



Reflections of a River Rat:

Learning from our developmentally challenged daughter

The party, by a consumer's standards, wouldn't rank with the glitz and hype of Adele singing at the Hollywood Bowl. Oprah didn't show for a softball interview. The food wasn't that good either. If those weren't enough, we endured several mechanical breakdowns.



Amy, Katie and Susan are pictured below Sarah and Jeremy.

But on an intrinsic level, this bowling party was a smash hit. If you measure the

laughter, smiles, joking, gifts, bowling, high fives, storytelling and sense of camaraderie, our daughter Katie and her five friends could not have scripted a better 36th birthday party.

Nobody topped 100. Nobody spent the evening texting. Nobody worried about how they were dressed. We simply had fun. This birthday party marked the first time Katie and her pals had socialized since the brunt of the pandemic rolled over New York and the world like a tidal wave in March 2020.

Throughout Katie's life, we have learned to make the best of any situation. Our first lesson happened 45 minutes after Kathleen Barbara Holleran was born on Nov. 9, 1985. The doctor entered our room to say Katie had "characteristics of Down syndrome." Thud! Our jaws dropped. We panicked inside. How were we going to handle this? Financially? Emotionally? Our measuring stick for life and parenthood changed immediately. Lesson #1 – don't take anything for granted.

It turns out that Katie – like any child – enriched our lives for who she was, not for what we wanted her to become. Mary and I learned not to compare Katie's development or achievement to our preconceived notions of success, but rather to help her maximize her potential. We treated her as a child with high expectations, not someone who deserves pity. So when a family member voiced disapproval when Katie's behavior deserved a timeout, we quoted our pediatrician: "The only thing tougher than raising a Down syndrome child is raising a spoiled rotten one."

You learn to appreciate Katie's party pals for their spirit and unique take on life. Mitchell is an active young man. Despite his challenges, he hikes, rides horses, bowls, competes in cross country skiing, and on this night, professed his love for the Munsters TV show. "Jim, can you change my name to Fred. I want to be like Fred Gwynne with the bolts in my neck. He plays Herman." Then he pointed out how Al Lewis played Grandpa and Yvonne De Carlo portrayed Fred's wife, Lily. Great memory.

Two of Katie's longtime friends happened to have Down's too. Amy has stuck it out with Katie for 9 years as her housemate. Susan lives independently with her cat, Snuggles, and has mastered public transportation. So too has Sarah, who said she sometimes feels like Cinderella because she was orphaned as a child and now has only a stepmother. Jeremy never loses his joy despite losing his father,

grandfather and mother. Today, he lives with his mother's boyfriend. That man must be a saint. Every statement Jeremy makes, he punctuates with a high five. His attitude is infectious.

You can learn a lot about patience, joy, hope and innocence from this group.

Birthdays carry a lot of memories, but we've learned a lot too. When Katie was 6 or 7 years old, we invited her classmates to a party and hired a magician. A friend walked in and saw black, white and Latina children and commented, "This place looks like the United Nations." We were proud of that.

She reveled in her friends, but the best part was when we told her a special mystery guest would arrive if she closed her eyes and wished. Mary's sister had arrived from the airport through the rear door. The magician snapped his fingers, Katie opened her eyes, and there stood her godmother, Aunt Annie. The shrieking is seared in our memory banks -- "He made Aunt Annie appear!"

Katie agreed to turn her 16th birthday party in 2001 into a fundraiser. We rented out the gym at our church and invited our family and friends and her classmates and former teachers to eat, drink and be merry, and listen to Irish folk music from the Dady Brothers. Katie's guests couldn't bring gifts, but they could give to Special Olympics. Contributions were way down because of the overwhelming focus on the victims of 9/11. Katie's high point was joining Joe and John on stage, receiving a Dady Brothers tour jacket, and singing "No Nay Never No More."

She is the antithesis of her grandfather, Fran Holleran. When the notes go up, her voice goes down. She improves the reputation of alley cats everywhere. She did something right, though, because her friends contributed \$1,900. It was a lesson in generosity.

When Katie turned 30, we rented space in a church social hall. Same deal -- no presents, but you could give money to the Rochester City School District marching band that was reforming after 30 years. The music teachers had formed a band named The Department. They played for free. The neat coincidence was that the vocalist, Alison, had been Katie's summer camp director about 25 years ago. It was a lesson in enduring selflessness.

Katie babysits her nephew Wesley Edwards.

The bowling party was a lesson in patience. We might have lost a few pounds

waiting for our food to arrive, then the pinsetter malfunctioned. So we all squeezed onto one lane. You never heard one word of complaint. When the electronic scoring went wonky, we didn't worry about scores or whose name came up, we just took turns.

This is the infant girl we hoped would go to the prom one day. She did. Along the way, she became our church's first altar server with Down's, won a few



hundred Special Olympics medals, moved into a group home at 20, got a cell phone and debit card, and held a job for 13 years. We've learned a lot from her.

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