

## Ace Right-hander

The protocol would be painful, a daily schedule of intrusions to be performed, opportunities to probe and poke. "procedures" they were called. I gave my written permission and he became theirs.

We stayed on Rankin, the Clinical Research Unit, two hundred miles from home. Our room was typical hospital décor with a wall-covering of institutional pink. Our one window framed an unsightly view of the central heating plant with its ugly brick smoke stack invading the sky. Off in the distance, the bell tower of Duke Chapel rose through the trees in Gothic grandeur.

During our two week stay, a barrage of medical students, nutritionists, neurologists, psychologists and metabolic specialists found their way to our room. One doctor will be remembered for his grandiose entrance, like a king arriving for his coronation. Another doctor, the Chief of Pediatric Genetics and Metabolism, was as brilliant as he was kind. I listened intently, but did not comprehend, his explanation of the "efficiency of certain monosaccharides in providing key metabolic intermediaries to regulate catabolism." My feelings of inadequacy were only intensified by his level of expertise.

The nurses became my soul mates as we complied with orders left behind by men retreating to their research. Making 24-hour urine collections for seven consecutive days from a child still in diapers was a challenge. Inserting a nasal gastrostomy tube into my screaming, kicking baby left me shaking. I felt like a demon. I felt what a nurse must feel at times. I felt strength. I could hurt my child to help him and I would have to do it again.

Our time spent at Duke was outside the mainstream of life with no place to be and no one to see. It passed slowly but it was beneficial to me in unsuspecting ways. It gave me time to be with my "chubby little person", to know him better and to like him more. It also gave me the opportunity to meet the warrior within me, an elusive fighter who only shows herself when battlefield conditions prevail.

Now eight years old, mentally handicapped, hearing impaired and almost exclusively tube-fed, these labels tell little about my son. His metabolic disorder is manageable. Life-threatening crisis no longer occur. The sound of his laughter cackles through our home and is intermixed with the cries of a child who does not understand.

Our son's disorder was the happenstance of heredity, the wrong gene from both parents. He also inherited clear blue eyes, thick brown hair and a passion for the game of baseball. Both his father and grandfather threw balls and strikes for professional teams. Like them, he loves to wear the hat, swing the bat and to throw the ball, most of all.

Unlike them, his game will be played on a different diamond. No one will care about the speed or accuracy of his pitch, no one will count the balls and strikes. As my son becomes a man I know his differences will become more pronounced. I can only hope his way of standing on the mound and facing each batter and his wind-up and delivery of the pitch, will be enough to please the hometown fans.

Ace Right-hander was written in 1992 for a creative writing class I was taking at the time.

Reuben will be 40 on his next birthday so it's probably time for an update. He's been very healthy since March 2020. Reuben attends a day program four days a week and a half-day program at our church, once a week.

He loves all things baseball and NFL football. Over the course of many Christmas's and birthdays he's accumulated almost all the team jerseys and hats. We know he's upset about something, which rarely happens, when he throws his hat. Reuben plays on a special needs baseball and basketball team and he loves bluegrass music in all its forms.

To live with Reuben is to be greeted in the morning with "Bless you Mom". His laughter can come for any reason or no reason at all and is as infectious as the common cold. He loves going to church and out to a restaurant, even though he probably won't eat anything, he just loves being around people. Reuben has been assigned the position of is Happiness Co-Ordinator at his sisters' Early Intervention company and is the primary reason she chose to work with children with special needs.

He is tube-fed all his nutrition, a mixture of Duocal, Anamix and Ensure and will snack on chips or Cheetos.

He has taught me so much about patience and enjoying the little things in life and being satisfied with whatever

comes our way.

Please feel free to contact me if you'd like to talk about our kiddos. I can be reached at  
[Patt@CarolinaBehaviorandBeyond.com](mailto:Patt@CarolinaBehaviorandBeyond.com)