around inside the culver to see if I could even establish that she was there. I was in the water doing that when the paramedics and police came, and at that point, they really didn't have a solution. There's another story that goes with this, are we going to talk about that?

Deborah: Well, maybe just in a sense that he was there.

Kent: Yeah, there's a really cool story that goes along with it, but not to follow that part exactly, at some point, another gentleman got into the water with me in addition to the rescue people, and he came up to the culvert. The culvert was not long enough for my shoulders to fit in, so all you could do as an adult was to reach in as far as you could without any other tools or equipment. He got up there and saw the situation, and he had a son with him who was about ten years old. He called his son to come down into the water as well, and we all got up there, and he was asking me what I knew. I said I wasn't sure, but I think my daughter is caught in that culvert somewhere, and obviously I can't get to it, and I can't stop the water. He had an older son with him, and they found some two-by-fours and some old carpets off some old equipment in a field down the way, and they used the equipment and that carpet to block the water about a half a block further down, then diverted it down another channel. That allowed the depth of the water to fall, and as the water fell, I looked in and I could see Heather's legs. At that point, I kind of fell apart. I had been hoping beyond hope that Natalie was wrong, that Heather had never really fallen in the water, that she had just wandered off somewhere and we were going to find her. But now I saw her, and at that point, the devastation hit, and the gentleman asked me to move aside from the culvert entrance. He tried to reach in but could not reach Heather, and then he called his son in and told him, "You've got to go in and pull her out." Again, the water was high. We could see, but it was still high enough that his head would have to go under the water to see her, and there was a lot of debris like broken glass and sharp rocks that was in this canal and in this culvert, and so it was a scary situation. I remember hearing the son at first say, "Dad, I can't do it. I can't do that." The dad turned to him and said, "If you don't do this, she will die, but if you do, you can save a life," and it changed the boy's attitude. He accepted that and made his way into the culvert with his head under water as far as he could, but he got in a ways and he panicked, and he came back out coughing and said, "I can't do it, Dad," and the dad said, "Yes, you can." So I held one of his legs, and his dad held the other. He took a deep breath, submerged, and then got his head up above it and then reached. We could hear him say, "I've got her, I've got her!" We pulled him back out of the culvert, and he had been able to grab her by her hair and pull her out of that culvert. She was obviously dead, she was blue with no movement, no activity at all. The paramedics were right there and took her out of our hands up on the side of the road and began to administer CPR. I remember hearing, "Hey, we're getting no response, no response."

Gerald: How long do you figure she was underwater?

Kent: I knew it was at least 20 minutes, because when I ran out of the house the first time with Natalie, I noticed the time, and when I went back again a couple of times to get the two-by-fours and the umbrellas and searched and so forth, it was probably longer, but it was at least 20 minutes.

Gerald: Deborah, what was the result? They revived her at some point.

Deborah: Yes, they were able to revive her at the scene. They threw her in an ambulance, and Kent went with them. They had a treacherous ride to the hospital, they had officers leap-frogging into intersections so that they wouldn't have to slow down. Once they got her to Pioneer Valley Hospital, they stabilized her there, it probably took a couple of hours to get her stabilized. Then they life-flighted her to the children's hospital. She was put into the ICU for children. We were put into what we found out later was called the grieving room, which is where they put families whose child was going to die, we didn't know it at the time. Heather was drugged so that she wouldn't fight the ventilator that they had to put her on to help her breathe. We just went into the other room and waited. We had talked to doctors and nurses, and family members came to visit us in the room. We tried to sleep a little bit, and a nurse came in the middle of the night and said, "You need to come see this." We went in to see Heather, and she had woken up. The drugs had worn off, and she was kind of fidgeting and moving. Her eyes were open, so of course we talked to her for a minute. They said they had to drug her again so her lungs can heal, but that was the first sign where we thought there's a chance. She was in the Intensive Care Unit for two weeks, and it was a roller coaster. One minute she was doing okay, and the next minute her blood oxygen levels had dropped and she was not going to make it. They had threatened surgery two or three times to do things they felt that they would have to do, and we gave her a blessing. I'll be darned if the next time they approached her to have surgery, they never had to do one surgery. After two weeks, they put her onto the main floor of the hospital, and she was there another six or seven weeks. We were told that she was cortically blind, she had no reflexes, and she was being fed through an NG-tube. Her eyes could see but the brain wouldn't register it. She was doing a low moaning and stretching like a board, stiff as a board, so I would go up there every day and try to give her sedatives. I would try to keep her muscles from atrophying into this stiff position, and we had therapists there who were trying to work with her. Every four hours, we were begging for these sedatives so that she could be more relaxed and not so agitated. She would do this horrible moaning sound; it was very traumatic. Kent and I stayed overnight while she was in intensive care, but we could tell the other two children at home were getting very upset and worried, and it was very hard and traumatic for them. After a couple of weeks, Kent tried to go to work, and we would both go home at night and be with the kids, then I would go to the hospital during the day. We had neighbors who would watch the kids while I would go to be with Heather in the hospital.

