Winter: A Sib Story

So, full disclosure, this was way harder to do than I thought it would be!

Initially, I didn't think it would be such a big deal to share my story, but then as I sat at the computer I really wasn't sure how to start. I became overwhelmed with emotions. Honestly, I had to take a few days of reflection … I realized that I could write an entire book about My (full) Story, and I'm definitely not prepared to do that. Ha!

So this is what I came up with…

"Winter, Do you have a sister named Summer?"

"Winter, Were your parents hippies?"

"Winter, Aren't you Bret's Sister?"

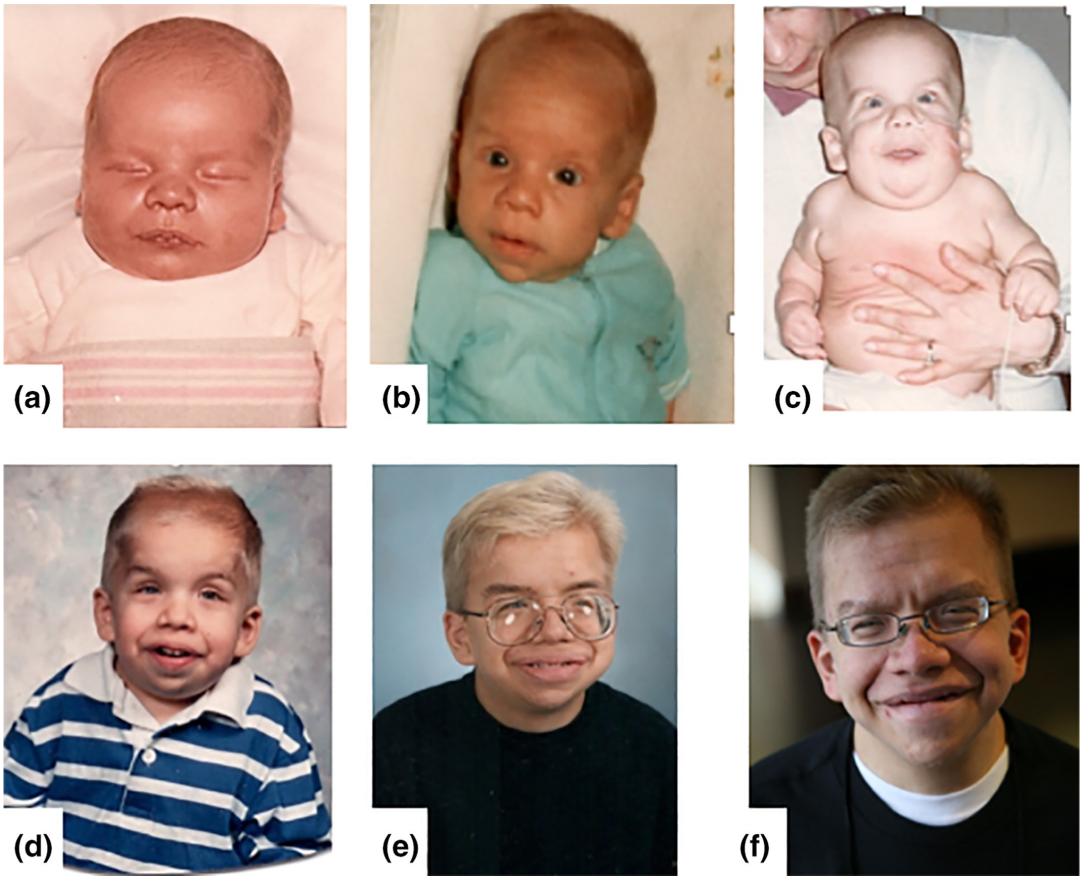
This is how most adults greeted me growing up. The girl with a weird name who had a brother named Bret.

I was born during the blizzard of '79. Depending upon who you ask you will get drastically different stories about how I got my name. Mom would tell you that I was named after one of her favorite actresses from a soap opera. Dad would tell you he personally shoveled the path for the car to get my mother to the hospital. As she labored, Dad suggested they name me blizzard and thankfully Mom said, "No! How about Winter?".. And so now you know.

