Her future at hand, a 14-year-old prepares for life without sight

By LEE HILL KAVANAUGH
The Kansas City Star

In music class at the Kansas State School for the Blind, Brittany Myrie whispers in the ear of a boy named Dustin Mejia. Soon they both erupt in giggles, teasing each other about crushes on other students.

A bell rings. Class is over. Dustin reaches for his white cane; Brittany turns her head to see through her left eye. Her right eye, half-closed, sees nothing.

But Brittany's sighted eye is failing her now. Within a few months, the disease that is damaging her body more than likely will steal the rest of her vision. Brittany has sickle cell anemia, an inherited blood disease. More than 430 children in the Kansas City area are treated for the disease.

Brittany is no different from other 14-year-olds who spend time at the mall, talk with friends about crushes and begin to think about their futures.

Except she is learning how to live as a blind person — before her world goes dark.

Sitting in her dormitory room at the school in Kansas City, Kan., Brittany, known as Brit, wears a T-shirt with "Glamour" spelled out in sparkles.

The Junction City, Kan., teen sits cross-legged in fringed designer jeans. Her hair is swept into a neat bun with a scrunchy, white ponytail holder. With her high cheekbones, almond-shaped brown eyes and mahogany skin, she seems to glow with good health.

Most of sickle cell anemia's destruction is inside the body, but with Brit there are exceptions. Scarring from blocked veins lines her legs. Three toes have been amputated, along with a section of her left foot. She has been unable to see out of her right eye since she was 7.

"What I hate the worst is hearing those five little words that kids in regular school always ask me," she says. Then with a high-pitched mocking voice: "*What happened to your eye?* Everybody asks me that, except for the kids here."

See BLIND, A-16

Photos by KEITH MYERS/The Kansas City Star

With fellow students such as Dustin Mejia, Brittany Myrie, 14, attends the Kansas State School for the Blind and learns to read Braille.

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As she talks, Brit's hand slides up to her face, covering her blind eye.

"I have a plastic cover, sort of like a contact that I can wear. It makes it look like I have a pupil, but it itches and makes my eye water, so I don't like to wear it," she says. "Besides, to the kids here, my eye doesn't matter."

Brit doesn't talk much about her disease, not even to her best friend and roommate, Hilary Birdwell, 12, from Bonner Springs. For three weeks she studied at the School for the Blind along with 77 other children, learning how to use Braille and computers, and to cook, and to "see" with a white cane.

"There isn't much to tell about sickle cell," Brit says. "It's a really bad disease to have, because you have pain just about every day."

The pain comes when blood vessels clog, starving tissues of oxygen. The red blood cells of a healthy person are round and soft, and they carry oxygen from the lungs to all parts of the body. In a patient with sickle cell, however, some of the cells are flawed.

They become hard and sticky and, ultimately, shaped like sickles. When these flawed cells go through the vessels, they clog the blood flow and break apart. In addition to the pain, this can cause damage and a low blood count, or anemia.

"I tell people when they ask that instead of round shapes, my blood turns into banana shapes and clots up. I just deal with it," Brit says.

Dealing with it meant getting over her fear of needles. For almost six years Brit went to sleep every night with an IV dripping medicine into either her stomach or hip, the IV attached by her older sister while her mother worked the second shift at a Junction City factory.

Dealing with it means enduring the daily pain that feels like a hammer pounding her bones. Her knees ache. So do her chest and back. Sometimes she's dizzy or extremely lethargic. And if she gets a temperature above 99, she must be rushed to the emergency room. An infection could kill her.

Dealing with it means traveling the 150 miles to Kansas City in a 12-year-old car that belches black smoke and doesn't have air conditioning. At least once a month she visits the Children's Mercy Hospital Hematology Clinic for blood treatments.

Her mother, who must miss work for these trips, doesn't complain.

"She's my daughter, and I'm grateful she's here with us," Margree Barlow says. "Anything could happen to her at any time, so we never think about the hardships. When she gets sick, we take care of her the best we know how and just pray."

Dealing with the disease also meant hearing the retina specialist's words in March, when he said in a quiet voice that there was nothing he could do to save Brit's eyesight.

Brit didn't cry. Her family and friends did.

"It's OK," Brit now says with a shrug. "I mean, I don't want to go blind, but if I do, I'll deal with it."

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"Anything could happen to her at any time, so we never think about the hardships. When she gets sick, we take care of her the best we know how and just pray."

