SARAH'S SECOND CHANCE: A 4-PART SERIES

The series follows a 6-year-old child with neonatal hepatitis and her family through the process of being listed for a transplant into the operating room for surgery and through the ups and downs of recovery. The series was nominated for and won a Michigan Associated Press Award.

On the waiting list

6-year-old Sarah and her family await a much-needed liver transplant

Part 1: July 5, 2005

By Stacy Kess
skess@civitas.com

A phone call that Tuesday afternoon gave Ron and Michelle Gravel a bit of hope.

On May 10, Michelle was notified her 6-year-old daughter, Sarah, was eligible for a much-needed liver transplant and soon would be added to the waiting list.

"The first night (we learned about the transplant option), I was petrified," the Monroe mother said moments after the phone call, her eyes still filled with a strange mix of fear and joy. "I'm still worried, of course. There are still risks, and it's not a cure-all."

But it could save Sarah's life, which has been marked by illness since birth.

The start of life and disease

In 1999, after a rough pregnancy, Michelle gave birth to Sarah. Michelle had developed preeclampsia during her first pregnancy with 8-year-old Jacob. The disorder returned during her pregnancy with Sarah and would show its worst symptoms with 2-year-old Anna. Preeclampsia rarely threatens the health of a child and it was not nearly as bad with Sarah as with Michelle's other two pregnancies. That's why Sarah's obvious condition was so strange.

"Her birth was normal, but she was small," she recalled. "I definitely noticed. I knew she was definitely not a normal color."

At the time, she was told jaundice was normal in a newborn and would disappear. It didn't.

When Sarah was 2 months old, her pediatrician noticed the "olive" skin and ordered blood tests.

"She called me that night and said, 'You're going to University of Michigan Hospital, 8 a.m.' " Michelle said.

At UM Hospital in Ann Arbor, a doctor delivered strange news: She could feel Sarah's liver.

"And she said, 'That's not good. I didn't want to feel it,' " Michelle recalled. "They tested her for everything they could think of.

"Once they ruled out everything else, they said she's a baby with neonatal hepatitis, and that just literally means a baby with a swollen liver," Michelle said. "They called it a wastebasket term … It was just something to write on the paper."

The diagnosis came with a price: Sarah probably would need a new liver someday.

It also came with complications.

At 2 months old, Sarah was airlifted to UM Hospital because a blood vessel in her cheek was expanding. It was accompanied by loss of clotting ability and bleeding into her brain.

Doctors told the Gravels their daughter had expanded, easily ruptured blood vessels in her throat wall, which usually occurs when blood flow diminishes in the liver. Vitamin K improved the immediate situation but Sarah continued to have complications from the disease affecting her liver.

By the time Sarah was 8 months old, she was diagnosed with cirrhosis of the liver.

At age 2, Sarah woke up in a pool of bloody vomit, another fault of the blood vessels in her throat.

For four years, Sarah's liver died little by little in her belly, which swelled as the liver enlarged and hardened.

Separated by disease

Her growth stunted by her body's failures, her skin a crayon mustard yellow, her eyes the color of sulfur, her cheeks covered by a web of thin red veins and her belly swollen and round, Sarah hides behind her mother, exhibiting another side effect of her disease: a severe shyness.

The disease has been tough on her, setting her apart from the other children in physical ability and in appearance. She had to worry about bumps and bruises that possibly could damage her liver.

"She cannot play contact sports … because her liver and spleen stick out so much, they're afraid she'll get injured," Michelle said. "(Her classmates) ask why she's yellow and why her eyes are yellow and it bothers her," Michelle said.

But once around her family or closest friends, Sarah explodes like a pinata with a Woody the Woodpecker giggle and a sharp wit developed far beyond her 6 years. She boisterously yells "loser" while holding her fingers in the shape of an L against her forehead when she shows her master prowess at her favorite board game, Sorry. She reads aloud to her sister, Anna. She teases her brother, Jacob.

Ready and waiting

Ron and Michelle Gravel first met with the transplant team May 3 to discuss the option of transplant, the risks of transplant rejection and the effects of lifetime anti-rejection therapy.

"They told us it's like trading one chronic illness for another," Michelle said. "But when it gets to this point it's the best option."

They agreed to the transplant and were notified a week later that Sarah met all qualifications for a transplant, so her name was soon to be on a list — one that she would top because of her condition. Her pediatric end-stage liver disease (PELD), ranked numerically for liver allocation, was 16, meaning she was in moderate need. Sarah also was the only patient with O blood type on the pediatric list.

Michelle later wrote in a journal shared with friends: "Unfortunately that means sorrow for another family. The reality is sort of getting tougher to face. But Jesus said not to worry about tomorrow. Today has sufficient trouble of its own."

A new liver could come at anytime once on the list, the doctors told the Gravels.

"I prayed … and I said, 'There's absolutely nothing I can do,' " Michelle said. " 'It's all in (God's) hands.' "

On the morning of May 10, Michelle took Sarah and Anna to the bank to open an account for fundraising to help defray Sarah's medical costs. Insurance, she said, likely would cover most of the hospital costs, but the family hoped to buy a reliable used car to take Sarah to her monthly pre-operative check-ups and to her post-operative visits at UM Mott Children's Hospital in Ann Arbor.

Michelle's mother, Maureen Palmer — known affectionately as Baba to her grandchildren — was ready with a plan, printing out fliers and collecting giant plastic jars for donation jars at local businesses. There would be T-shirts, with the popular organ-donation slogan "Don't take your organs to heaven … heaven knows we need them here" on the back.

A good Friday

On May 13, around 12:30 p.m., Sarah officially was placed on the transplant waiting list.

Later that day — just three days after the bank account was open — Baba, who drove from her home in Belleville, opened the door to the Gravels' Monroe apartment full of news. She had the first check, $250 from Bill Brown Ford, a Livonia car dealership. Sarah quickly snatched it and held it close to her chest.

"We're raising money to help. There's going to be a lot of cost when you're in the hospital," Baba explained to her in soft tones. "People are being so generous."

Sarah settled into Baba's lap while Baba explained the source and destination of the funds to her. Around them, the family settled into a Friday night routine, playing and laughing and finishing chores.

About 7:30 p.m., as Anna, Sarah and Jacob settled in for a story before bed, the phone rang.

"We got the call," Michelle said.

SCORE DETERMINES WHO GETS AN ORGAN

An organ-transplant waiting list is not first-come, first-served. In fact, many factors play into who gets an organ when.

