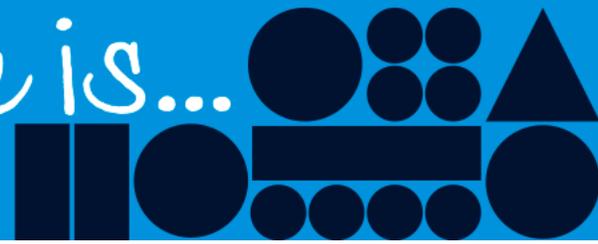




Courage is...



ONE-OF-A-KIND: MAYA BATTLES THE RAREST OF DISEASES

It all started with high fevers in the winter of 2014. Seven-year-old Maya, who loved soccer and math, was not feeling well. Her pediatrician ran lab work, which showed an abnormal white blood cell count. Something was wrong.

Maya came to Children's Hospital Colorado, where doctors did a bone marrow biopsy. At first, when the test results came back, Maya's parents were relieved to learn it wasn't leukemia. Then came the bad news. They learned that their daughter's health and future were moving into uncharted territory.

Doctors discovered that Maya has an extremely rare and life-threatening form of a genetic condition called hemophagocytic lymphohistiocytosis (HLH). Maya's immune cells do not work properly, causing them to overreact and damage her body's cells and tissues. Her specific type of HLH is so unique that it requires expert clinicians, state-of-the-art facilities and novel approaches to diagnose and treat her.



Maya's parents always knew she was special. But it turns out that she is truly one-of-a-kind.

When Maya was first diagnosed with HLH, her body's immune cells attacked other healthy blood cells. Later, as the disease progressed, it struck her spleen, lungs and, eventually, her brain. This was highly unusual, so there was no typical course of treatment.

In October 2016, Maya underwent a bone marrow transplant with her older sister, Marley, as her donor. The transplant was successful in keeping Maya's disease at bay, but a few of the rogue immune cells were still hiding in her brain. Radiation isn't an option. Instead, doctors are now targeting these cells with chemotherapy and steroids.

TREATING THE WHOLE FAMILY – INCLUDING STUFFED ANIMALS

While there is no cure for Maya's condition, her family credits her nimble care team at the Children's Colorado Center for Cancer and Blood Disorders, which includes [Dr. Taizo Nakano](#) and [Dr. Amy Keating](#), for uncovering novel treatments and medicines to help Maya. "They've really gotten her to a point where she is so much better than she was in 2014," said Marci, Maya's mom.

Not only did her care team take care of her body, they also took care of her soul and mind. Dr. Nakano's goofy singing and dancing lifted Maya's spirits. Dr. Keating showed Maya solidarity by wearing a Wonder Woman T-shirt, while Maya would wear her superhero socks and cape for her weekly lumbar punctures, a difficult procedure where fluid is removed from the spine with a long needle. During the long weeks of isolation, Jen Hilliard, an inpatient school teacher at Children's Colorado, wrote math problems on Maya's hospital room windows to engage the little girl in her favorite subject.

Through it all, Dave has also been by Maya's side. All the doctors and nurses know him and treat him like a member of her family. Dave is a very good listener, but he doesn't say a word. That's because Dave is a stuffed monkey. He goes everywhere with Maya, hospital stays and doctor appointments included. Maya's health care providers know just how much Dave means to her, so they've gone out of their way to make the monkey an integral part of Maya's care.

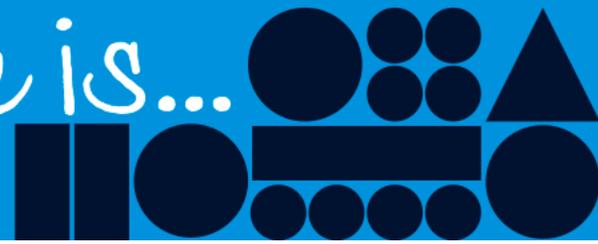


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Dave often wears Maya's hospital wristband, because it's too uncomfortable for her. When Maya has an IV, she rests her hand on Dave. Sometimes, Dave even gets his own identification bracelet with his name on it.

Now 10 years old, Maya looks forward to going back to school when her immune system isn't compromised. In the meantime, she loves eating her favorite food – plain waffles with butter – as well as swimming and spending time with her friends.

DONOR-SUPPORTED RESEARCH GIVES HOPE

Because Maya's condition is so unique, Children's Colorado doctors are mapping a new course in treating her. Health care providers say her story will write the book on her disease.

"Her doctors have been so amazing along the way," said Michael, Maya's dad. "They are charting a path to overcome obstacles, merging what they know about this condition from other HLH patients along with incorporating cancer strategies for treating this disorder."

Maya is enrolled in numerous trials, and her immunologist, [Dr. Elena Hsieh](#), has sent Maya's blood and labs all over the country as part of her clinical care and research studies. Philanthropy is playing a critical role in Dr. Hsieh's ability to search for new discoveries and clues to the causes and potential treatments for diseases like Maya's.

Dr. Hsieh studies immune dysregulation disorders and says that although we are learning so much every day about these kinds of conditions, we are just at the tip of the iceberg. The Anschutz Medical Campus is poised to be at the epicenter of understanding and treating immune dysregulation disorders thanks to the collaborative efforts between the dedicated clinicians in the sections of Allergy and Immunology and Hematology and Oncology at Children's Colorado. The campus is also home to the Human Immunology and Immunotherapy Initiative (known as HI3), a trailblazing research program designed to lead the world in developing human immune system-targeted therapies, both for children and adults.

"As government funds dwindle, philanthropy plays a crucial role in research, especially in pediatrics. I anticipate that it will only become more important," said Dr. Hsieh. "The kind of research that philanthropy makes possible enables us to go beyond just looking at effective therapies and treatments to manage the symptoms of an immune disorder for patients like Maya. It allows us to search for the underlying problem in the immune system and fix it."

Dr. Hsieh was awarded the Boettcher Foundation Webb-Waring Biomedical Research Award in 2016. This prestigious biomedical research grant supports scientific innovation by providing research funding for early-career investigators like Dr. Hsieh. When donors and foundations invest in physician-scientists and their research at Children's Colorado, new treatments are identified, lives are saved and children benefit – not only in Colorado but around the globe. Philanthropy from generous donors like you is truly making all the difference in the world in the quest for answers and innovations.

SEACREST STUDIOS, SUPPORTED BY PHILANTHROPY, PROVIDES WELCOME DISTRACTION

After her bone marrow transplant, Maya spent weeks in the hospital recovering in isolation. Her immune system was so fragile that she couldn't leave her room. She had to avoid infection at all costs, so she had very limited visitors. For anyone, this would be extremely difficult. But for a little girl accustomed to having freedom, friends and family around her, it was excruciating.

Tuning in to BBOY 45, the Children's Colorado TV and radio station broadcast from [Seacrest Studios](#) inside the hospital, helped the time go by more quickly. Daily trivia games. Bingo on Wednesdays. All of it got Maya's mind off her condition and treatment. These were welcomed distractions.

Seacrest Studios and BBOY 45 were made possible by the generosity of TV and radio host Ryan Seacrest and his family, through their Seacrest Foundation. Today, the studio depends on donors like you to provide the equipment, prizes, and staffing needed to run this state-of-the-art station that is designed to help ease the burden of a hospital stay for kids like Maya.



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