Little boy goes on tough journey to battle neuroblastoma, a rare cancer

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Written By **Gretchen Rubin**

Charlie Betzold loves playing with his collection of toy animals. He's happy to tell you his list of favorites: elephants, giraffes, zebras, gorillas, monkeys and sloths.

Having so many favorites would keep any child busy. But back in the fall of 2014, Regina Wan and Eric Betzold became concerned when their young son stopped being active. "He started getting really sleepy, not really eating and not playing like a toddler is supposed to," Regina said.

When Charlie didn't get better, the Jefferson Park couple took him to a nearby emergency room.

There, they got a heart-wrenching diagnosis. Charlie had a rare pediatric cancer called neuroblastoma. He was transferred by ambulance to Comer Children's Hospital at the University of Chicago Medicine.

"And then our lives went into a whirlwind," Eric said. "All of a sudden we were living at the hospital. Charlie had lost a lot of weight and looked very sick."

Pediatric oncologist Susan Cohn, MD, an authority on neuroblastoma, met with the family soon after they arrived at Comer Children's. The news became even harder to bear. The cancer, which had started in his abdomen, already had spread. The treatment for the high-risk tumor would be complex.

"High-risk neuroblastoma is particularly hard to treat," Cohn said, noting that only 50 to 60 percent of children with the disease achieve long-term survival. "We're always looking for new and better treatments."

Regina and Eric remember Cohn's team walking them through a rigorous care plan that included a clinical trial of a new combination therapy. "They didn't make it sound easy, but they gave us the knowledge to make decisions every step of the way," Eric said. "And they put us at ease."

Cohn told Charlie's parents about the clinical trial testing the effectiveness of adding a drug called MIBG that contains a form of radioactive iodine (I^{131}-MIBG) to standard high-risk neuroblastoma therapy, which can include intensive chemotherapy, surgery, stem cell transplant, radiation and immunotherapy.

MIBG, or metaiodobenzylguanidine, is a compound that is actively absorbed by neuroblastoma cells. For the therapy, the I^{131}-MIBG is given to patients through an IV. As the cancer cells absorb the MIBG, the linked iodine delivers cancer-killing radiation to the tumor cells. Comer Children's is the only hospital in Illinois offering the treatment.

"We've been using I^{131}- MIBG therapy for children with relapsed disease for more than two decades and have seen good responses," Cohn said. "This is one of the most active agents available to treat relapsed neuroblastoma. We next wanted to evaluate if MIBG therapy will improve survival rates for children with newly diagnosed neuroblastoma."

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In March 2015, after five cycles of chemotherapy and surgery, Charlie received the I^{131}-MIBG treatment. A few weeks later, he underwent high-dose chemotherapy followed by stem cell transplant and radiation. He then received an additional six months of treatment with immunotherapy.

"The whole treatment was hard for a little person to handle," Regina recalled of her little boy's journey.

"We knew it was going to be intense," Eric added. "Charlie was young and won't remember, but the experience is seared in our minds. "

Through it all, the couple tried to stay strong for Charlie and keep his life as normal as possible. They leaned on their families, an online neuroblastoma support group and the care team at Comer Children's — a potent combination in helping Charlie.

"Neuroblastoma can lead to significant side effects and long hospitalizations," Cohn said. "The experience is tough on the patient but also very stressful for the entire family. Even when Charlie wasn't feeling well, he and his parents managed to stay positive. They were remarkable."

Today, the 5-year-old is happy, healthy and full of energy and life.

"Cancer can't compete with the amazing research that's taken place over the years," said Eric. "It's all coming together to give kids like Charlie a better chance to beat neuroblastoma and other childhood cancers."

And that's the ultimate goal: "We are going to keep working hard until we cure every child," Cohn said.

MIBG Therapy

Comer Children's Hospital is proud to be one of the few medical centers in the nation to offer MIBG therapy for neuroblastoma.

Learn more about our neuroblastoma services

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