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McDonough toddler battles rare condition

By Jaya Franklin

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McDonough resident Kelley Hoffman says her 3-year-old daughter Madison is her hero.

Madison was born on Jan. 8, 2004 with a rare disease called Goltz syndrome, also known as Focal Derma Hypoplasia.

Madison was among a small number of patients affected by the disease who assisted researchers at Baylor College of Medicine in identifying a gene mutation that causes Goltz syndrome by donating their DNA for a recent study.

"Every family that has contributed DNA to the study has made a tremendous contribution to the research," said Dr. Ignatia Van Den Veyer, lead researcher and associate professor of obstetrics and gynecology and molecular and human genetics at BCM.

"Now that we know what causes the syndrome, it will help us. We can now use the gene to diagnose the syndrome," said Van Den Veyer.

Since birth, Madison has had 21 surgeries, including some plastic and reconstructive surgeries.

She has 17 treating physicians, seven therapists, two vision teachers and a orientation and mobility instructor. Madison is blind and hearing impaired, and she suffers from skin lesions, cleft lip, sparse hair and ectrodactyly, a deformity of the hand also known as lobster claw.

She is also unable perspire. According to WebMD, Goltz syndrome is a genetic disorder which causes skin abnormalities and defects which affect the eyes, teeth and skeletal, urinary, gastrointestinal, cardiovascular, and central nervous systems. Madison's birth defects have also affected her speech. She uses her hands to communicate.

"To see her get up every morning smiling and laughing inspires me," said Kelley Hoffman, 30, who stays at home to care for Madison and her four-month-old sister, Mackenzie, who is does not suffer from the syndrome.

"Her medical bills are about \$750,000 annually," said Hoffman. "By the time she was a year and a half, they were about \$1.2 million," she said.

Madison receives Social Security income and Medicaid but the Hoffmans have to come out of pocket for some of her medical expenses.

Doctors still have not figured out why Madison was born with the syndrome. "There is no family history on either side and neither one of us carry the gene," said Hoffman.

Madison is fed through a feeding tube and is missing some fingers and toes but her mother keeps her active by enrolling her in local activities and classes.

"She has music class on Tuesdays, tumbling on Wednesdays and on Thursdays we usually do something with the visually impaired center," said Hoffman. Madison is home-schooled, and has a total of eight teachers who come to teach her each week. One of Madison's favorite hobbies is listening to Veggie Tales on her iPod.

Outdoor activities, however, could prove damaging to the toddler's delicate skin.

**Photos**

Photos by Renee Richardson
 Kelley Hoffman, 30, of McDonough says her daughter, Madison, who was born with Goltz syndrome, is her hero. Madison has undergone 21 different surgeries since she was born. Madison plays with her sister, Mackenzie, who is four months old. **None/** (Click for larger image)

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"We have seven layers of skin and she has one to two so if she scratches or gets a sun burn she'll bleed," said Hoffman, adding that because her daughter does not have sweat glands, she can easily overheat.

Hoffman said that she and her husband Mark were told that one day her skin may erode, which could be fatal.

The National Foundation for Ectodermal Dysplasias reports that there are only 35 cases of the syndrome known in the United States and only 250 worldwide.

Hoffman said despite Madison's illnesses she is thankful to have her. "I have a child that's special and that's multiply disabled but I have a child," said Hoffman. "God gave us the opportunity to have a child," she said.



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