# The Hasan Family Adds to the Community "Garden"


*Big sister Raya helps Naveen build cognitive skills aided by a special learning tablet.*

COVER STORY

*By Jenna Caputo*
*Photos by MarkBolles.com*

SM Shajedul Hasan ("Hasan") has learned firsthand how important it is to not only be open to new experiences but also to make room in your life for people with disabilities. Originally from Bangladesh, a small country in South Asia on the eastern side of India, Hasan never thought that his journey to the U.S. would lead to a passionate mission for the disabled community and their families.

Growing up in Dhaka, the capital of Bangladesh, Hasan was surrounded by a population of 19 million people and a vibrant cultural life. He enjoyed attending many festivals, fairs and concerts as well as playing soccer and cricket. Now a U.S. citizen, Hasan came to the country 15 years ago to do his Master's at the University of Tennessee. He then completed his Ph.D. in Electrical Engineering at Virginia Tech before moving to the Capital Region for a job at the GE Global Research Center and a second MBA from the University at Albany. He is now a Senior Engineer and Project Leader at GE, responsible for generating new product ideas for various GE businesses. His most recent project requires him to work with GE Healthcare to design and develop a wireless patient monitoring system. "I have always been passionate about the latest and greatest technologies," says Hasan. "I feel great that the research and development I am doing at GE Global Research is ending up as a product in hospitals to monitor critical patients and that this technology will help them to recover fast."

*"We think of Naveen as a real life superhero - who is fighting everyday to survive and live," says Rimi & Hasan. (Photo by SM Hasan)*

Hasan's family now includes his wife, Rimi, daughter, Raya (6) and son, Naveen (3). Every childbirth is life altering, but Naveen's birth was the event that sent Hasan's family in a different direction. After an uncomplicated delivery, Naveen initially seemed like a normal baby. He was a happy child but quiet. He did not cry very often. As with many babies, he had problems with sucking and

was changed to a formula diet to help. As he reached the six-month milestone, Hasan and Rimi noticed that he was developmentally behind. By nine months, he lost the ability to drink from the bottle and his breathing became noisy. They had to feed him water and milk using a spoon. The doctor referred them to a neurologist to do some testing. They were sent around to multiple doctors but Naveen's MRI, EEG, pulmonary and initial genetic tests all came back normal. His genetic doctor recommended they do a whole exome sequencing test, which is a much more comprehensive genetic test also using blood samples from both parents. It took almost five months for them to receive the results, but they found out that Naveen has a very rare neuro-genetic disorder called Angelman Syndrome (AS).

AS is a severe neurological disorder that is characterized by profound developmental delays, problems with motor coordination and balance, and epilepsy and is often initially misdiagnosed as cerebral palsy or autism. People with AS cannot develop functional speech and often have feeding disorders and sleeping difficulties. They require life-long care, intense therapies and close medical supervision. AS affects all races and genders equally. AS patients generally have a happy demeanor with an excitable personality and usually are smiling and laughing. They tend to be attracted to water and enjoy swimming and bathing.

After the diagnosis, life obviously changed. "Life became overwhelming and challenging," Hasan recalls. "As parents, we realized something was wrong with him, but never expected that diagnosis." Rimi, also a graduate from Virginia Tech in Accounting and Information Systems, left her job as a Senior Auditor in NYS Division of Criminal Justice Services to stay home and care for Naveen full time. While most families dream about what their children will become one day, Hasan's family has to focus on teaching Naveen basic survival skills like using his hands, drinking from a straw, self-feeding, using the bathroom and walking. His life is full of therapies and doctor appointments. It is hard work and they often have to teach him the same things over and over again. He is progressing, but very slowly. Rimi explains their new life focus: "Since he is missing so many things in his life, we want to give him more opportunity and fun in his life. We celebrate when he reaches a small milestone. His disability teaches us that we should all feel blessed and lucky that we were born as a typical human without any disability. He makes us passionate, strong and kind parents."