Margree Barlow, Brit's mother, right

BLIND: One step at a time, teen faces a new life

When she was 6 months old, doctors knew there was something wrong with the little baby named Brittany, the third of Barlow's four children.

"Brit would fall asleep anywhere.... When she was on the living room carpet, or on the lawn, or even playing with her brother in the snow," Barlow says.

At age 1, Brit was diagnosed with sickle cell anemia. Her sisters, Ciara, 10, and Shameka, 16, and brother, Bilal, 18, do not have the disease, although they may be carriers.

Sickle cell creates a pain so severe it is called a pain crisis or pain event. Many complications can occur as the tissues are deprived of oxygen: strokes; massive infections; body parts that die or are damaged and must later be amputated.

Brit had her first major pain crisis when she was 7.

One morning her mother tried to wake her for school, but Brit was unconscious. Barlow scooped up the second-grader and rushed her to the local hospital.

Doctors couldn't help her in Junction City. They opted to fly her by helicopter to Children's Mercy.

Before she left, Brit regained consciousness just long enough to tell her mother that she didn't want to die. Then she defiantly told her mother that she *wasn't* going to die.

"They lost her twice during the flight," Barlow says.

At 7, Brit had suffered her first stroke. She was listed in critical condition in intensive care. She had bruises all over her body that ranged from red to purple to black where the blood was clotting. One eye was sewn shut because of severe swelling. She also had developed pneumonia and meningitis. When she occasionally awakened, she hallucinated about monsters or bugs in the room.

"They told me all the things wrong with her. ...They said if she made it through the night, she'd probably be brain-dead," Barlow says. "I guess they were preparing me for her to not make it."

Barlow was a divorced single mother, raising four children by herself and with little help from the children's fathers. She was used to dealing with life's hardships and losses and struggles.

But this was above her threshold of coping.

As she listened to doctors explain her daughter's medical condition, Barlow began to shake and passed out before they were finished.

"I finally told them they could tell me all that science was telling them, but ultimately Brit's life wasn't up to them," she says. "I began praying."

Brit woke up in intensive care two weeks later, smiling as she heard her mother's voice.

"Mama, why are you here? Why aren't you working? You don't have to be here. I'm OK," she said.

The swelling in Brit's body went down. New hair was growing where the old had fallen out. The stitches on her eyelid were removed. But when Brit opened her eyes, everything was black. When she tried to move, her body refused. She was paralyzed.

For three months she lived in a dark, immobilized world. Eventually she would see again in one eye, and slowly she regained the ability to touch.

But she never lost her ability to feel. And when she finally came home, her world had changed forever.

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When Brit returned to school in Junction City, teachers brought in grief counselors for her classmates, fearing the worst when they learned how sick she was.

But as Brit improved, the school hired Sonia Sittingdown, a counselor, to help the little girl's re-entry into classes. Sittingdown's job was to take care of Brit the entire school day.

"Oh, she was cute as a bug," says Sittingdown, remembering meeting Brittany as a tiny girl who wore a sun hat to hide her bald head.

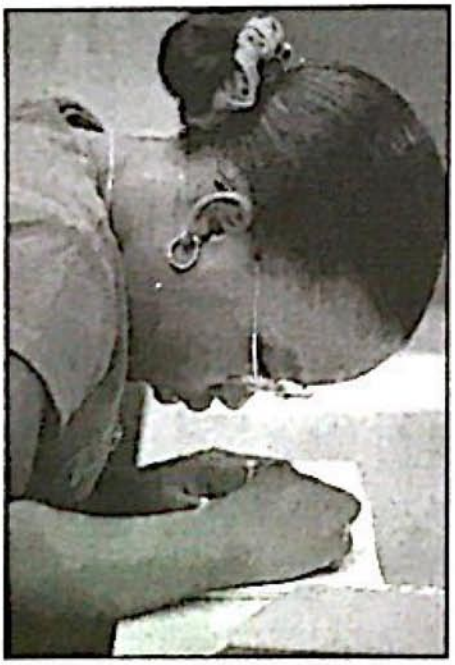
Sonia Sittingdown

"I thought she was shy, not realizing that all this had to come back into focus: the speech, the movement, everything had to come back. Only now is she developing enough touch sensitivity for Braille."

Sittingdown assisted Brit daily with everything for those first two years, and then taught her Braille three times a week every year since. Brit now refers to Sittingdown, who had worked as a dorm teacher at the School for the Blind, as "my second mom."

Brit and Sittingdown recently went on a hiking trip together on the Oregon Trail with several children from blind schools throughout the Midwest. Sittingdown pushed for Brit to go, to have the experience of achieving such a physical feat.

