THE FORMAN FAMILY
Living for a Cure

BY JENNA CAPUTO
PHOTOS BY TARA WILEY PHOTOGRAPHY AND CONTRIBUTED BY THE FORMAN FAMILY

Like most first-time parents, Stephanie and Aaron Forman were excited while they prepared for their first child. Olivia made her entrance into this world four weeks early in October of 2014 and spent 21 days in the NICU. Finally, she was cleared to go home, but they noticed over the next few months that her development seemed slower than normal. By five months old, Olivia was diagnosed with Wolf Hirschhorn Syndrome (WHS), a rare chromosomal disorder with a deletion on her fourth chromosome. Life instantly pivoted to a whole new purpose.

Stephanie was originally from Slingerlands and Aaron from Ballston Lake. Growing up, they both enjoyed spending time with their family and friends, swimming and biking. Stephanie also practiced art as a hobby. Receiving her bachelor's degree in mathematics and a master's in education, Stephanie went on to get a job as a high school math teacher in Philadelphia. After three years in Philadelphia, she decided to move back home and began teaching online. While serving as a bridesmaid in a friend's wedding, she heard about Rational Enterprise—a company that sells an enterprise software platform for data management. Stephanie was intrigued and began working there as a client manager, then transitioned into multiple positions before ending up as the Director of Product Management during her 12 years there.

Meanwhile, Aaron began his career in accounting, working in Atlanta as an executive at the Weather Channel. But he, too, needed a change and planned on moving to Montreal. He was stopping home on his way there when his mother suffered a massive heart attack. Luckily, she survived, but he never left. He began working with his father, Dr. Everett Forman, a well-known physician in the area. In the 1980s, Everett had developed an e-prescribing software. As a self-taught programmer, Aaron decided to start the family business, DAWSYSTEMS, and became CTO of ScriptSure, their e-prescribing software. He's worked there ever since.

Stephanie and Aaron met on match.com in 2008. "We were both sort of done with dating sites," Stephanie says, "and he happened to message me one afternoon, and I caught the message. Instead of talking to me at length online, he just asked me to come meet him. We met, and that was it!"

They decided to look for a home in Niskayuna, knowing it was a good place to raise a family, and ended up buying a family friend's house on the spot before it even went on the market in 2010.

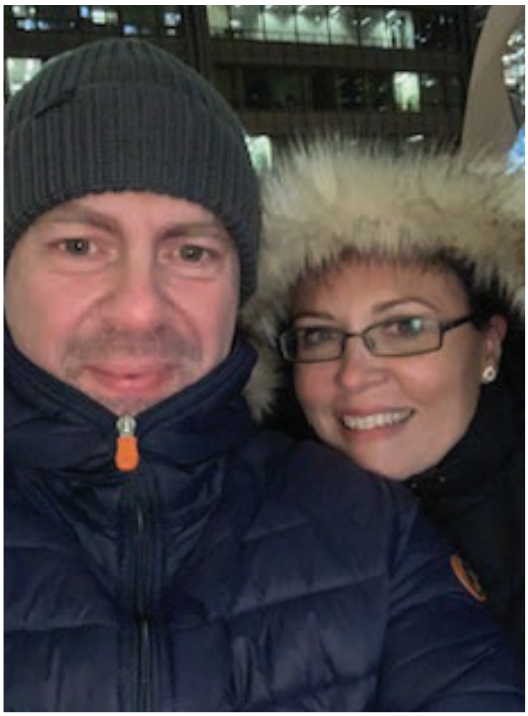
After Olivia was diagnosed with WHS, Stephanie initially wanted nothing to do with fundraising or family groups. She

wanted only to concentrate on her family. "It took me two years to get to the point that I turned a corner and said, 'Wait a minute, there's no research going on for kids like Olivia,' and I decided that I would start the organization."

In June 2017, Stephanie started Liv4TheCure (L4C), and within a month, they were already founded with a board of directors. A year later, they had a scientific advisory board, which included Anthony Wynshaw Boris, the President of the American Society of Human Genetics. L4C's mission is to advance the science and technology for rare chromosomal deletion syndromes like Olivia's. Originally, they concentrated on WHS, but as the Formans learned more about the disorder, they realized it was about the bigger picture—replacing what has been lost with large chromosomal deletions in general.