On a pediatric liver waiting list, patients are assigned a Pediatric End-Stage Liver Disease (PELD) number. The number is used to rank patients in a way that the patient is on the list among others waiting. An adult waiting for a liver is assigned a similar score called a Model for End-Stage Liver Disease (MELD) number. The United Network for Organ Sharing began using the PELD score in 2002.

Factors used in calculating a PELD score are:

- Laboratory values of albumin (liver protein), bilirubin (a product found when hemoglobin is broken down by the liver) and blood clotting capacity.
- Failure of growth.
- Age when added to the transplant waiting list.

The PELD scale ranges from 6 to 40, predicting the likelihood the child will die within three months. The higher the score, the more likely the child is to die before a transplant within three months.

But the PELD score is only one part of waiting for a liver. Blood type is used to finding a matching donor. Both factors play into how long a child might be on a waiting list.

BORN YELLOW

About 20 percent of neonatal hepatitis cases, the cause of Sarah's jaundice, are caused by a virus in utero or just after birth, the American Liver Foundation said. The other cases have unknown causes. About 20 percent of cases showing combined cells in biopsy will progress into cirrhosis of the liver.

The night before

Her parents worry, wonder and wait as Sarah spends her last night with her diseased liver

Part 2: July 12, 2005

By Stacy Kess
skess@civitas.com

ANN ARBOR — After only 8½ hours on the transplant list, Sarah Gravel was settling into a hospital room at the end of the hallway at University of Michigan C.S. Mott Children's Hospital, 5-West.

The 6-year-old neonatal hepatitis patient officially had been placed on the liver transplant list at 12:36 p.m. May 13. Doctors located a potential liver about two hours later. At 7:30 p.m., as Sarah, her brother, Jacob, 8, and her sister, Anna, 2, were finishing their nightly chore of picking up the living room and choosing bedtime stories, their mother, Michelle Gravel, received the call: a potential liver had been found.

The family flew into action and said a quick prayer for the family of the person who had died, possibly saving Sarah's life in the process. Jacob and Anna were sent off with Baba, their grandmother, Maureen Palmer, to their grandfather's house, while Mrs. Gravel and her husband, Ron, began the trek to UM Mott Hospital, the state's only pediatric liver transplant facility, where a second chance at life awaited their daughter.

An Evening News reporter and photographer documented the experience.

9:15 p.m. May 13, Mott Children's Hospital, fifth floor west, Room 514

Sarah explored the new surroundings of her room — a small cube of hospital-white walls, punctuated with a large framed picture of Donald Duck, computers, equipment and a small alcove off to one side leading to a bathroom — while Michelle filled out a thick packet of registration and consent forms.

"Now I'm shaking," Michelle said, following each line of the form with the pen. For only a moment, the shaking stopped — enough time for her to tease her daughter. "Sarah, do you smoke or drink?"

Sarah giggled and shook her head no.

"Any problems peein' or poopin'?" Michelle asked.

"Who?" Ron said, looking up with a grin from his spot wedged between a duffel bag and pillow on the vinyl bench along the wall. "Oh, you mean Sarah."

Sarah, shy around most people, displayed the giddiness and energy of a child headed to the amusement park as she played with the pedal-operated hand sink across from her new bed and dug through the salmon pink bucket of amenities — a pair of yellow slipper-socks at least two sizes too big for her, a stethoscope and several wash cloths — on the table.

Her excitement turned to fireworks when Baba appeared in the door caring a plush, stuffed duck, affectionately called "Duckina" after Jacob's similar stuffed animal, "Ducky."

"Happy new liver." Baba embraced her granddaughter.

"Happy new liver," Sarah parroted.

10:01 p.m., Room 514

Ron watched Sarah, her golden skin, yellow eyes and ballooned abdomen carried by a tiny body stunted by illness.

His eyes welled up from panic. He pushed himself off the bench and slipped out into the hallway, standing just out of sight from the hallway window into Sarah's room.

"I just had …" he trailed off, his eyes shifting from the floor to the ceiling. "I can't let her see me like this."

He drew in a long, slow breath, then swallowed hard.

"I've just stuffed, I've stuffed everything inside and it's just …" He motioned forward.

Over his right shoulder, the hallway window framed Sarah in her hospital room, flipping through "Lizzy Gets a New Liver," a children's book describing liver transplants.

The hospital room was a somewhat familiar setting for Sarah, who was at Mott only a few months earlier because of a high fever. It wasn't long after that the family first met with the transplant team.

“You know what’s amazing?” Baba asked, ready with an answer. “To think we won’t have to do hospital stays after (the transplant).”

Baba, Michelle and Ron — who, now composed, again sat wedged between bags and pillows — exchanged exhausted glances.

Sarah looked at her dad, her head tipped to one side.

“Go to sleep,” she instructed nonchalantly, “You look tired.”

“Thanks, boss,” he said, cracking a smile.

11:15 p.m., Room 514

Dr. M. James Lopez greeted the Gravels with a toothy smile.

“Dr. Magee tells me you want a liver transplant tonight,” he said.

Sarah rolled her eyes, pulled the stethoscope from the bucket on the table, wrapped it around her neck and stood up on the bed.

“I’m the doctor,” she said.

Despite her efforts, Dr. Lopez continued with his intended purpose: “Once she’s asleep, she’ll get an arterial line. It’s a special line that goes into the wrists,” he said. “We use every monitor possible to see how her physiology’s doing at all times.”

The transplant would take anywhere from six to 12 hours — that is, assuming the liver was usable. Dr. Magee and his team had not yet seen the liver and would not see it until it arrived, when would decide if the liver was healthy enough for transplant. The procedure itself was not risk-free, carrying with it the possibility of bleeding, blood clots, complications from anesthesia and malfunction of other organs. Infection is possible, as is rejection of the new organ.

Sarah’s vigor faded as Dr. Lopez described the process, and the severe shyness that plagues her around most people returned. She clutched Duckina and curled into a ball, burying her head in her mother’s lap. She pulled a plaid pastel blanket over her small body, remaining silent until Dr. Lopez bid the family good night.

“I want to get a movie,” Sarah whimpered.

“She’s tired,” Ron said, pulling out an energy drink.

“You know, at some point, I’m going to have to catch some sleep,” Michelle said.

“Maybe next Tuesday,” Ron quipped.

“I guess the enormity of it hit me when (Dr. Lopez) started talking about the lines,” Michelle said.

Ron nodded in agreement.

“My anxiety level went up times 10,” he said. “You run into a brick wall.”