"But I was petrified, too," she says. "Brit can't participate in a lot of activities, because of her vision and her foot. She's missed so much because of this disease.



Blind in one eye and losing sight in the other, Brit must get close to anything she wants to read. She still is developing the touch sensitivity to read Braille.

"But on the trail she did it all. Two weeks of hiking through Devil's Pass in Wyoming, camping in tents, walking along old wagon ruts, visiting graves. When Brit was tired or complained of any pains, I'd let her take naps in the car sometimes so she wouldn't overdo it. ...My prayer is for them to find a cure in time for Brit."

A cure for sickle cell disease has eluded scientists for decades. The disease can be eradicated with a successful bone-marrow transplant, but the transplants are extremely dangerous. Other therapies are a patchwork.

Children with sickle cell disease face a lifetime of medical care, but the disease is not an automatic death sentence. A 1994 study, the latest available, estimated the median age of death at 48 for women, 42 for men. Many children graduate from college and go on to raise families, with only occasional episodes of pain. Others suffer lifelong complications and pain.

Sittingdown's eyes pool with tears.

"I love that child," she says. "My dream for her is to see her graduate from high school, walk across that stage and throw her cap into the air."

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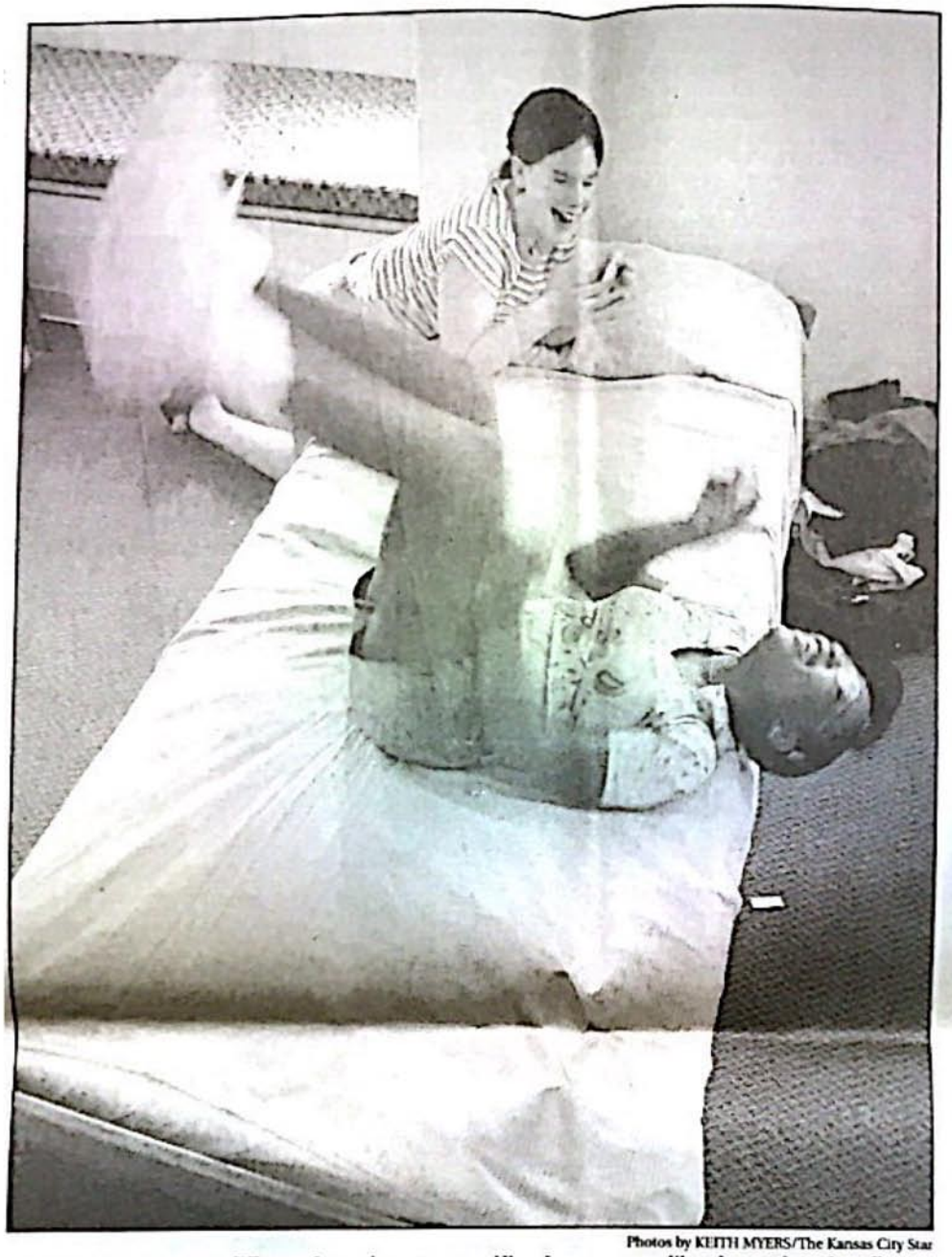
The children at the School for the Blind attend eight classes every day. They learn not only math and English, but also how to get around in a crowded hallway using only their canes.