Over the first few years of Olivia's life, the Formans spent their time seeing doctors and learning how to be advocates for Olivia. It was a rough road as she had to immediately begin intervention services, using physical therapy, occupational therapy, speech, special education and vision services to help her with her development. She had her first seizure, a common aspect of the syndrome, at eight months old. Much of her life was spent in the hospital as the seizures, feeding issues, hypotonia (decreased muscle tone), cognitive and developmental delays and an atrial septic effect took over. And she is one of the lucky ones.

WHS is a partial deletion on the short arm of the fourth chromosome, usually caused by genetic changes during embryonic development, but sometimes caused by parents having a "balanced translocation," which is when two or more chromosomes break off and trade places to create an altered, although balanced, set of chromosomes. Since they still carry all the necessary genetic material for normal development, there are usually no signs in the parents of the alteration, but it does affect their offspring, generally affecting multiple genes with varying effects. These could include physical characteristics like wide set eyes, broad nose, cleft palette and club foot, as well as internal effects like seizures, heart and kidney defects, hypotonia, low birth weight, prematurity due to growth restriction and problems gaining weight in general. Motor skills and verbal communication can be significantly delayed, but these children generally have strong socialization skills. Currently, there is no straightforward treatment for WHS, only early intervention therapies to help the children eventually gain the skills they need.



Through it all, Olivia continues to amaze her parents every day. She taught herself to sit, roll, stand and is now learning to walk. She cannot yet speak, but she understands perfectly well and communicates through gestures and smiles.

"Olivia was a year and a half the first time we heard her laugh," says Stephanie. "We were on vacation in Florida with my parents and brother and sister-in-law, and we got to hear her laugh for the first time and caught it on video. Her laugh is contagious and brightens up a room!"

They've had to put some of their work on hold due to COVID but have plans for a new tactic for the organization. "Right before COVID hit in March, we had a Scientific Advisory Board meeting to discuss the next steps for research with L4C. We are hesitant to fall into the same pattern that most research organizations do (e.g., starting a registry, getting cell lines, etc.) because we feel that science really needs to take a step back and look at the origin of the deletions issue *first*. Once COVID is over, we are looking to connect with cell biologists to begin to explore what happens on the cellular level that causes these issues," says Stephanie.

To help with the cause, they normally hold several events throughout the year, including the Niskayuna Food Truck Festival normally held in September each year. This family event draws thousands of people with its food trucks, live music, bouncy houses, animal rides, the Spotted Zebras Bizzy Bees Kids Zone and other attractions. Most of L4C's events are currently on hold due to COVID, but they plan to hit the ground running again as soon as it is safe to do so.

L4C also works with ex-pro football player, Jermon Bushrod, and his organization, Visualize and Rise, to help raise money for children with WHS. In 2019, Stephanie partnered with him to create a list of families in need of equipment, and his family donated $15,000 to buy that equipment for these families of children with WHS. He also donated $10,000

directly to L4C, and they continue to work together to help the cause, now creating a new list of families in need of equipment for this year.

Stephanie and Aaron's family has grown and now also includes Jack (3), two Devon Rex cats—Benjamin and Oliver—and another child on the way. They enjoy spending time together with other family and friends and love swimming in the pool and hiking. In her spare time, Stephanie likes to paint, and Aaron is a cyclist and plays the guitar. Olivia loves music as well and can listen to someone sing for hours. She is now in first grade, and although she has global developmental delays, she doesn't let anything limit her. She does not yet talk, but she has learned to walk with a walker with some assistance and crawls, scoots and climbs all over everything.

The thought of eventually being able to take away Olivia's ailments has fueled Stephanie's passion as she runs L4C. It is their hope that they can someday make a difference in the scientific world for chromosomal deletion syndromes. In the meantime, they are always looking to grow their community and would like to connect with more families of children with chromosomal deletion syndromes in the Capital District. "They are the reason we are doing all of this and we would love to have a greater community!" says Stephanie.

The Formans learn every day from watching Olivia and have incorporated their resulting family motto into everything they do—"Never stop trying. Never stop believing. Never give up. You are stronger than you think."

To learn more about L4C, their work and how you can join the community or help with their mission, visit www.liv4thecure.org and their Facebook page at @liv4thecure.