1:14 a.m., Room 514

“You don’t have to like it, but you have to get it.” Michelle coaxed her daughter to calm down.

Nurse Hannah Bufford held a tray of plastic needles and tubes, all for Sarah’s IV line.

“Mama will be right here with you,” Michelle said.

“One, two, three,” the nurse counted, puncturing the skin on Sarah’s right hand.

She screamed in pain.

When the nearly two-minute process ended, Sarah again buried her head in her mother’s lap, holding out her limp hand like an injured paw. The needle had to be redone.

Michelle rubbed her back. “It’s okay.”

“I don’t want another one,” Sarah shrieked.

“You keep holding still and saying ‘ow,’” Michelle said.

Sarah quieted and looked with curiosity at her right hand, capped with tubes.

Michelle and Ron looked at each other, both clearly exhausted from the sight of Sarah crying from needles, her face twisted with pain.

Baba, quiet in the corner for most of the procedure, broke the silence that settled in after the nurse left. She told the family of 99 jars she had spent the day finishing by pasting on printed explanations of Sarah's condition. The jars would be scattered around southeast Michigan to collect donations to help defray the costs of Sarah's surgery and perhaps help the family purchase a reliable vehicle to transport Sarah to and from her appointments in Ann Arbor. Now the jars were in need of an edit.

"We'll have to add 'Sarah had her transplant,' " she said.

"It's been a long time since we've had to pull an all-nighter at the hospital," Michelle said.

"Somehow, I don't miss it," Ron said.

Michelle handed Sarah two stickers, one earned for each IV.

"Am I going to have this when I have surgery, Mama?" Sarah asked.

"Yes," Michelle answered. She opened "Lizzy Gets a New Liver" and began to read aloud, a comfort for the adults in the room as well as Sarah.

2:46 a.m., Room 514

"I look silly," Sarah whined, looking at the "before" image of herself on the screen of her mom's digital camera.

"You look cute," Michelle said.

Sarah's silliness turned to thoughts of food. She hadn't eaten since dinner and would not have anything else to eat before surgery. Dreaming of bacon pizza, she grabbed a tissue and bit.

"This isn't food," she said with a giggle, shoving the rest in her mouth. "I can eat it."

"That's why I have problems with my back," Ron said, sighing dramatically. "I'm wrapped around her finger."

Michelle, stretched out on Sarah's bed, looked up, tired.

"Do you have an off switch?" she teased her daughter. "I'm going to ask them to install an off switch."

"Ask them to take her batteries out," Ron added.

"I don't have batteries," Sarah yelled.

Baba, awake but tired, nods to the bag of saline attached to Sarah through the IV. "Are you sure this is normal saline?"

3:36 a.m., Room 514

Baba sat in a rocking chair in the corner, Sarah nestled in her arms like a baby.

On the other side of the room, Michelle and Ron spoke to each other quietly.

"I opened up the thread on the (Web) forum," Ron said. "Capital letters: Sarah is going to the hospital now for her transplant."

"I'm just sort of numb," Michelle said. "I'm waiting."

"I want it to be 24 hours from now," Ron said. "Brain's going a million miles a second … Actually, I'm very concerned and a bit worried. I had the worst vision, and I just had to stuff it."

"It's okay for you to be terrified," Michelle told him.

"I'm past that," he said.

3:58 a.m., University of Michigan Hospital Emergency Room

The donated liver intended for Sarah arrived at Mott Hospital.

5:18 a.m., Room 514

“Sleeping beauty,” Michelle whispered, gazing at a finally napping Sarah.

“She’s a silly kid,” Ron said.

Michelle studied her husband’s face. “You look miserable.”

“Tired,” he answered. “It set in a while ago. I’m just too tired.”

“It hasn’t really set in yet,” Michelle said. “I keep expecting them to call it off.”

“We’ve been in the hospital so many times. This doesn’t feel any different,” Baba said.

5:42 a.m., Room 514

Dr. Magee stood by the door, not yet dressed for surgery. It was the last time he would see the Gravels until after Sarah’s surgery.

“She’s still obviously sick. She’s just sick enough to benefit from this,” he said. “The operation may take six to 10 hours, maybe shorter.”

Michelle and Ron nodded, taking it in.

“Any questions? If I had answers, I’d be useful,” Dr. Magee joked.

“I’m glad, and I’m sad at the same time that it’s a whole liver,” Michelle said. “I’m glad for Sarah and sad for that (donor).”

“Thank you, God, for the liver and thank you, God, for the family that made that decision,” Baba added.

Nurses scurried around Sarah, readying her for transfer to the operating room. The motion of the gurney woke her to unrecognized surroundings; she whimpered softly, then began to cry.

“It’s okay, Mama’s got you,” Michelle cooed, walking along side the gurney. “Dr. Magee came in. He’s the one who’s going to do your surgery, and he says your liver looks perfect.”

The gurney moved down the hall, leading a solemn precession. Ron followed with bags and Baba with blankets to take with them to the waiting room.

“It’s okay to be upset,” Michelle continued. “You’re going to go in and get your new liver. I love you.”

The family squeezed into the elevator alongside Sarah’s gurney and anesthesiologist for the trip down two floors. The elevator doors opened in front of the massive doors leading to the sterile operating rooms, one of which was for Sarah.

“You’re going to do just fine,” Ron said, kissing her forehead.

“I love you angel baby,” Baba said as Sarah faded from the first anesthesia.

Asleep from the anesthesia, Sarah was wheeled through the heavy doors, down the hall and into the bright operating room.

6 a.m., Mott Children’s Hospital, third floor, Pediatric Operating Room 4 …

DONATING LIFE: HOW IT WORKS

When a patient designates his organs and tissue for donation after death in Michigan, Gift of Life, the Michigan nonprofit donation group that acts as an intermediate between donor and recipient is called into help.

When a potential organ donor is admitted to the hospital, every attempt is made to save the patient’s life, compliant with the patient’s wishes and the family’s wishes.

- When death occurs, Gift of Life is notified. Gift of Life checks the patient’s name against the registry to determine if the patient had intended for his organs and tissues to be donated. If the name is not on the list, the family is offered the opportunity to make such a donation. If the family agrees, they provide written consent to organ and tissue donation.

• When organ donation is approved with the family (and, in some instances, the coroner or medical examiner), the donor's body is maintained with a ventilator and drugs while tests are performed for each organ's viability. While tests are completed, potential recipients are identified through the United Network for Organ Sharing. Donors in Michigan will first be matched to Michigan recipients. If no Michigan recipient are identified, the organ will then be matched to Indiana and Ohio residents.

