



Mending broken hearts



*A Northland couple
faces the decision
of having a baby
with Down syndrome*

Todd and Karen Bryant met at a bowling party in 1997.

He made her laugh, and her smile felt like home.

They married in 2000.

They weren't sure they wanted to add to their blended family, but when Karen discovered she was pregnant in January 2005, they were excited.

Karen bought newborn clothes at thrift stores and garage sales, filling two Rubbermaid containers with her finds.

Todd painted the baby's room the color of sunshine.

Then, one Thursday afternoon in early May, Karen entered a perinatologist's office expecting a routine sonogram.

What she found out would change their lives.

story by Betsy Lee

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photos by Matt Frye

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CONTRIBUTED PHOTO

About five months into the pregnancy, Karen and Todd celebrate Memorial Day with family at Weston Bend State Park, where Todd is a park ranger.

With green Missouri fields on either side of him, Todd Bryant grips the steering wheel of his white Ford truck with thick, strong hands.

White lane dividers mark the highway in front of him, and as each one streaks by, it brings him three feet closer to home.

Country music plays on the radio, and as he listens, his mind wanders.

Since finding out his wife, Karen, was pregnant

with a boy, Todd has imagined moments he'd share with his son: playing catch in the backyard of his Kansas City home, fishing off the docks at Lewis and Clark State Park.

Now these dreams grind salt into an open wound.

Meanwhile, in Kansas City, Karen Bryant, 34, stands in a parking lot, fighting back tears. Karen's height and broad shoulders give her the look of someone always in control, but her eyes reveal inner vulnerability.

She leans against the window of the dentist office, rubbing her rounded belly. Inside the office, her 10-year-old daughter, Hunter Johnson, is getting a tooth pulled.

On the way to the appointment, Karen pulled a jacket over her turquoise maternity shirt, hiding an oval bloodstain created by the amniocentesis.

But the crimson mark is still there.

And although she tries to hide it, Karen's fear for her baby also remains.

pinpricks of fear

Two hours earlier, Karen, now 21 weeks pregnant, entered a perinatologist's office expecting a routine sonogram. With the nausea and vomiting behind her, her earthy, tan skin exuded a quiet radiance.

But when a genetic counselor guided her into a small conference room, Karen felt pinpricks of fear.

They sat down at a small table.

The baby has soft signs of Down syndrome, the counselor told her. Fluid on the kidneys. Thickening of the neck. Heart defects. Sandal toe.

That last one deafened Karen's ears.

The week before Karen and her husband marveled at a photo of the tiny big toe; it was adorable the way it reached outward.

Weren't big toes supposed to be separated from the other four?

She snapped herself back to reality.

Karen called Todd, who was spending the day with his mother and two children from a previous marriage. After hanging up, the 39-year-old park ranger climbed into his truck and began the two-hour drive home from Lincoln.

The amniocentesis, which could confirm the sonogram diagnosis by testing fluid from inside Karen's womb, would take four days to process.

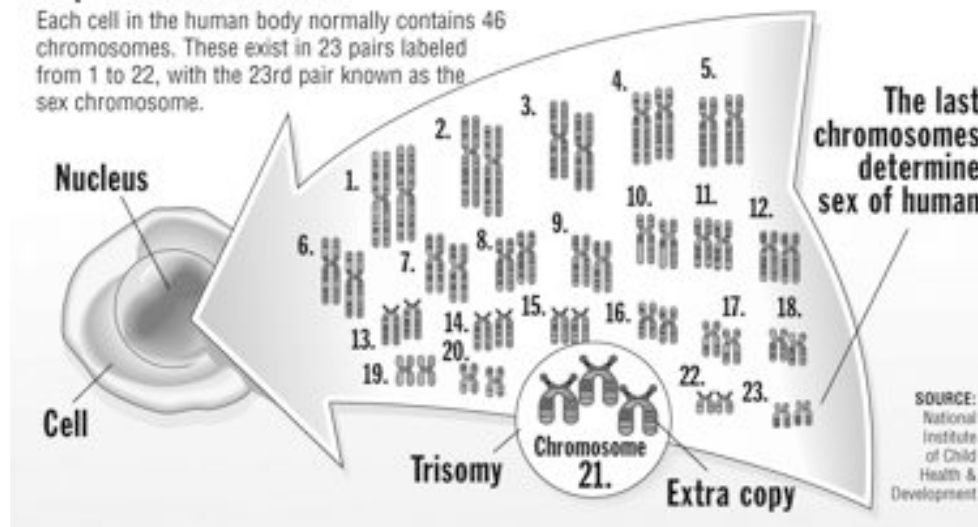
The couple could expect a call the following Monday.

Down syndrome chromosomes

Down syndrome is usually caused by the presence of three copies of genes on chromosome 21 instead of two, also known as trisomy 21. Each human has 46 chromosomes, 23 from each parent. Each is a tightly wrapped package of gene-carrying DNA. They are the blueprint of a human, determining how a person looks, develops and which diseases he or she may get.