Children run into doors and one another. But above the clattering of canes there is laughter, too. Children try to help their peers if they can. Classroom numbers are announced. Friends call out if they are lost; others steer them the right way.



Photos by KEITH MYERS/The Kansas City Star

Brittany Myrie's life is no different than other teen-agers' lives in many ways, like, above, when she talks with roomate Hilary Birdwell about boys. But Brit is learning to live as a blind person and learning to "see" with a cane, right.

All the children have private lessons on using their canes on the streets of downtown Kansas City. On this July morning, it is Brit's turn.

The school van rolls up to the curb at 10th and Jefferson streets. For the next hour instructors will work with Brit.

Like a practiced pro, she unfolds a cane and snaps it together. This is not her first time using her cane. But in Junction City she shuns it: It announces to seeing kids that she is different.

"Brit, what we want you to do today is walk down the sidewalk, step around any obstacles and then let us know when it's safe to cross the street," says Chris Short, a student at Western Michigan University who is working as an intern at the Kansas school.

Brittany nods her head and begins. Her cane and ears become her eyes. Along the street a work crew repairs a pipe. Birds in a nearby tree warble. Brit's cane sweeps back and forth in front of her in small arcs just wider than her shoulders. Her head is straight, her body erect.

"Her technique," Short whispers, "is textbook-perfect."

Brit "sees" a crevice in the sidewalk, the roped-off construction area, the overgrown bush limbs protruding onto the sidewalk. She steps around them all.

At a curb she listens for traffic. Her instructors hover nearby, making sure she does not step out in front of a quiet car.

Brit stands at the corner, waiting. Her head slightly turns to the left.

"Is it safe to cross yet, Brit?" asks Paul Clary, another instructor.

"No. The cars aren't stopping like they should," she says with a frown on her face. Car after car slows down but then rolls through the four-way stop. At least seven vehicles in a row don't stop.

"Could a police officer arrest them for this?" she asks. Both instructors laugh.

"It's amazing, but drivers see a person with a cane, and they speed through thinking that the blind person might run out in front of them," Clary says. "I've even seen drivers motion for a cane-carrying blind person to go out into the intersection."

Both instructors smile again. But not at their jokes. Brit announced that the intersection was clear, safe to cross.

Their student is getting it.

"Sometimes it's obvious when a student with some sight is cheating," Clary says. "Not Brit. She's succeeding on her own — without the use of her good eye. She's not looking where she's going, she's feeling her way through."

Brit grins at his words.

Yes, she is feeling her way through.

One step at a time.

To reach Lee Hill Kavanaugh, call (816) 234-4420 or send e-mail to lkavanaugh@kcstar.com.

SICKLE CELL ANEMIA

■ **WHAT:** An inherited blood disorder, causing chronic anemia and pain.

NORMAL RED BLOOD CELLS

Smooth and round and able to move easily through the body, normal red blood cells last about 120 days in the bloodstream.

SICKLED RED BLOOD CELLS

Hard and crescent-shaped, they cannot squeeze through small blood vessels, so they stack up and cause blockages that deprive organs and tissue of oxygen-carrying blood. Cells die after 10 to 20 days.

■ **COMPLICATIONS:** Besides anemia and pain, the disease causes infections, organ damage and jaundice. It also can cause strokes.

■ **TREATMENT:** Includes medications, blood transfusions and IV therapy.

■ **WHO'S AT RISK:** Children of parents who carry the sickle cell trait.

■ **TESTING:** In Kansas and Missouri, a blood test screens newborns for sickle cell disease. Also, you can be tested to see if you have the sickle cell trait, which can be passed onto your children.

Sources: The American Sickle Cell Anemia Association, Sickle Cell Disease Association of America

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