

This Little Light of Mine!

March 2022 Caregiver of the Month, Martha Smith
Missouri Department of Health and Senior Services



Tommy is a super hero! He is fierce, intelligent and courageous. Tommy was born with Congenital Hypoventilation Syndrome (CCHS), a rare neurological, genetic disorder that affects the central and autonomic nervous systems. CCHS is a serious lifelong and life-threatening illness affecting about 1200 individuals worldwide. Individuals with CCHS cannot sense oxygen or carbon dioxide levels in their body and therefore require objective measures of oxygenation and ventilation. Tommy uses a ventilator for mechanical breathing and a feeding tube for all nutrition. He has on-going medical needs requiring nursing care throughout the day and night.

Tommy was born in Oklahoma City, OK and required hospitalization for ten months before coming home. Tommy's family made the decision together that Tommy's home would be with his grandma and grandpa due to the level of care he required. Tommy's grandparents became Tommy's guardian at six months of age. Martha Smith, grandmother, is Tommy's primary caregiver. Martha stated, "We made the decision together as a family, what was best for Tommy to thrive." Martha could not do this alone. She heavily relies on the help of Tommy's grandpa, Mark, and aunt, Amanda.

In January 2022, Tommy turned six years old. Martha describes Tommy as "very expressive, emotional, joyful and happy-go-lucky!" Martha is vigilant about monitoring Tommy's emotional needs. As we know, life is a series of highs and lows – which is more often true for a child with special health care needs and their family. Tommy sometimes cries when he is overstimulated which causes anxiety and affects his breathing.

There are many times in Tommy's life where he has required EMS and the use of an ambu bag to encourage breathing. Martha explained, "It is not unheard of for Tommy to become overstimulated or have a crisis to where we find ourselves 'bagging' him on the side of I-44 or in the grocery store parking lot." These situations have left Tommy and his family trying to understand trauma and find ways to mitigate traumatic stress. Martha explained a recent situation where the family was in church and an ambulance had to be called for another church member. Tommy was markedly affected by the stimuli,

reminding him of the many times he needed acute care from emergency and hospital personnel. Tommy quickly became distressed and had trouble breathing.

Martha is a constant source of comfort for Tommy as he learns to navigate life's challenges. Tommy "loves people, music, riding horses and playing outside" just like other kids his own age. He is currently enrolled in kindergarten at Plato Elementary, 8 miles from his home. Grandma transports Tommy each day to school. School session is full days and Tommy attends as his health permits. Martha states, "He loves school and is very peer motivated."

When Tommy was transitioned from mainstream classes to a special education classroom, he felt punished and missed his regular routine and classmates. That very same week, his nurse of more than four years moved away. Tommy was affected emotionally which caused him anxiety and more trouble breathing. When he came home from school crying, Martha just held Tommy and sang "This little light of mine, I'm going to let it shine. Let it shine, let it shine, let it shine." She felt this was the best way to calm Tommy's worries and emotions. And, it worked!

Martha finds herself managing Tommy's reactions to social situations. As overstimulation affects Tommy's health and his ability to breathe, Martha finds ways to comfort Tommy so that he feels safe. Tommy uses sign language as a "secret language" with his grandma, especially when he's in the hospital or feeling vulnerable. It is a way he can block out things that cause him stress and stay connected to his grandma.

Martha works as a Certified Medical Technician and Nursing Assistant in health care facilities. Tommy's grandfather is a traveling Licensed Practical Nurse and often works away from home. Martha stated that although they had both worked in a health care setting before caring for Tommy, they did not have the level of experience necessary to manage Tommy's specialized medical needs. Martha and her family had to learn and master the technical skills necessary to perform Tommy's routine care which included responding to an emergency. Martha works for an agency on a PRN basis which allows her the flexibility to care for Tommy without reprimand from employers when nurses aren't available or when Tommy's health requires her to be with him.

Tommy receives about 40 hours a week of Private Duty Nursing services through the Bureau of Special Health Care Needs although he is authorized for more. In planning for Tommy's care, Martha remembers, "It's tricky when you're in the hospital, people say you'll qualify for nursing but that doesn't mean you will have a nurse. It's no one's fault that you don't have nursing." Martha wants people to not be afraid to recruit their own nurses. She encourages others to "to step out to advocate for what you need." She emphasizes, "Systems are in place to help people, but we know our own geography better than anyone. Nurses become a part of the family."

Martha's motivation to care for Tommy is faith-driven. She believes the best thing to do is prepare and educate yourself. "It's not magical thinking. You must build a tribe of support and you have to learn the language." Martha remembers finding someone on the health care team to help navigate the system and learn the care. "For us, it was a nurse practitioner. She taught us how to look for resources outside of a caseworker, and look outside of the box for solutions." Martha describes a technical language that families must learn when dealing with children with special health care needs. "At every corner of the journey, there will always be people who don't know things. You need to know what to ask for and ask for what you need. Never give up! If someone tells you no, you find someone else."

Tommy relied on a ventilator 24 hours a day, 7 days a week to breathe for many years. In October 2020, Tommy received diaphragm pacer surgery at St. Louis Children's Hospital, a procedure which involves placing a pacemaker lead on the phrenic nerve to send a signal to the diaphragm muscles to contract and expand. This was a "game changer" to help Tommy breathe without the use of a ventilator during the day. Tommy is now "free to run, climb and live his best life" without 6 feet of tubing attached to a ventilator.

When asked "What do you wish you would have known before becoming Tommy's caregiver?" Martha stated, "Try not to be too hard on yourself. There is a lot of information. Accept the fact that it's a process and you don't have to know everything. Be gentle on yourself and get enough sleep."

Martha would like others to know that medical needs bring anxiety and trauma. She encourages family counseling from a qualified professional, someone who has experience with medical trauma. Martha feels this is not only important for caregivers but siblings and other family members. Martha said, "We are learning to manage our fight and flight responses and learning how deeply these situations have affected Tommy and everyone in his life."

Martha finds purpose in advocating for children with special health care needs and plans to attend Disability Rights Legislative Day at the Capitol this year.