23 pairs of chromosomes

Each cell in the human body normally contains 46 chromosomes. These exist in 23 pairs labeled from 1 to 22, with the 23rd pair known as the sex chromosome.



SOURCE:
National
Institute
of Child
Health &
Development

our decision to make

To Karen and Todd, Down syndrome is a mystery. When Karen thinks about the disability, a picture flashes in her mind: her son with blank eyes and saliva dribbling from his lips.

They don't know what people with Down syndrome are capable of or even the physical aspects of the condition.

But they do realize they have a decision to make.

They can continue the pregnancy, as only one of 10 in their situation do, according to national Down syndrome organizations.

Or they can have an abortion.

By the time Todd reaches the Parvin Road exit off Interstate 29, heading toward their modest neighborhood, his thoughts fly past him like the trees outside his window.

The only one he can grasp focuses on abortion.

The emotional pain of an abortion would be temporary, he concludes. But a lifetime of caring for a handicapped child seems hopelessly difficult.

It's nearly 5 p.m. when his truck reaches the driveway of their ranch-style house. Karen notices and rushes to the front door.

Outside on their tiny concrete porch, Todd, nearly 6 inches shorter than his wife, slips his arms around her growing belly. Tears fill her large green eyes. He whispers words of comfort.

Later, with Hunter in bed, Karen drops into an overstuffed teal chair in their homey living room. Behind her on the sofa, Todd turns off their small TV.

Abortion is an option, he says, continuing to talk about the difficulties they could face.

Karen, a woman who alphabetizes her CD collection, can't organize her thoughts. The idea of abortion lurks in the back of her mind, making her feel selfish and cold.

"Those thoughts cross your mind before you even know it. And it makes you feel like a terrible person," she says later.

Suddenly the discussion seems like a tremendous betrayal.

That night, they slip into their queen-sized bed, Karen on the left and Todd on the right, for a restless night.

Karen, a woman who alphabetizes her CD collection, can't seem to organize her thoughts. The idea of abortion lurks in the back of her mind, making her feel selfish and cold.

By Friday morning, their phone is ringing constantly.

A friend calls with a story of misdiagnosis; doctors had said her baby would have Down syndrome until the amniocentesis proved otherwise.

Todd clings to this anecdote.

Members of Karen's family phone, offering support.

We're discussing our options, Karen tells them. Horrified, some say abortion is out of the question.

But Karen bristles. It's our decision to make, she asserts.

When she does think about abortion, her baby turns somersaults inside her. In the only way he can, Karen believes he's saying, "Don't give up on me, Mom."

Friday evening, Karen answers the phone and hears a familiar yet unexpected voice. It's Brad, one of her supervisors

at North American Galvanizing, where Karen has spent the past seven years working in sales. She hasn't met Brad's daughter Bailey, but she's heard stories about her.

Karen, Bailey has Down syndrome, Brad tells her for the first time.

Down syndrome doesn't define Bailey, he continues. She does everything at her own pace, in her own time.

For the first time since her doctor's appointment, Karen smiles.

When she sets the phone down, she stares out their French doors to a tire swing. She imagines her son there, his legs dangling, swinging back and forth in the sunlight.

By Sunday, Karen makes her choice.

In the family's living room, the afternoon's lazy orange light gleams off the wood floors. Perched on the edge of their flower-print sofa, Karen asks Todd to sit. He faces her, his knees almost touching the coffee table.

If you're asking me to end this pregnancy, she begins, I can't do it. He's kicked in me for 20 weeks. And I just can't.

Todd doesn't say much.

Deep down he believes the amniocentesis results will come back negative. And if they don't, he thinks, they can continue their discussion later.

PRENATAL TESTING

Because Karen's baby showed signs of Down syndrome during a routine ultrasound, doctors recommended an amniocentesis. During an amniocentesis, doctors stick a long needle through the mother's stomach and into the uterus to draw out amniotic fluid. Analyzing this fluid can determine a baby's risk for Down syndrome. An amniocentesis is about 98 to 99 percent accurate when diagnosing Down syndrome, according to the American Pregnancy Association.

Several other screens can determine whether a child might be born with Down syndrome. A triple screen or quad screen, a blood test conducted during the second trimester, also can indicate an increased risk of fetal neural tube defects or Down syndrome. These tests are just screens, according to the American Pregnancy Association; they do not diagnose Down syndrome or any other birth defect.

For more information about prenatal testing, visit the American Pregnancy Association Web site at www.americanpregnancy.org/prenataltesting.

the phone rings

Both Karen and Todd stay home on Monday to await the results of the amniocentesis.

They try to busy themselves with housework.

Karen cleans.

Todd works outside.

But just before Hunter's school bus arrives, Karen can't wait any longer. She calls the doctor's office.

Oh, he has the results on this desk, a nurse tells

Karen, her voice happy and light. He just hasn't had an opportunity to call.

