

Kids Crusaders Corner

By: Julie Fioravanti

Happy Spring, finally!!! Welcome back to Kids Crusaders Corner. The month of May (at least in the area in which I live) usually brings wonderful spring-like weather, flowers blooming (as well as allergies), and Mother's Day among a long list of other things. This year we saw a final snowstorm, torrential rains, flooding, and then some sun and spring, almost summer-like weather.

And then there was Mother's Day. As a Mom, I have always loved the little projects my kids used to bring home from school, delicately handcrafted with their tiny fingers. Now that my kids are older, the handmade projects have pretty much stopped but the memories are still there. I rank it up there amongst one of the highest "Hallmark Holidays" around. Seriously, if you asked any mother if she really wants you to stand in a store for hours filing through cards that basically say the same thing, blah, blah, greatest mother ever...and another \$5.00 handed over, I'd be willing to bet most moms would say skip the card. Snuggle with me in bed. Bring me a cup of coffee. Look through old pictures with me because you have all grown up so fast.

For me Mother's Day also represents an anniversary of sorts. 23 years ago, on a Sunday (Mother's Day) we walked into the neonatal intensive care unit where we had spent the previous 25 days of Nick's life. It had become almost our second home. There were Familiar beeping monitors no longer phased us as much as they had in the beginning. New parents were coming in Watching new parents coming in with their babies looking like we probably had a month earlier. Uncertain, alone, and scared. Nick had three primary nurses that took care of him around the clock, - Kathy, Ginny and Kathy. 25 days into our journey, Nick had stabilized but the doctors still had not given us any real prognosis or even an idea of when we would be able to bring him home with us. But 23 years ago, on Mother's Day, those 3 nurses pulled together and gave us the best gift ever. They got the chief neonatologist to sign discharge papers so that he could go home with us that day. It was one of the best and worst days of our lives. We were so happy to finally be able to bring him home. We were also terrified of all the special equipment and monitors that he was coming home with. What we really wanted were those 3 nurses to come with him.

But we left, and we managed to get through the first day and then the next day. And little by little the days turned into years and here we are, 23 years later. What I want to focus on this month in Kids Crusaders is Love, Life and Loss. I will try to keep this upbeat but I need to keep it real. Not only for me, but for all of the other mothers that may possibly be able to relate.

I just finished watching a movie that aired on Lifetime Movies, "Return to Zero". "Based on a true story, Return to Zero, tells the story of a successful couple, Maggie and Aaron, who are preparing for the arrival of their first child. Just weeks before their due date they are devastated to discover that their baby son has died in the womb and will be stillborn. The two attempt to go on with their lives but cannot escape their postpartum grief and their relationship has been forever altered by this loss." (Courtesy of www.mylifetime.com).

I completed 19 years of postpartum nursing recently. I lost count of the numbers of newborn babies I've held in my arms. The healthy ones, the ones with congenital anomalies, the stillborn ones. When Nick was just a toddler I remember trying to do my "job" with compassion and empathy. I remember so many times having to fight back tears as I watched teenagers having babies, healthy babies. And at home, my baby slept with an apnea monitor because he would stop breathing. He always had portable suction machines with him wherever we went. I was determined to separate my experience from the rest of the world. On the rare occasion I would have parents that were faced with a "diagnosis" instead of a healthy newborn, there I was...always at the forefront. It was during those times that I was able to not feel so alone. I was able to use my skillset not only as a nurse but as a "warrior" mom. A mom who fought hard for everything she believed in for her child, and the word "no" just wasn't an option. I was able to spend time with these parents and share my own personal experiences, always hoping deep inside that I was somehow making a difference. I was letting them know that no matter how afraid they were, they were never alone.

Then there were the moms that delivered their babies just like in the movie. Stillborn. And guess what? These moms needed a nurse just like any other mom, if not more so. Someone who could sit quietly with them and allow them to grieve their loss, to hold their baby, and to not try to make sense out of something that would never make sense. I have close friends that have endured this very loss. I reflect back on the day Nick was born and I can't help but think how my life would be different if we had asked them to stop the resuscitation efforts. We could have, and they would have, but we didn't. Were we being selfish?

I have cared for families that have had tragic accidents happen to their children. Babies that were born healthy, and the dreaded word “normal”. What is “normal” anyhow? Is there such a thing? The children who were happy, healthy, laughing, and playing one moment and then fighting for their lives the next. Did they win the fight? I suppose it depends on who you are asking. What I do know is that we all share a common triad thread of Life, Love and Loss. And there is a huge social stigma attached with the loss portion of what we share. What the movie *Return to Zero* did eloquently was to focus in on the isolation that is often felt after the loss; the social awkwardness that people have when they don’t know what to say to you. And as a parent I lost count of the number of times that people said things to me (and still do) that just made me want to scream. The clichés that people think are comforting are not. Not ever. I’m not going to endorse any religious views here. I believe that is very personal and private. What I will say is, please don’t ever say to someone whom has experienced a loss (be it in utero, or secondary to an accident, or something present since birth) “God doesn’t give you more than you can handle.” Or, “God only picks special parents for special kids”, or “You can always have more kids”, or (my personal favorite from my very own mother-in-law) “I had 5 perfectly normal, healthy babies. I don’t know what the hell you did wrong.” Yeah, ouch.

The list is endless when it comes to common day clichés. And not one of them ever made me feel any better. Not about myself, not about my situation, not about my child. How about the cliché...”until you have walked a mile in my shoes...”? I am grateful for every day that I have with Nick and I have never taken for granted the gift of his Life. I have also never dismissed the depth of my pain from the Loss of a dream that I once had. When all of my friends were having babies, I was supposed to join them in the circle of birthday parties and playdates. Instead I found myself separated by Loss; a loss that they couldn’t understand. I always felt it was my “job” as a mother to my baby to bring safe passage into this world. And to this day I still feel that I failed Nick in doing so. It’s a guilt that only a mother can know.

Yes I made the best of the situation I was in. In my head I like to believe that I somehow loved Nick back to life. Reality stands that machines brought Nick back to life because I said “yes”. And, without sounding cliché, because maybe he is in my life for a reason. No doubt my life has changed since we began our journey together. And yes, I went on to have 2 more perfectly healthy, “normal” (by whose standards?) children. They showed me that a heart shut down from the pain of loss can open up and love without fear. They showed me that they are stronger than I ever gave them credit for; they are kind and compassionate and love unconditionally. They learned patience at a very young age and they understand when they see me with tears in my eyes that I just need time to be alone with my pain. It is a pain, a loss,

mixed with love and life that one simply cannot quantify unless they have lived some portion of it. I cry. Every single day. And it's ok. It's a healthy release and it's never for long. For me personally it's about trying to keep the world in perspective when the ground that you were once standing upon has been ripped out from beneath your feet. It's about keeping some sense of balance in a triangle that will always tip from corner to corner. Life, Love and Loss. It's about understanding that there are so many other "triangles" around you, and that you are never alone.

So for all of the moms out there, Happy Belated Mother's Day. If you know someone who has suffered a loss, know that it's ok to talk to them. The most comforting words we can ever hear are "I love you and I'm here for you". Skip the social clichés. Speak from your heart and know that another heart will listen. Don't be afraid to catch a falling teardrop. The silence of your actions will speak louder than any words. If you are just starting out on your journey, don't be afraid to look up and around. You will see that you are not alone. If you have been on this journey for a while, please reach back and grab the hand of someone who needs it. "Never get tired of doing little things for others. Sometimes those little things occupy the biggest part of their hearts." (Heart touched quotes).

Together we can embrace Life, Love and Loss. Isolation should never have to be an option.