Kent: Just a quick comment regarding the surgeries that were thought to be needed. There were two things that were happening, one was they constantly had to take blood because they were trying to measure the level of oxygen in her blood to give an idea of how much was being received into the body. Too much oxygen kills the lungs, not enough oxygen causes the brain to die, so they were walking this tightrope. Every 20 minutes, they would take a measurement, so Heather was literally a pin cushion. She had been drained of blood so many times that it was just an awful situation. As Deborah said, the other side of this was there wasn't a lot of response, there wasn't any movement of any significant kind, so the doctors had no idea what the level of brain damage was. The reason they thought there might need to be surgeries was they would take x-rays of her body, and initially it would show there was fluid outside of the organs. They felt that when she was in the culvert, perhaps she had been pushed up against rocks or other debris and had internal bleeding. They concluded that she did, and that's why the surgeries were needed, but as Deborah mentioned, after some blessings were given, they retook those x-rays and concluded that no surgeries were needed. We were in a situation at that point where the doctors had no idea of her capabilities, but it looked like from a physical perspective, in that organs and stomach and body were okay, there wasn't any significant damage so then we got down to the end of this.

Deborah: Well, one other thing.

Kent: Period.

Deborah: One thing that we did know was that occasionally she would hear. She would stop and listen, and one of those occasions was when we brought the two children up to see her in the intensive care unit. They came to talk to her, and then they sang "Incy Wincy Spider," which was a song she was just learning in nursery, and she just stopped, and you could tell she could hear. She knew they were there, and she knew she understood what was going on. Nothing else seemed to be working, but it seemed her hearing was working, so whenever I was with her, I would talk to her all the time, try to calm her down and let her know I was there. We got to the day when they were going to release her, and they told us we needed to send her to an institution. "She is way too much work for you to take her home." She turned two while she was in the hospital, and Kent and I both felt that this is a little baby, and we weren't about to send her to an institution without at least trying to take care of her ourselves. The insurance company was kind of crazy; they told us that if she went from the hospital straight into a facility, they would fund it, but it we took her home and it didn't work out and we wanted to put her in a facility, they would not fund that. I guess the hospital staff were thinking that we would definitely do this facility, but it never occurred to me to do that. There was not even one second that I thought of doing that. This was my little baby, and I was going to take her home and take care of her whatever way I could.

Kent: We asked multiple times what can we expect here, and I think in his effort to level with us, he used the term, "what you see is what you get," so his prognosis was the likelihood of any improvement in her ability to ever see again, to talk, to move her extremities, that wasn't going to happen. I hate that term they use, but that term of vegetable was what he described, and that's what we would have, and he encouraged us as well as others to put her into this institution.

Gerald: You didn't; you took her home. Let's fast-forward just a little. When did you find out the extent of her disabilities, because you had a prognosis that was very bleak. The reality was that it wasn't quite like that, correct?

Deborah: We were very fortunate, I think. I figured I would be home with her for a year and everything would be fine, because once she was home, she knew she was home. She calmed down and was off her sedatives in about six weeks. Her reflexes started coming back. I was able to start dropping liquid into her mouth, and she started showing physically that she was beginning to progress.

Kent: Just to clarify, when we brought her home and she couldn't swallow, that's why the tube was necessary as she had no ability to swallow.

Deborah: She had no reflexes anyway, they just started happening, but after a year into it, I realized this is probably pretty permanent. We are going to have some issues here for a longer time than I had hoped, and it kind of hit me hard after about a year. I thought, "Wow, this is going to be more than I had anticipated, and things are going to be very different." We had another very fortunate thing. Kent's insurance company had no limit on therapy; we could go to the PT, OT and speech therapies as much as we wanted, so I took her five and six times a week so that we could take advantage of that. We were grandfathered in after they changed that policy, I'm sure because of us, because I think your company was self-insured, wasn't it?

Kent: Well, it was a big company.

Deborah: Yeah, big international company.

Kent: I don't think it was because of us.

Deborah: Anyway, we took advantage of that, so she made some good progress.

Kent: Even the first day there was progress. It was amazing to get her back into our home with her family around her, away from the tubes and all of the equipment back at the hospital. She began to do some really cool things, not in most people's minds, but in our minds it was impressive. As Deborah said, we had tremendous hope at that point. Man, it looks like she can do this now, and she began to move her little toe, and this is happening, and we were very excited. That's why we had this great hope initially, that all of this was going to return to normal again if you can understand that term normal.

Deborah: After about six months, I saw her eyes follow somebody across a window, and her eyesight came back in fully. She did have some amazing progress, there were little miracles along the way that kept our hopes up.

Gerald: Caring for Heather at home isn't easy. As she grew, the difficulty of caring for her physically increased. They moved three times to create better accommodations, and with each move, they had to battle with each school to create an appropriate educational program for Heather.