• An organ recovery team, a special surgical team that removes the organs from the donor and prepares them for donation, begins removing the usable organs from the donor. Organs are cooled and prepared in a special solution to preserve them until transplant. Once all organs are removed, the tissues are removed and prepared for transplant. The heart, kidneys, liver, lungs, intestines and pancreas can be harvested for organ donation and the cornea or eyes, skin, bones, heart valves, veins and tendons can be harvest for tissue donation.

• Once the process is completed, the donor is released to the family for funeral arrangements. During the donation process, all attempts are made to maintain the body's appearance so the family can plan an open-casket funeral if desired.

Because donating an organ postmortem can be an emotional experience of loss for the family, Gift of Life and the United Network for Organ Sharing attempt to maintain the anonymity of the donor for at least a year after the donation process. At the end of the year, the opportunity is given to the donor and recipient family to make contact.

Although organ and tissue donation may be marked on the back of a Michigan driver's license, driver's licenses are not available or consulted for many hospital deaths. As the Michigan organ and tissue donation network, Gift of Life is notified when any Michigan hospital death occurs. Gift of Life urges all Michiganians to sign up on the Gift of Life registry at www.giftoflifemichigan.org to avoid any confusion or delays if they wish to donate their organs and tissues at death, and to discuss their donation wishes with their families.

BY THE NUMBERS

386

The number of Michiganians listed on the transplant waiting list in need of a liver, as of July 1.

12

Age, in days, of the youngest liver recipient at the time of transplant.

20

Percentage of liver transplants at University of Michigan Hospital performed on children.

A new liver, a new lease

Sarah undergoes a six-hour surgery and days of recovery for the prospect of life with a healthy liver

Part 3: July 19, 2005

By Stacy Kess
skess@civitas.com

ANN ARBOR — Six-year-old Sarah Gravel was a firecracker, full of energy the night before the surgery that would remove her failing liver and replace it with a healthy cadaveric donor liver.

On May 13, Sarah's name was added to the transplant list at 12:36 p.m. At 2:23 p.m., a liver was identified. At 3:30 p.m., after reviewing the case, Dr. John Magee, University of Michigan assistant professor of surgery and pediatric liver transplantation surgical director, officially accepted the liver after reviewing the case. The family was notified at 7:30 p.m. that Sarah would have her transplant surgery in the morning, assuming the liver arrived in good shape.

With her parents, Ron and Michelle Gravel, and her grandmother, Maureen (Baba) Palmer, at her side, she laughed and played and read in her room in UM Mott Children's Hospital the night before the surgery. Sarah's siblings, 8-year-old Jacob and 2-year-old Anna, spent the night at the house of their grandfather, Don Cleveland, where Jacob spent much of the night worrying. Early the next morning, Sarah said goodbye to her parents before she was wheeled into the operating room.

A Monroe Evening News reporter and photographer documented the surgery and the events that followed.

May 14, 6:01 a.m., University of Michigan Mott Hospital, third floor, Pediatric Operating Room 4

Sarah lay on the gurney sleeping as the first anesthesia circulated through her system. Her stomach reached high above her jaundiced body, swollen from the liver that had caused her trouble for six years. Against the white sheets, her naked body seemed to glow yellow.

Scrawled writing on a wipe-off board in the corner confirmed the information: Sarah Gravel was the patient and this was a surgery to replace her liver.

Nurses punctured the skin of her neck for a central line, then taped her eyes shut, transforming Sarah into a limp marionette — tubes splaying from her in all directions.

Intense white light drenched the operating room, paired with a deafening silence broken occasionally by the subtle beep of a monitor or exchanges by Dr. John Magee and his resident, Dr. Shawn Pelletier, who hunched over the new liver, preparing it for surgery.

"This is a beautiful liver. None of our livers look that beautiful," Dr. Magee said, wrapping the liver in sanitary plastic. "This is minimally bigger than I like it, but not much." He returned it to a small plastic picnic cooler.

As Sarah's stomach rose and fell with measured, machined-controlled breath, float nurse Lynn Kaminski covered the area below her ribs with iodine, turning it a deep shade of orange. She wiped Sarah's stomach again then covered it with a sheet of adhesive plastic.

Within minutes, Sarah disappeared under sheets of sterile, blue cloth.

7:19 a.m., Pediatric OR 4

The doctors cut a curved line across Sarah's stomach, the only visible part of her body. A small wisp of white smoke curled up from the argon-beam coagulator that immediately cauterized each cut. A smell akin to burned hair slowly forced the sterile hydrogen peroxide smell from the room.

Sarah's flesh opened like a mouth, revealing the surface of her liver, a swirl of blacks, browns and sickly shades of red and green on bubbled and pocked tissue. The size of two large grapefruits, it appeared to be the only organ occupying her tiny abdomen.

Dressed in green gowns, masks and gloves as if they had stepped out of a science fiction film, Dr. Magee stood to the right of Sarah, Dr. Pelletier to the left. They studied Sarah's stomach with intensity and began disconnecting the vascular web — vein by vein.

"Sometimes the liver is nice and small, sometimes the liver is kind of big," Dr. Magee said. "We're kind of having to wrestle it out of here."

9:09 a.m., Pediatric OR 4

Dr. Magee reached his hand behind Sarah's toad-skin liver which was held in place by only a few veins.

"So, we're well past the point of going back," he said.

9:30 a.m., Pediatric OR 4

"There's her old liver," Dr. Magee said, lifting the mass of knotted tissue. He looked down at the cavity. "There's a hole where her old liver used to be."

He placed the old liver in a small tray, which was placed carefully on one of the sterile tables like a centerpiece.

After nine minutes, the donor liver was removed from ice and readied for its new body.

10:30 a.m., Mott Children's Hospital, third floor waiting area

Michelle's eyes searched the room and hallway behind it. She, Ron and Baba hadn't heard from doctors or nurses since the family left Sarah in front of the operating suite doors.

"Anxiety," she said, rubbing her eyes. "Every time we hear feet shuffling, is it someone coming to give us news?"

Ron, who lay on the couch next Michelle, and Baba, who slumped in a chair across from her daughter, opened their eyes.

"It's so weird to think she's got a new liver, isn't it?" Michelle asked.

Ron sat up, his attention immediately focused. "It's so surreal. I almost want to go in there."

"You can't," Michelle smiled. "Parents aren't allowed. I can't wrap my head around it to think she's got a new part."

"I know it's real, but …" Baba trailed off.

What sleep they had been able to catch since Sarah went into surgery was dreamless.