As you can see in the photos I actually grew up with three brothers: Baron, Bret, and Kyle. I was the oldest. Anyone who is the oldest knows that this is an important fact.

Each of us related to Bret in a different way, and as we grew up those relationships changed.

Bret was my mom's third pregnancy. This pregnancy was much different from the others. Bret was born failure to thrive. He was unable to nurse or feed from a bottle so he wasn't able to get the nutrition he needed without being tube fed. He first had an NG Tube (Nasogastric-through the nose) and later a G-Tube (Gastrostomy tube-directly to his stomach, requiring surgery). Bret's prognosis was poor and my parents were told that he probably would have a short life expectancy. He had global developmental delays and a heart condition (HOCM-Hypertrophic Obstructive Cardiomyopathy). Bret wasn't diagnosed until he was 10 years old with Costello Syndrome.



Costello Syndrome was (and still is) a very rare genetic diagnosis. It is the mutation of a gene called HRAS. This happens in the DNA prior to birth impacting the development of the heart (not in all cases), muscles, bones, skin, brain, and spinal cord. Costello is a spectrum disorder meaning that it can have a moderate to significant impact on a person's intellectual development and overall health. The most identifiable characteristic of a person with Costello are their hands and feet. For more on Costello Syndrome check out the Costello Syndrome Family Network https://costellosyndromeusa.org/

So you know a little bit about Bret in regards to his diagnosis, but that doesn't really tell you anything about him as a person. Bret endured what felt like endless doctor and therapy appointments. Many, many surgeries! He might be the most resilient person I have ever met. Not to say he couldn't get a bit cranky sometimes, but for the most part that kid was always smiling. That's how I remember him anyway. Before he could talk he spoke to you through his eyes, and then later he was the King of Jokes! Bret loved to make others laugh and very much enjoyed slap-stick humor. His favorite comedians were the Three Stooges and possibly Bugs Bunny. He would imitate them allllllllll of the time. At any given moment he could be heard singing opera and the next making loud monkey or other jungle animal noises. Bret's first foods always included ketchup. It was very exciting to watch him learn to eat real food and progressively wean off the feeding tube. It became very apparent that Bret loved bold flavors and he would joke that his food was so hot we'd probably have to call the fire department. Some of Bret's heroes were Michael Jordan, Dale Earnhardt, Tim the Tool Man Taylor and the Super Nanny. Oh my gosh I could go on and on… He loved bowling, Walmart, his dog Simone, first responders, and so much more. Bret was an amazing person who brought a bright light to all of us who loved him. … But this story isn't just about Bret himself, but about how being a Sib has connected me with Options & Advocacy. Bret is definitely a big part of "My Story. "

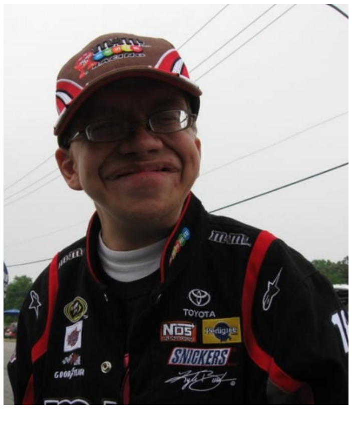
As I mentioned before, all of us related to Bret differently. I was Bret's protector and caregiver whenever my mom and dad were away. When we were small there were real Respite Workers that could come to your house. I remember my parents utilizing Respite Workers and worrying that they couldn't possibly care for Bret the way I could. I recall watching over them very closely and volunteering to manage his feeding machine when he was very little. Of course the Respite Workers were very capable, but this was my role. I worried about him constantly. As I grew older I at times found myself in scuffles because someone had used the R-word or made a joke about my brother. I didn't realize then how much worry I carried for my brother, but as an adult it makes sense as I am in fact a worry-wart!

Baron and Bret were closer in age and so they fought more often than not. This used to drive me bananas! I can see now though that Baron was more empowering than I was. I was a doer, always wanting to make things easier. Baron didn't see why Bret should get special treatment or not be expected to follow the same rules in the house. This in the long run was probably very good for Bret. Baron would be the first to say, "He can do it! "

Kyle, our baby brother was often mistaken as Bret's older brother, because as a baby he surpassed Bret developmentally within his first years of life. I think that Kyle was also a model for Bret and a motivator developmentally. Kyle was walking, running, jumping, talking.... As he watched Kyle grow, we saw Bret make gains as well.