Deborah: After she got into the preschool, I heard the use of the term SMH, that Heather's diagnosis was SMH, and I asked what that stood for, and they said, "Severe multiple handicaps." That was the first time somebody actually said that's what your kid is, and it really hit me hard. I didn't think of her that way. I thought, "Yeah, look where she's come from, she's done amazing," so that label really kind of set me back. I thought, "Wow, that's how other people think of her," and if it's your own child, I don't think that you always see the deficits that other people are going to see.

Gerald: Describe Heather now, how old is she?

Deborah: She is 34.

Gerald: She is 34.

Deborah: Yes.

Gerald: She is not blind.

Deborah: She is not blind.

Gerald: So, what did she end up with her abilities?

Deborah: What we found out is that Heather has a very fun personality, She loves teasing, she loves humor and she loves people. She is very much a people person. She does speak but it's a little hard for people to understand her if they don't know her well, but she is very able to tell us about her needs, which is another miracle, and we are very grateful for that. She cannot walk and will probably never walk. She kind of lost interest. We had her working on walking, and it was very difficult, and she finally just said "I don't want to do this. I am fine in a wheelchair." She does use a wheelchair, but she can roll around and get herself around on the floor remarkably well.

Kent: She'll pull herself up into chairs if she wants to sit with people, and she's very determined. You can tell that as difficult as this was for her, she was not going to let it impact her having a good life.

Gerald: So, do you have to do a lot of personal care?

Deborah: Absolutely.

Gerald: Heather has been at home now for 34 years. Relative to the care for Heather, what is the hardest part?

Deborah: The constancy of it. It is 24 hours. She is fortunately a very good sleeper, so most nights we don't have to deal with night issues, but there are some times where we do. We do have caregivers who help us, but it's always in the back of your mind. It's just a constant, I don't want to say it's a burden, but it's a constant.

Kent: Awareness.

Deborah: Yeah, awareness in your mind. Every time I get a text message, I have to check it to make sure it's not some issue with Heather.

Gerald: Deborah told me that because Heather was home, she was unable to be employed because as she put it, she is unreliable. Deborah is perpetually on call, previously because of unexpected issues and school, and currently when home care attendants can't come as scheduled.

Deborah: I spend a lot of my day dealing with her medical issues or her therapy issues or her staff issues. It does take up the bulk of my time. We are very fortunate that Kent can work and support us so that I don't have to, so yeah, it's the constancy I think that's hardest for me, and the physical now as I get older. It's much more difficult for me to physically take care of her.

Kent: What I want to add to that is from what we initially thought was going to be her quality of life; it is absolutely night and day. As Deborah said, she can kid around, and she loves to do it. When people come in, she wants to meet them, wants to show them her room and talk to them about her. She loves animals, so all these things she can do are miracles, they really are. They are tremendously positive, and it brings great joy to our family. The things that our other three children have learned from Heather are dramatic. I'm really proud of these three kids, because they have always kind of sought out the person who might be alone or who's a little bit different or who might not be fitting in some way with the group, and they physically or figuratively put their arms around them and pull them in. They have seen how Heather is different, but how if you don't look at that difference in the normal way, you get benefits, so they do that, and they get benefits from these other individuals whom they assist. I think Heather has had more of an impact on our family in teaching us how to be quality human beings, not that we are there yet by any stretch, but we are much better.

Gerald: Yeah, you actually anticipated my next question, which was about the joys and the impact on the family, anything you want to add?

Deborah: It's a very rich experience to have a child with a disability in your family. They make you think in a different way from a different perspective on what is important, how important family is and how important just loving she is. She is full of love and teaches us how to love better. She is also full of patience, which is probably my worst attribute, and she teaches me a lot about it. I can watch her often just being patient for things she has to wait for people she has to wait for, or just getting herself somewhere. It takes so much patience for her to do any task, and it has taught me a lot about what patience is and how poor I am at showing it.

Gerald: Essentially you were told that your daughter would be a vegetable, and you were strongly encouraged to put her in a institution and walk away. You did not do that, but opted to take her home. You had some rewards along the way as she progressed, but you also had a lot of responsibilities for the care of this child. No one would have blamed you if you had institutionalized her, and they probably would have thought that was a smart thing to do. You've now had 34 years of hard times and joys; was it worth it?

Kent: No question, it was definitely worth it.

Gerald: Deborah, was it worth it?

Deborah: Absolutely yes. She's made our lives so much more than things would have been had we not done this, and I can't imagine the vacuum that we would have had if she was not in our family.

Gerald: Thank you both. You might be wondering about the man who assisted in the rescue. Deborah and Kent only know about him because the next day he came back and put a grate over the culvert to protect other children in the future. He was seen by a neighbor who asked his name and his 10-year-old son's name. He was publicly recognized for his bravery, and is now 42 with a family of his own. Deborah and Kent still exchange Christmas cards with the family each year.