"At first when we first came down here, Michelle and I were pretty scared," Ron said. "Reality was closing in around us."

"I cried and I got it out," Michelle said. "I trust the doctors, and I trust the Lord will take care of her."

10:51 a.m., Pediatric OR 4

The humid air of the operating room wrapped itself around everything.

A smooth, rose-colored liver sat in the cavity once occupied by Sarah's leathery black liver. The doctors again worked vein by vein, sewing back each connection they had cut earlier.

Within an hour, the sound of her blood pumping into the new liver was audible on the Doppler sonar machine.

"See the difference," Dr. Magee instructed.

12:08 p.m., Pediatric OR 4

Residents sewed up the cut in Sarah's flesh, quickly revealing the change: Her once distended belly appeared to have the normal curvature of a 6-year-old's abdomen.

Float nurse Tony White nodded at Sarah, whose abdomen still was her only visible body part. "They're like little grown-ups."

For a half hour, the doctors sewed the incision shut, leaving a seam that frowned above her belly button.

"The liver was a little harder to get out than average, but the new liver looks good," Dr. Magee said. In fact, the new liver immediately began producing bile. "This is kind of the first big step. The next 24 hours are important. The next three days are important and the next week."

12:51 p.m., Mott Children's Hospital, third floor waiting area

Michelle, Ron and Baba sat at attention, hungry for news, when Dr. Magee entered the waiting area.

"Everything went great," he said, smiling. "No real problems during the operation … Any questions?"

"How soon will we see a difference in her color," Michelle asked.

"In the next three days to five days, we'll see a difference," Dr. Magee said.

Michelle smiled.

“It’s okay. She’s good. She’s out,” she said. “I don’t know whether to laugh or cry.”

“I think my heart hurts,” Baba said.

Ron looked at his wife, allowing a quick laugh of relief. “I think gray hair weighs more, because my head feels heavy.”

12:56 p.m., Pediatric Intensive Care Unit

Sarah lay in her bed while nurse Edward Alderman checked her vitals. In the corner, a filter machine buzzed and hummed as it cleansed the air.

“It’s the cleanest environment that can be,” Mr. Alderman said.

Michelle peaked her head in with some uncertainty; Ron and Baba stood behind her.

Mr. Alderman beckoned them in.

“Sarah,” Michelle began, leaning over her sleeping daughter, “I’m sure you can probably hear me, and I know you’re sound asleep, but Daddy’s here and Baba’s here. You need to get lots of sleep so you get better. They gave you a new liver. Did they tell you?”

“She probably does hear you,” Mr. Alderman reassured her.

“She almost looks like a normal kid,” Baba said.

“Soon, she’ll be pink,” Ron added. He looked at the new scar above her belly button. “I can’t believe she has an innie now.”

Baba reached down and caressed Sarah’s forehead.

“What a miracle. What an absolute miracle,” she said, beginning to cry. “I haven’t cried through the whole thing.”

“Well, you picked a silly time to start,” Michelle said softly.

Baba smiled, tears streaming down her cheeks. “Well, she’s doing good now. I can let my guard down.”

May 15, 4:50 p.m., PICU

“Are you hurting?” Michelle asked, sitting next to Sarah’s bed, now piled high with stuffed animals. “Where?”

“My belly hurts,” Sarah moaned. Michelle reached down and rubbed her daughter’s stomach. She planned to stay with Sarah in the hospital until her release while Ron remained at home to take care of Anna and Jacob.

“That’s the one plus of having major surgery as a young child: You get spoiled rotten,” Michelle teased.

Sarah, the yellow of her skin paling, laid quietly, buried by the gifts on her bed, and watched television. A nasogastric tube entered her nose winding through her body into her stomach to collect excess stomach fluids and IVs capped both hands.

“We’re running out of space on your bed, Sarah,” Michelle said.

Sarah nodded, signaling her mother to press the button connected to her morphine, an action Sarah could, but preferred not to do herself.

“You don’t have to hurt to get better,” Michelle cooed. “You don’t have to talk to me, but you should know, you don’t ever have to hurt.”

May 17, 2:30 p.m., Mott Children’s Hospital, 5-West, Room 514

On her first full day out of the pediatric ICU, Sarah sat up in her bed, her stitches visible, playing Sorry with Baba and a family friend, Angela Firth. When she rolled a number on the dice that meant a move to the other side of the board, Sarah looked at her grandmother for help. She was still tethered to IVs of morphine and saline.

Her hair, dry and matted, was looking less golden, more the familial brown. Her skin retained a pale olive shade.

“Jacob was very, very worried about her,” Baba said.

“I can’t feel my belly,” Sarah whined, itching around the scabbed incision.

Michelle leaned over and gently tickled her. Sarah responded with her bleating laugh.

“Dr. Lopez said she’s soaring, she’s flying,” Michelle said. “She’s kicking butt.”

“I don’t like doctors,” Sarah said.

Despite Sarah’s feelings, Dr. Lopez had given Michelle good news: Sarah’s stay in the hospital might be short.

May 19, noon, Room 514

Sarah’s blood work came back with elevated white blood cells, and bacteria were present in her stool, indicating an infection, meaning Sarah must stay longer. She moved about her room freely, not that most of her IVs were gone. Instead of medicine, a necklace hung from her IV post strung with several large beads, one for each procedure Sarah underwent in the hospital.

Around the room, Sarah’s artwork decorated the walls. Paints, crayons and pencils crowded the table her mother attempted to clear for lunch: SpaghettiOs, Sprite, Doritos, cole slaw and string cheese. Despite the prescribed lunch, Sarah’s preferred diet remained Doritos, popsicles and Sprite.

Michelle sighed. Sarah didn’t even glance at her lunch.

“She’s so focused on her art today,” Michelle said. She turned to her daughter. “Do you want your cole slaw?”

“Cole slaw? No,” Sarah said without looking up from her painting.

“Didn’t you just say yes?” Michelle grinned.

“No,” Sarah reaffirmed.

“Doritos?” Michelle offered.

“Yes,” Sarah answered. “SpaghettiOs? Yes.”

Michelle handed her the requested items and opened the string cheese. She pulled off a piece and dangled it in front of her daughter. Sarah reached for it just as Michelle pulled it away, popping it in her own mouth.

“I’m trying, Sarah,” she laughed.

Sarah, unfazed, continued painting.

“You’re feeling good, aren’t you?” Michelle asked.

“Yes. No. No. Yes,” Sarah said, giggling.

“I think I’m still processing Saturday,” Michelle said.

