Sadie

"WE ARE ETERNALLY GRATEFUL"

SADIE'S STORY

When Sadie was only a few weeks old, her family began to notice how weak and "floppy" she seemed and how she didn't seem to be gaining any weight. Soon after, she was diagnosed with failure to thrive—a term used to describe infants who can't get enough calories and are not growing properly.

Doctors then discovered Sadie had an ovarian torsion, a condition that causes an ovary to twist around its surrounding ligaments and cut off circulation. This had caused a large mass in her abdomen that needed to be removed immediately. Her family hoped this would be the turning point for Sadie—but, unfortunately, it was not.

Sadie was also diagnosed with hypotonia (decreased muscle tone), and soon after, hip dysplasia and infantile scoliosis. Sadie's doctors recommended she undergo genetic testing to better understand what was happening. The results showed Sadie had a genetic mutation that causes a rare disorder called Sotos syndrome. Children with the condition require ongoing care from a team of specialists.

After much research, Sadie's family found Suken Shah, M.D., a Nemours pediatric orthopedic surgeon and a leader in the field of spinal deformity. Sadie's family was so relieved to have a treatment plan underway. To help Sadie's spine, Sadie received a series of three casts, and she wore each one for three months. Sadie went into her initial cast shortly before her first birthday. After almost a year, Sadie's family saw her curve come down a manageable range. By the following summer, she was able to take more baths and spend the warmer months splashing in the water.

"Our care at Nemours has been incredible and we are eternally grateful. The level of personalized attention has been unparalleled. We genuinely feel like part of a family. Everyone we have worked with at Nemours has gone out of their way to make stressful experiences feel controlled and empowering, and I can rest easy knowing my daughter's care is being handled by the best of the best," explained Sadie's mother Ashley.

Now almost three, Sadie wears a back brace 23 hours a day and even asks to put it back on when the one-hour break is over. She has learned to walk, run and dance, and she can keep up with her friends and big brother. "She has never once let the adversity she faces daily hold her back from doing what she wants to do, and seizes life like any toddler would--with wide open arms," says Ashley.

Help us give every child like Sadie a healthy chance. Donate Today!

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