

The People Behind Colton's XXXtraodinarY Cause



By Marybeth Cale

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Less than a year into the relationship, Michelle unexpectedly became pregnant with Ella, "a wonderful surprise," as she said. "Our family and friends shared in our joy; everything was as it was meant to be. There was no pressure to get married before her arrival, so we did not. She was born in September of 2011, and on the morning of my first Mother's Day (May 2012), Erik proposed to me with a ring in one hand and Ella in the other."

Michelle, a graduate of Pace and competitive soccer player, worked in the Pace Athletics Department for 10 years before the couple began their romance. Today, she works part-time for Crown LP Gas, the company Erik's grandfather launched (now run by Erik, who knew from the time he was 13 that he wanted to take over the business, and studied Heating, Air Conditioning, and Gas Technology at New England Tech to prepare). By 2013, Erik and his father purchased Dutchess Oil and Propane, now Crown Energy, and offer propane, fuel oil, diesel, and gasoline delivery/service.

The job they clearly love the most, of course, is raising their children: Ella, who turns 6 in September, and Colton, age 3. It has not been without challenges... but their response to their adversity sets a gold standard for us all.

Colton's Story

When their sweet little boy Colton was 9 months old, he was failing to thrive and showing signs of developmental delays. Erik and Michelle were referred to a geneticist; it was a day that would not only change their lives, but have a huge impact on the lives of so many others as well. "We thought we were just covering our bases. We couldn't believe the diagnosis: Colton's delays were the result of a rare syndrome called 48XXXY."

48XXXY results in low muscle tone, complications with speech/language, developmental and behavior problems, and varied health issues. However, according to Michelle, Colton's future looks much brighter than that of others because of his early diagnosis; the sooner children receive much-needed hormone treatments and therapies, the better their long-term outcomes.

"It is critically important to get a diagnosis as early as possible, but many families miss the opportunity. 48XXXY is a rare condition that occurs in only 1-50,000 births. Although Colton's specific variation is rare, there are several X & Y Variations which are occurring in 1-500 births - but sadly, 7 out of 10 cases will never be diagnosed. Failure to diagnose and treat these children can jeopardize their future; learning disabilities, language impairment, motor planning deficits, reading dysfunction, attention disorders, and behavioral problems worsen without treatment," Michelle explained.

The Birth of Colton's XXXtraordinary Cause

"Our world shattered a little bit on that day of diagnosis. After 2 full days of being sad.. and mad..and asking why him? and why us?, we decided we could either feel sorry for ourselves or we could proactively find ways to provide the best possible life for him. After stumbling across a 48XXXY group online, I received a message from a mother who had a 2.5 year old boy with 48XXXY who had been diagnosed at the same age as Colton. She urged me to visit The Focus Foundation in Maryland and schedule an appointment with Dr. Samango-Sprouse. She said that Colton was right at the age where early hormonal treatment is most effective and would most certainly change the trajectory

Everyone has a story of course,

but Michelle and Erik Hutchinson's is extra moving. Their tale reminds us that with challenge comes opportunity - and when you use your own adversity to help others, you can truly make an impact.

Both locals - Michelle graduated from Rhinebeck HS (1997, maiden name Tozzi), and Erik from Stissing Mountain Jr/Sr HS - the couple met as teens through mutual friends. Over a decade later, their friendship turned to romance.

Michelle shared, "full disclosure is that our love story is not traditional, but it suits us and we are proud of it. Erik and I had been friends for many years, involved in other long-term relationships for the duration of our friendship, but found ourselves single at the same time. I had not thought anything of it, but he had been texting me for a period of time, and now I believe he was laying the framework for something more. After 2 months of intermittent contact, I mentioned I was heading to Rhinebeck for the weekend (from Westchester County), so he asked if I would join him at a friend's birthday. Coincidentally, I was obligated to my sister's birthday that night, so I politely declined. Later that evening, I found him at the same place he knew I would be. He managed to rally his friends into going there, and his persistence paid off. After that, we started seeing each other every weekend. Things progressed naturally and quickly. With a foundation of friendship, we had a mutual respect and trust in one another from the very beginning."

of his life. Without hesitation, I made a call, and by luck of a cancellation, Dr. Samango-Sprouse was able to see us in 10 days. The Focus Foundation and Dr. Samango-Sprouse changed everything. Our grief and confusion turned into hope and optimism, and we have not looked back since. We quickly realized how lucky we were to have an early diagnosis and the resources to treat Colton. Not all families get an early diagnosis, and even if they do, many don't have the financial resources needed to get proper treatment. From the beginning we felt a strong desire to help others - to take the cards we were dealt and figure out how to turn it into something positive. That is where the vision of Colton's XXXtraordinary Cause came from."

The couple's nonprofit is designed to raise awareness about rare disorders and to raise funds to support research and treatment for local children who have been diagnosed with a rare disorder. The group hosts special events and relies on the generosity of individuals, foundations, and corporations to bridge the gaps between financial needs and resources for benefactors.

"Ultimately, we seek to raise the kind of awareness necessary to promote early diagnosis and intervention in honor of children like Colton," says Michelle. "He has a smile that will melt your heart and he brightens our every day. There are so many kids just like him who deserve the same shot at quality of life that we want for him."

A Rare Affair

Their major fundraising event this year, "A Rare Affair," will be held on Sat., Sept. 23rd at 5pm at Globe Hill at Ronnybrook Farm, Pine Plains. Tickets are \$85 per person and include dinner, an open bar, live music, dancing, and a silent auction. Sponsorships are also available starting at \$100.

In addition to raising awareness for X & Y Variations and supporting The Focus Foundation, the organization will also honor Maddie Clements of Red Hook and the Cure JM Foundation this year. Says Michelle, "like Colton, Maddie is a

delightful presence in the lives of all who know her. Diagnosed with Juvenile Dermatomyositis, an inflammatory disease of the muscle, she has faced a number of medical challenges, but has done so with a brave spirit that has inspired so many."

Through their work, Michelle and Erik also hope to create a culture of compassion for children who are struggling with rare diseases or syndromes, or who have other special needs. "I know that many children face bullying, but the rates increase for children like Colton who may be picked on because they are 'different.' We want kids in the community to learn about these differences and create an environment of support and encouragement rather than making them feel isolated."

Help this wonderful Rhinebeck family continue to help others in honor of their adorable son. Visit coltonscopycause.com to purchase tickets for the 9/23 event. ■



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