Sarah looked up. “What do you mean?”

“That you had a liver transplant.” Michelle said.

“Why?” Sarah prodded.

“Because it still feels like you’re sick,” Michelle said, forcing the last word out. “In some ways, you are.”

“What?” Sarah teased.

“Sick,” Michelle answered.

Sarah grinned mischievously. “Six?”

“Well, no, sick,” Michelle said.

Sarah shook her head. “No, I’m not.”

Michelle hugged her daughter and the two laughed.

“I think they fiddled with your brains while you were in there,” Michelle giggled.

“Yup,” Sarah nodded.

“Yup,” Michelle repeated.

“A silly brain,” Sarah explained.

“A silly liver?” Michelle asked.

“A silly brain,” Sarah repeated.

Sarah and Michelle sank into a fit of giggles.

“Should I go back and tell them to put a sillier brain in?” Michelle asked between laughs.

1:50 p.m., Mott Children’s Hospital, ultrasound lab

With a mask over her nose and mouth, Sarah sat on Michelle’s lap in a wheelchair on the way to an ultrasound — one of the deciding factors in how soon Sarah would go home. Outside Sarah’s hospital room, she wore a mask to avoid infection from germs in the hospital.

The ultrasound unit was quiet, except for the occasional click of the ultrasound machine and the audio-feed of blood rushing through her system.

“Mom,” Sarah whispered, her discomfort audible.

About half an hour later, physician’s assistant Charles Moore: delivered the news. Sarah looked fine, but the infection would keep her in the hospital over the weekend on a course of oral antibiotics and oral vitamin K to help battled the illness.

“We’re doing okay,” he said.

“All right,” Michelle encouraged. “Did you here that? You’re here until Monday. This is a good thing.”

Sarah sighed. “I can handle three days.”

2:30 p.m., University of Michigan Hospital, MedInn

With the prospect of at least three more days, Michelle decided to check out of the MedInn, the in-hospital hotel for patients’ families.

“I haven’t stayed there at all since she was in the ICU,” Michelle said, adding that she slept next to Sarah on the hospital bed in her room. “I’ve just used it for storage.”

It was a rare moment away from Sarah.

The bed, still made, was buried under a pile of clothes.

Michelle picked up a copy of the Ann Arbor News lying on the bed.

“Day of the transplant,” she said, pausing.

She shook her head and began packing her bags.

“I saw a mom this morning… and she had her hair done and her make-up on and I thought, man, this must be your first day (as a hospital mom),” she said. “That doesn’t happen for me.”

She slung her bags over her shoulder headed back up to Sarah’s room to settle in for the weekend...

SURGEON TEACHES STUDENTS, FAMILIES

ANN ARBOR — “It’s kind of a good thing to not know me too well,” Dr. John Magee quipped.

After all, he said, as surgical director of pediatric liver transplantation and attending surgeon at University of Michigan Mott Children’s Hospital, Dr. Magee is the kind of doctor patients get to know much better the poorer their surgical outcome or particular health situation.

Dr. Magee began his training at the University of Pennsylvania, studying biology with a concentration in cellular and molecular biology. In 1984, he began his medical degree at Jefferson Medical College in Philadelphia and joined the University of Michigan team in 1988 as a resident.

“I was always interested in medicine,” he said. “I kind of think the focus of the challenge and the need to keep thinking about situations interested me.”

He remained at UM until 1991, when he took a research fellowship at the Duke University Medical Center Department of Surgery in Durham, N.C. He returned to UM in 1995. Along the way, he collected numerous awards and honors. Since 1996, he has taught at UM Medical School.

Dr. Magee said his teaching often extends beyond his residents to families.

“You’re kind of constantly involved in teaching both patients and families,” he said.

Since he began practicing, he’s performed about 150 liver transplants on adults and children in addition to numerous kidney transplants. He said, he’s reached peace with the fact that he’s in a risk- intensive field.

“If everything’s perfect in your life, you shouldn’t go into medicine,” he added. “Liver transplants, you always ought to have A, B and C … What happens next may never happen.”

He said that’s why he never talks to families until surgeries are over.

“You can tell them things are going great, then hang up the phone and you’re on plan D.”

But at the end of each transplant, he breathes a little easier.

“It’s really routine,” he said. “But it’s still kind of a miracle every time.”

Dr. Magee also is surgical director of adult and pediatric kidney transplantation at UM Hospitals. He serves on the Organ Procurement and Transplant Network’s pediatric committee, kidney-pancreas-pediatric subcommittee and the liver-pediatric subcommittee, as well as on the Michigan Gift of Life liver and pancreas committee. He has published 54 peer-review articles, among numerous other publications and articles.

— Stacy Kess

WHAT DOES LIVER DO?

- Stores iron, vitamin and mineral reserves.

- Stores sugar, carbohydrates and fat for energy.

- Makes bile, a digestive juice.

- Makes clotting factor.

- Makes growth protein.

- Detoxifies poisons including alcohol, drugs, foods and the chemicals included in the air breathed into the body.

- Helps the body destroy germs it encounters.

Source: American Liver Foundation, www.liverfoundation.org

BY THE NUMBERS

5 hours 55 minutes

Time from the initial incision until Sarah was released from the operating room to the intensive care unit

1

Unit of packed red blood cell received by Sarah during surgery

3

Units of fresh frozen plasma received by Sarah during surgery

800

Milliliters of Sarah’s blood lost during surgery

150

Transplants Dr. John Magee estimates he has performed

A new life at home

Six-year-old Sarah Gravel, recovering from a liver transplant, is released from the hospital to a different world than she knew before

Part 4: July 26, 2005

By Stacy Kess
skess@civitas.com

It only took two hours for a liver to become available for 6-year-old Sarah Gravel, who had spent most of her life with a liver torn apart by neonatal hepatitis. Doctors transplanted a healthy liver into her abdomen during a six-hour procedure. The recovery process also seemed to move quickly — until tests indicated she had an infection.

Sarah’s mother, Michelle Gravel, remained by her daughter’s side throughout the recovery, while her father, Ron Gravel, stayed at home in Monroe caring for her brother, Jacob, and sister, Anna. Sarah’s grandmother, Maureen (Baba) Palmer, visited as often as her schedule would allow. As the days passed, Sarah continued her campaign to return home in time for Anna’s third birthday May 26.

A Monroe Evening News reporter and photographer documented Sarah’s homecoming and transition into her new life.