But this journey has been paved with many challenges. They first had to accept this new reality and get through the resulting self-questions like, *Why us? What did we do wrong?* It is a lonely time while a family is coming to this acceptance. They have also had to deal with a lot of fear. *How would they explain it to their family and friends? How will people treat them and their son? How would this affect their daughter and her relationship with her friends? How would Naveen cope in a judgmental world?*

*Rimi engages Naveen with activities to develop fine motor skills.*

Their other big challenge has been balancing raising Raya as well. As a "typical" child, she doesn't need the constant attention to the degree that Naveen does. But as an active child who enjoys dancing, swimming and martial arts, and with only three years difference between the children, Raya also needs and deserves attention from her parents. "She also needs us," says Hasan. "She also wants to spend time with us. As parents we always feel guilty that we cannot give her as much time and focus as she needs. My wife and I can barely make some time for each other, either. We don't have any family here to take care of our children. We have to give most of our time and energy to our son. This kind of diagnosis is heart breaking. During this difficult time parents need support from family, friends and neighbors. With that support, they can feel that they are not alone. We want people to ask and talk about Naveen and his diagnosis but most people don't want to talk about it and many times they think it may hurt us."

Everything about Naveen's diagnosis has been a learning process, even more so due to the rare nature of the disease. There is not a lot of knowledge about AS, even within the medical community. They have had to find support groups through Facebook and other places as well as doing a lot of their own research. They also joined the Foundation for Angelman Syndrome Therapeutics (FAST). FAST was formed by Paula Evans after her daughter was diagnosed with AS. She realized that big pharmaceutical companies were not investing any money into research because of the small number of patients. Hasan explains FAST as an "all-volunteer organization of families and professionals dedicated to finding a cure for AS through the funding of an aggressive research agenda, education and advocacy. The Foundation is committed to assisting individuals living with AS to realize their full potential and quality of life. Their goal is to bring practical treatment into current medical practice as quickly as possible."

AS is caused by the loss of function of the UBE3A gene

in the brain, which prevents neurons from functioning correctly and leads to the resulting learning and memory deficits. But the loss of this gene does not seem to affect neuronal development, which leads researchers to believe that normal neuron function could be restored if the UBE3A function could be restored. Based on this principle, FAST focuses heavily on gene therapy research. They have provided funding to several medical universities, including gene therapy pioneers, University of Pennsylvania, as well as small pharmaceutical companies, to develop multiple gene therapy approaches for human clinical trial within the next 3-5 years.

In the meantime, Hasan's family is also working on the community level to raise awareness not only for AS but for all rare diseases and people with disabilities.

"Most parents have a typical child," says Rimi, "but we cannot guarantee that their children or grandchildren will be typical children without any genetic disorders. As parents, we should try to make this world safer and more beautiful for our children and grandchildren. As human beings, we should care about each other. It should not matter whether it's a rare disease or not. Our goal is to raise awareness and money to find a cure for as many rare diseases as possible. In this way, we will be able to leave a safer, rare disease-free world to our next generation."

Their first step to that goal is with an annual walk held on Rare Disease Day (the last day of February every year) and to help spread awareness so other people can understand what it means to be living with or caring for a person with a disability, as well as having a more inclusive mentality and remembering that people with disabilities want to be a part of the community's life as well.

"Naveen is very social and he likes people. He wants people to talk to him – he really enjoys it. Our dream is one day Naveen will go to a normal school with typical children. We want parents to teach their children about disabilities and rare diseases so that they can understand why Naveen and thousands of others like him are different. There are a lot of good things children can learn from a disabled person too. We need to think about this world as a flower garden. As different kinds of flowers make a garden more beautiful, different kinds of people also make this world more beautiful."

*For more information on FAST and AS, please visit cureangelman.org.*

*To help Team Naveen in their efforts for FAST, visit tinyurl.com/y9z5kmra.* ■

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