None of us were very fond of his doctor and therapy appointments. It felt like we were always in the car and having to go to far away places for this, that, and the other thing. We ended up spending a lot of time at our grandparents' house. That was much more fun than tagging along!

This part of my story isn't about complaining, but to acknowledge the challenges that families face when caring for a child with significant medical and developmental needs. My parents had to work a lot to afford the care that my brother required. They were often gone seeking medical advice. Bret had so many different doctors we used to joke about it because if you didn't laugh then you were definitely going to cry. His needs were clearly a stressor on my parents' marriage. Don't get me wrong, they were (and still are) amazing parents! I wouldn't trade them for the world. They loved all of us! Bret simply required more. They had to be focused on his health as it was literally life threatening. They had to make impossible decisions about his care and how to prioritize our family's needs. My brother Baron and I often wondered if they would divorce.



Bret also taught us that there is no such thing as normal. He taught us about the importance of authenticity and how to love others for their unique qualities. He taught us about perseverance and to never let others limit your potential. He taught us to be compassionate, never discriminate and to always stand up for those whose voices need to be lifted.

Before Bret passed away at the age of 27 he made so many wonderful loving friends, graduated high school, had a job, and became an uncle. He was a very proud uncle! When my Lilly was born he lit up with pride and enjoyed looking after her. As she grew into her toddler years, and my son Will also came a long, Bret thought it all a bit less cute and more disruptive. They would invade his space, take over his TV and at times they would argue over whose Happy Meal toy it really was. He started to quote Super Nanny to me and opt out of spending time with me. He strongly believed that I needed to learn how to manage my poorly behaved children. I laugh as I write this because it was all such typical family behavior to get into these types of tiffs and become frustrated with those younger than you. For so many years I was Bret's go to Sib, but things were changing now as he started to prefer the company of his brothers instead of me. It was sort of awesome to watch those relationships mature.

When Bret passed it shook our family to the core. Grief is impossible to truly understand until you have had to endure it. It has been 11 years. I grieve for him today as if it were just yesterday. Of course we have all learned to live with our grief, but for those who have lost know that void and longing to see your loved one never truly goes away. Bret is still a part of our lives. My oldest three children were 5 (Lilly), 3 (William), and 9 months old (Isabelle) when Bret passed. Lilly especially remembers Bret as they were buddies. They saw each other almost everyday. My youngest Charleigh joined our family three years after he passed. She has heard so many Bret stories she talks about him like they once met and had adventures together. ... Who knows maybe he has visited her.

When my husband Scott and I married he made a commitment to me and understood that I was a package deal. That some day Bret might live with us if ever my parents could not care for him any longer. Bret was woven into all parts of our lives. Baron was to be the executor of his trust, I the caregiver, and Kyle would probably have been the fun brother he could escape with.

My parents did eventually divorce. *(That's a story for them to tell)*

Here we all are now. Still together. Growing. Stronger. Tackling new challenges and embarking on new adventures. Bret is always with us in our hearts and continues to be an inspiration for us all.

Bret definitely has impacted me as a person, a professional, and as a mother. Had there been no Bret I don't know that I would have made the relationships that I have or found my way to Options & Advocacy (O&A). Six months after Bret passed away I was gifted the opportunity to help start up the Sibshops program at O&A. To this day it is one of my most favorite support groups that we offer. I have met the most remarkable Sibs! I encourage you to check it out. Those Sibs are most likely to be your child's closest friend, advocate, and life long supporter.

Thanks for reading my story... My next chapter includes all of you!

Be kind and love each other unconditionally! ~Winter

You Are Invited to Share Your Story!

How and why are you connected with Options & Advocacy?

What is your mountain to climb?

Let's embrace the hardships and celebrate the successes!

Welcome to our O&A community. I'm glad you're here!

Bret & Stef– "Sweethearts"