



Rare cancer inspires new foundation

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Five-year-old Malia Heck helped her brother Jonah, 3, climb onto the little motor scooter, and the two soon cruised gently across the driveway of their family's home in Hebron, Ky.

Their brother Elijah, 4, rode circles around them on another scooter while the baby, Ryan, 1, toddled amid the flurry of activity.

Their parents, Kara and Dan Heck, looked on, laughing at the children's antics.

Dan, an electrical engineer, and Kara, an occupational therapist who decided to become a stay-at-home mom before their second son was born, say they know they are blessed.

They remember all too well when Malia started getting sick.

"Malia was a normal child; she was healthy," Kara said. "But then she started complaining about belly pain. She also had this little spot on her ribs she would just rub and rub, and she said that it hurt."

Initially, her parents thought she might just be seeking attention because Jonah was the new baby in the house at the time.

But over about two months, the pain got worse and became more frequent, Kara said.

Malia's posture changed and she sometimes didn't walk normally, Dan said.

"By Christmastime 2002, it became apparent that something was absolutely wrong with her," Kara said.

"She was up all night crying. We didn't work. We'd be up with her all night, and she would be crying all day," Dan said.

"She was in just terrible pain."

Because she complained of abdominal pain, doctors initially studied her gastrointestinal tract.

Finding nothing wrong there, the Hecks' pediatrician arranged a consultation with a neurologist.

"Sure enough, they found a tumor," Kara said.

Malia was diagnosed with an intramedullary astrocytoma, a slow-growing tumor within her spinal cord.

"Some doctors call it a cancer, others do not because it's not a fast-growing tumor," Kara said.

The tumor was on the upper part of her spine, between her shoulders. A doctor at Children's Hospital Medical Center operated.

"He did a wonderful job," Kara said.

"They told us it was basically a freak thing; go home and live normally," she said.

Six months later, however, the tumor returned.

"And we realized life wasn't going to be normal for us," Kara said.

Before deciding what to do next, Dan and a friend started doing some research.

The Hecks found out that Malia's condition was so rare that their surgeon from Children's operates to correct it only about twice a year.

They decided to seek out a doctor with more experience at treating the malady.

"We got wonderful care at Children's," Dan said.

"We just felt like we needed more of a specialist in that type of surgery."

So the Hecks interviewed five doctors from across the nation.

They settled on Dr. George Jallo, clinical director of pediatric neurosurgery at Johns Hopkins Hospital in Baltimore.

"Malia had her surgery, and it was amazing. She walked before she left the hospital," Kara said.

But the news wasn't all good.

Surgeons were unable to remove the entire tumor. Because the tumor cells had so infiltrated the tissues of the spinal cord, full removal would have resulted in neurological damage ranging from minor sensory loss to major paralysis.

Some children die from the procedure, Kara said.

"As it was explained to us, the gold standard in treating these kinds of things would be surgery to debulk the tumor, then radiation," Dan said. "In adults, that's typically, what they'll do.

"But in children, the side effects of radiation are much more dramatic. Not only is the tumor site radiated, but so is the normal, healthy spinal cord that's around it, and spinal bone. And that stuff, essentially, gets stunted in growth."

Each doctor the couple talked to had a different plan for post-operative treatment, Dan said. So decisions on what treatments to try were heart-rending, he said.

After Malia's second surgery, she underwent chemotherapy once a month for a year. Even though chemotherapy is an experimental treatment, the Hecks hope it will slow down the tumor's growth until more research can be done or until Malia goes through puberty, when other treatments become viable options.

The chemotherapy has worked for now. The tumor isn't growing.

"She didn't lose a hair on her head, she was very minimally sick, and it really went very, very smoothly," Kara said. "So we feel very fortunate.

"But we know there are cells there invisible to the MRI and at any time they could fire up and we could be right back in the thick of it with more surgery and potentially a life-threatening situation again."

If it came to that, and they didn't have a safer alternative, "we would radiate Malia to keep her," Dan said. "But we felt like we wanted to come up with a safe alternative not only for us, but for others."

But those alternatives cost money in the form of research dollars, and funding for such research is scarce, Kara said. In fact, Jallo, Malia's surgeon, may be the only doctor in the nation currently doing research on spinal cord tumors.

So the Hecks' family and friends gathered and decided to start a foundation to support Jallo's work.

"We just felt that we were meant to do this," Dan said. "We were convinced that God brought us together with Dr. Jallo so that our family could support him and he could help us."

The Hecks named their foundation Malia's CORD, with CORD standing for Cure for Others through Research and Development.

"We wanted to make it clear to people that the money we were raising was not going to the direct benefit of Malia. We wanted to make it clear it was going to research," Dan said.

"And we wanted to make sure the foundation stayed focused on other children, despite what Malia's situation might be at any time."

The foundation, with its Web site at www.Cordfoundation.org, has raised \$135,000 since it was created last fall to support Jallo's work.

"Even if it came too late for Malia, we wanted to make sure parents have more options than we do," Dan said.

"We decided we need to be part of the cure, for Malia and for all the children that this affects," Kara said.

Kara said that she hopes the Web site brings people dealing with the disease together.