A trip to Florida!

Our son Kyle was born on a beautiful October day in 1996. All our hopes and dreams for a healthy baby boy were shattered for a second time in the delivery room, where he showed obvious signs of respiratory distress and muscle weakness. The NICU became our new home away from home for the next 2 1/2 months as we watched, waited, and prayed for our second baby boy to gain strength enough to come home. We had lost one newborn boy before, I didn't want it to happen another time, it seemed too much to bear.

Our prayers were answered with him coming home. In the first weeks it was a huge adjustment because of the new normal--noisy machines, nurses, and therapists of all sorts were regularly in and out, disrupting what would normally have been a serene beginning to Kyle's new life. But they were all a necessary part of keeping him from going into respiratory distress, and hopefully keeping us, his parents, from complete and total exhaustion. Nurses had to be in our house late at night and in the wee hours of the morning, or we would lose out on sleep; so privacy and feeling rested were rare luxuries.

Small steps became exciting milestones, the norm of parenting special needs. Kyle's two older sisters adapted to the new, busy household as nurses sometimes (but not always) befriended them. We did not have a clear diagnosis until he was nine months old. When we learned what it was, we felt lifted up as we could now reach out and find others like us...other parents who had walked the same paths, other children perhaps who had grown up into adults. This is when we found Alison and Paul Frase, and their son Joshua! And we learned of their Foundation which funded the ongoing research that would someday maybe help our son and boys like him! We were so excited!!

A few years later we decided to make a long trip to visit the Frase family. It was so important to us to see them, and to have our sons meet, too! That was the sweetest part, seeing these two boys, with one of the rarest of diseases, meet each other and bond over video games! Sharing time together talking about their favorite movies! While we visited with Alison and Paul, and their daughter, I think the two boys swapped stories of their own, too!! A real bond had been formed!

A few years later, we made the trip again and the two boys picked up right where they left off, greeting with grins and "how are you's?" that made our hearts swell! What could be sweeter than seeing these boys, with hearts of courage that we can barely imagine, giving each other high-fives? Nothing could compare!

Such is the bittersweetness that is the breath of special needs parenting. The celebration of life, and the grief of losing a beautiful life running side by side.

~ Betsy Grant