3:30 p.m. May 25, C.S. Mott Children’s Hospital, Ann Arbor, fifth floor west, Room 514

“Don’t worry,” Michelle said, smiling at her husband. “I’m not going to forget anything.”

Just after 2 p.m., the nurse told Michelle that she and Sarah were going home. Ron already was on his way for a visit and arrived about 3 p.m. to good news and a room buried in cardboard boxes, blue bags labeled “Patient Belongings,” stuffed animals and Sarah’s artwork.

Sarah pushed another stuffed animal into an already-brimming box, closing the lid as best she could. She grabbed a marker and looked up inquisitively. “How do you spell ‘animals?’ ”

Ron rattled off the answer: “A N I M A L S.”

Sarah danced around the room, laughing. Although the tubes remained in her hands, she was not attached to any IVs. It wouldn’t be long before those, too, were gone. Each step forward was a step closer to home.

“So long as I can sleep in a people bed and eat people food,” Michelle said, sighing. “I was really hoping she could at least get out today. I mean, Anna has no clue it’s her birthday (tomorrow), but we do.”

Sarah especially was aware of that fact, spending much of her time drawing pictures, painting carved wood animals and setting aside stickers for her little sister, which she stuffed in boxes and bags around the room. She declared herself done with packing and escorted her father to the arts-and-crafts room next to her hospital room.

“We came with a duffel bag,” Michelle said. “I’m just so glad to be leaving … We’ve been together so much through all her illness. She’s always by my side. Maybe it was just reconfirming she’s silly and she’s sweet and way too smart.”

She paused. “I learned how strong she is.”

In the arts-and-crafts room, Sarah sat opposite her father at a short table, making her dad appear like a giant. She slapped paint on a star, part of a project that involved most of the children in the ward in celebrating the “American Idol” finale.

Ron watched her, smiling serenely.

“I’ve realized how important she is and how bad it would be if she wasn’t around,” he said. “I’ve realized how important I actually am to her.”

Michelle sat down next to her husband, the packing in Sarah’s room finished. “I’ve put myself aside for the whole week. There hasn’t been ‘self’ since last Friday.”

5 p.m., Mott Hospital, fifth floor west, Room 514

Bottle by bottle, a nurse handed Michelle Sarah’s medications from a large bag.

“Holy cow,” Michelle gasped.

Ron’s eyes widened. “Oh my gosh. Sarah’s pharmacy.”

In all, Sarah was instructed to take 14 medications — 10 pills and four liquids — each day to help her body adjust to the transplant. In all, she would take 20 doses a day. Although many of the medications will be tapered off eventually, she always will remain on anti-rejection drugs and a regimen to ensure the foreign liver functions in Sarah’s body.

“Look at this, Sarah,” Michelle cooed. “This is all for one little 6-year-old girl.”

“I don’t want a lot of medicine,” Sarah pleaded.

After nearly 10 minutes of discharge instructions, the nurse turned to Sarah with the words she had waited to hear: “We need to take that IV out, Sarah.”

After a moment of struggling with the well-taped IV, Sarah was free, sporting a new Looney Toons Tasmanian Devil bandage on her hand.

“Sarah,” nurse Lori Amos announced, “You get to leave.”

With a pale yellow mask covering her nose and mouth to protect her from germs, Sarah marched out of the hospital room she had occupied for more than a week, her parents following with boxes and bags.

6:04 p.m., US-23 South, Ann Arbor

“I like it when we’re not in the hospital,” Sarah said as the gray Ford Taurus borrowed from Michelle’s father rumbled down the freeway, brimming with artwork made by Sarah during her recovery.

“Me, too,” Michelle agreed.

Sarah repeated the sentiments to Baba over the cell phone. When the conversation ended, she declared herself bored and began another drawing.

6:36 p.m., I-275, exit 2, Ash Township.

Sarah squealed with excitement as the car turned south on Telegraph Rd. toward Monroe and the family’s apartment.

“We’re closer,” she cried.

“Yeah, we’re getting closer,” Michelle said.

Sarah pointed to each passing landmark, cheering, “Yay.”

“Just think, last Friday when we left, it was all dark and rainy, and now it’s sunny and warm,” Michelle said.

“Is it almost summer?” Sarah wondered aloud, then quickly returned her attention to the signs of home.

“Excited?” Michelle inquired. Sarah responded with a nod.

“Me, too,” Michelle said, yawning.

At 6:45 p.m., the family pulled into their apartment complex off Stewart Rd.

Sarah looked at the rows of tidy brick town houses. “It seems like I’ve been gone so long.”

6:55 p.m., Gravel home, Stewart Rd., Frenchtown Township

For almost a week and a half, the apartment had been quiet. Within minutes of Sarah’s arrival, it filled with noise and excitement as Sarah, Jacob and Anna joined in an impromptu celebration.

Sarah quickly read through a colorful pile of construction paper cards sent by her kindergarten class.

“Get well Sarah, feel better Sarah,” she read. “I miss you.”

“You have a boyfriend, you have a boyfriend,” Jacob sang, dancing around his sister.

“Anna, I have a present,” Sarah called.

Anna clapped her hands and cried out with excitement.

“Rocks,” Sarah explained, handing her a bag of clay beads.

She picked up a painted wood cutout of a pig. “Anna, I have another present for you. A pig.”

“My pig,” Anna exclaimed, her voice rising with excitement. “Thank you, Sarah.”

The presents continued, some for Jacob and most for Anna. When the distant song of the ice cream truck was detected, Anna’s and Jacob’s squeals snuck in between the noise of conversation. Sarah quietly asked for ice cream, a little uncertain in a situation she had not seen for nearly two weeks.

“It’s been so quiet around here,” Ron said with a strained smile. He had attempted to keep the house spotless while Sarah was in the hospital, but the living room already had disappeared under drawings, toys and homemade greeting cards. “It will (return to normal) shortly.”

“Mama, please,” Jacob pleaded as the ice cream truck grew nearer.

“It’s coming,” Anna gasped.

“Yeah, it’s back to normal.” Ron chuckled. “Situation normal: out of control. I’m just glad to have them home. I just kind of realized how important I am to her.”

He leaned back in the armchair, looked over Michelle and smiled, then looked back at Sarah, who had joined her sister and brother in the window anxiously awaiting the ice cream truck. “Before, I thought it was just Michelle and Sarah, but I’m a part of it too.”

2:40 p.m. June 8, Gravel home

Sarah wandered around her bedroom.

“It was fun coming home, because I don’t want to stay at the hospital,” she said, picking up a stuffed animal, examining it and setting it down.

“I got a bad (liver) and it was too bad. I was yellow,” she said.

