

Written by Kim Kowalski in 2008

‘What did your son have?’ she asks me as she picks her daughter’s jacket up off its tiny hook. She stops and looks to my eyes as I answer. ‘A genetic neuromuscular disease,’ I say, “its very rare, I’m sure you’ve never heard of it. Only about ten kids are born with it each year’. I bend down to grab my son’s backpack, while my seven month old happily busies herself with my hair. “Oh” she says as her gaze shifts downward to a child size bench across the room. Is she wondering what it would be like to have *her* child die? Is she looking at me, with mother’s eyes, and feeling sorry? I stand in front of her and wait...hoping she’ll continue and ask me more about my son Sam.

If she asks I will tell her about his eyes. Giant pools of crystal blue big enough to jump right into - lashes any girl would envy. Eyes that could speak sentences and make his face smile without moving his lips.

If she asks I will tell her how he loved birds and planes. Smiling, I’d recount the time he was laying in his hospital bed signing ‘plane’ over and over, pointing to the window. My husband, looking out at the empty landscape, told him, “*Yes* Sammy, planes *do* fly in the sky”. A minute later, what must have been a tiny dot in the corner of the window was now a large passenger plane cruising by and my elated son lay there triumphantly clapping his hands.

I will tell her about a gentle child who couldn’t speak. I’d explain how weak facial muscles make it difficult to form words and that it actually takes a good bit of strength to push out a sound. “You don’t realize how much noise your child makes until they don’t make any,” I’d say. Studying her face, I’d then decide if I wanted to tell her how Sammy learned to say one word - mama.... I have so many stories to share.

Seconds have passed; her gaze turns upward to meet mine. A slight head nod and polite smile tells me our conversation has ended and we walk into the hallway side by side. Chaos abounds behind the door that corrals forty preschoolers waiting for their parents. Children are embraced tightly, it’s been three long hours since their parents have seen them last.