She held her arms out in front her stomach. “My belly was like that big.”

“I don’t like being yellow… because the other kids made fun of me on the bus.” She stopped in front of her pink plastic storage bins and looked up thoughtfully. “They did. I just ignored them.”

She pulled out a coloring book, “It’s Good To Be Me: The Story of My Transplant.” The book asked her to tell about her feelings. “Different,” she answered it in red marker.

“My life is,” she began in purple, then switched to yellow, “different.” In blue, she added, “And it’s funny that I have a new liver.”

She looked up from her colorful essay to explain: “I’m so used to having a bad liver.”

3:30 p.m., Gravel home

The Gravels’ kitchen was filled with boxes of T-shirts, all printed with the slogan “Don’t take your organs to heaven, heaven knows we need them here.” Although Sarah’s surgery was three weeks in the past, the family’s fundraising effort continued with T-shirt sales and collection jars at local businesses. Baba, bubbling with ideas and energy, remained the mastermind behind the fundraisers. She and other family members planned to sell T-shirts for $10 at the Redford Township Festival.

“We’re promoting organ-donor awareness,” Baba said. “I think a lot of people just have no idea. People think … it costs money to donate. There’s no cost. You’re giving of yourself.”

Sarah’s daily life had less to do with fundraisers and more to do with medication. Medication maintained her new liver, which, according to all tests, was working well. Her stitches were nearly healed. She had taken off her own bandages weeks earlier, leaving a brown frown of a scar on her now-flat belly. Her skin had taken on a healthy pink hue and her hair had begun shedding the silver and gold highlights brought on by the jaundice with which she once had lived.

Sarah’s personality had begun to change, too. Although often silly around her family, she once had refused to talk in front of strangers. After coming home, she became vocal and loud, much more like other children her age. She adopted new fashion sense, too, begging her mother for only the trendiest clothing when the two went to buy clothes that fit Sarah’s new body.

While Sarah played with her siblings, Michelle and her mother rested at the kitchen table.

“I said I thought her liver came from a funny little girl who is really into fashion,” Michelle said after an afternoon of swimming with her three children.

“She’s an absolute nutcase now,” Baba nodded. “She’s just on all the time.”

Personality changes in transplant patients are possible, according to Sarah’s surgeon, Dr. John Magee. Sarah’s body was working well and acting healthy for the first time. She was taking prescription steroids and finally had a non-jaundiced appearance. Any such situation could have caused changes in her.

“She’s just extra silly,” Baba said. “Extra giggly.”

“They lowered her steroid level yesterday,” Michelle said, throwing her arms up in a silent cheer.

“She’s never known anything but being sick,” Baba said. “I think it’s like all of a sudden she’s just a normal kid.”

4:30 p.m. July 1, Claire’s Boutique, Frenchtown Square mall

“I’m going to get pink flowers,” Sarah announced from her perch on a bench outside Claire’s Boutique.

The pink flowers marked a milestone in her recovery. Sarah's body was healthy enough for her ears to be pierced, a procedure that had been put off until July to give her time to heal enough to allow two new wounds, which would be an infection risk.

"I'm going to sit on Daddy's lap," she said, but her attention shifted quickly to the next exciting piece of news. "We got a van today."

After months of borrowing Michelle's father's car, the family finally had raised and saved enough money to buy a used van to transport Sarah and her siblings to the University of Michigan for Sarah's doctor appointments.

Sarah watched intently as two Claire's employees readied the equipment to pierce her ears. There would be other milestones to come: a first bicycle ride since her surgery, reductions in medications, six-month and one-year checkups. She sank into Ron's lap as he sat on the tall stool at the entrance to Claire's.

"We need you to hold really, really still," the store manager told Sarah, holding the piercing gun up to a tiny dot on her ear.

"One, two." The piercing guns clicked, pressing small pink jewels into Sarah's ears. "All done."

8 p.m. July 18, Gravel home

As Sarah took her night medicine, Michelle noticed something was wrong: Sarah's skin was warm to the touch and she had a headache. When the thermometer read 102 degrees Fahrenheit, Michelle called UM Mott Children's Hospital. She was instructed to bring Sarah into the emergency room.

9:55 a.m. July 20, Mott Children's Hospital, 5-West, Room 5682

Sarah sat on her hospital bed, her legs crossed underneath her pink-checked My Little Pony hospital gown. She colored and chatted as if nothing had happened — not the return to Mott Hospital, not her fever spiking to 104.5 degrees the night before.

"It's only 100 today," Michelle calmly explained. "To me, that's not even a fever."

"And I threw up," Sarah volunteered.

Sarah's left hand was hidden under a mess of tape and IV tubes leading to a bag of potassium chloride hanging from an IV pole high above. Her arm lay useless at her side, taped to a board to stabilize her hand and prevent the tubes from moving.

"As long as it's not her liver," Michelle added, ever stoic in the face of her daughter's health tribulations. "I mean, I'd rather her not be sick, but …"

She trailed off and watched her daughter giggle and play.

Once again the family was dispersed across southeast Michigan: Sarah and Michelle in Ann Arbor, Anna and Jacob at Baba's house and Ron alone in the family's Monroe home when not on the road to or from his new job in Toledo.

The quiet at home was hard on Ron, who worried and waited, thinking of the previous week when Sarah had learned to ride her bicycle without training wheels and had proudly completed a stack of second-grade flash cards. He called early in the morning to check on Sarah and Michelle and called again just before 11 a.m.

"Mama, I want to go home," Sarah announced when Dr. Najeeb Zouri entered the room.

"So do I," he told her.

He explained that her fever was gone, but he was ordering several nasal and blood cultures, a task that would fall to a nurse who would have to battle Sarah's screams of discomfort. The cultures would look for viruses and bacteria and allow doctors determine how to best treat Sarah. In the meantime, she would continue to take three antibiotics.

"Mama, I want to go home," Sarah repeated.

"No," Dr. Zouri insisted. "You're going to go home, but maybe tomorrow."

11 a.m. July 21, Room 562

Although all the cultures came back negative for both viruses and bacteria, Sarah's fever returned to 101.5 degrees. She was ordered to stay in the hospital until she remained feverless for at least 24 hours.

Friday night, after doctors had written new orders for medications and blood work throughout the day, the order was given to let Sarah go home. Her body temperature had remained normal throughout the day and her other symptoms, including a cough and headache also were gone. With a final diagnosis of viral pneumonia, Sarah was released at 7:30 p.m.

She has not returned to the hospital since.