What? Todd exclaims when Karen hangs up. Our life is on hold, and he can't take 15 minutes to pick up the phone?

Just after 5 p.m., the phone rings. Their wait is over. Their son will be born with Down syndrome.

No longer able to soothe his worries with optimism, Todd breaks down crying. He sits on the couple's bed, mourning the life he imagined for his family.

But in the next few days, a series of doctor's appointments brings Todd comfort.

Specialists at Children's Mercy Hospital tell the couple that Down syndrome occurs because of an

A MOTHER'S AGE PLAYS A ROLE IN DETERMINING INCIDENCES OF DOWN SYNDROME BIRTH

MOTHER'S AGE	<30	30	35	36	37	38	39	40	42	44	46	48	49
INCIDENCE OF DOWN SYNDROME	Less than 1 in 1,000 births	1 in 900	1 in 400	1 in 300	1 in 230	1 in 180	1 in 135	1 in 105	1 in 60	1 in 35	1 in 20	1 in 16	1 in 12

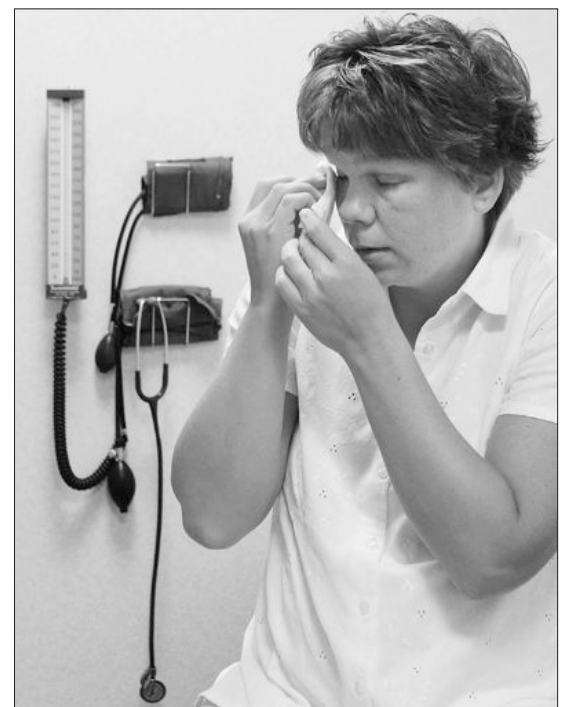
SOURCE: National Institute of Child Health & Development



After a stressful prenatal visit, Karen talks outside the obstetrics office at Northland Ob/Gyn with Melissa Adair. Karen's relationship with Melissa, who has a nephew with Down syndrome, has helped her feel more comfortable during her doctor's visits. Below, Karen begins to feel the stress of a high-risk pregnancy.

*We are grateful you will be OUR son,
not given to someone else, but to us.
I know it will be tough, mostly on you.
I promise to do all I can to make
your life the very best it can be.
I will love you, protect you,
defend you and nurture you.*

Kisses-MOM



extra chromosome in each cell. The extra genetic material affects each person differently, and most people with Down syndrome have some form of mental retardation.

But that doesn't mean their son won't learn.

He will walk, talk and eventually attend school. He'll just face more challenges along the way.

A cardiologist explains their son's heart defects, which were first identified by the sonogram, and tells them the baby will need a relatively minor heart surgery shortly after birth.

On a Saturday in mid-June, while heading back from a family reunion, Karen, Todd and Hunter stop at a truck-stop diner. As they finish their meal, Todd notices a young man with Down syndrome clearing dishes from a nearby table.

He's working, Todd says to Karen. Just like everyone else.

It's a turning point for Todd. He can picture his son now, and that alone



eases his fears. Life might be different than they imagined, he thinks, but it will continue.

By August, Karen can comfortably rest her arms on top of her swelling

belly. She strokes the underside of her stomach in a flowing motion, the way one might soothe a fussy baby.

Her instincts tell her to comfort her child, so one sunny afternoon, she types her unborn son a letter on the family computer.

We are grateful you will be OUR son, not given to someone else, but to us. I know it will be tough, mostly on you. I promise to do all I can to make your life the very best it can be.

I will love you, protect you, defend you and nurture you.

Kisses-MOM

At 3 a.m. Sept. 11, 2005, after almost 18 hours of intense contractions, Karen's water breaks.

And as the liquid hits the floor, feeling like a warm 32-ounce Coke being poured down her legs, butterflies swarm in Karen's stomach.

She calls Todd's name. It's time.

RESOURCES

The Greater Kansas City Down Syndrome Guild hosts new-parent breakfasts at its office at 10200 W. 75th St., Suite 281, in Mission, Kan. The guild also hosts a variety of other support-group meetings, including a teen club.

To learn more about the meetings, call the Greater Kansas City Down Syndrome Guild at (913) 384-4848, or visit www.kcdsg.org.

The guild is affiliated with the First Downs for Down Syndrome annual Buddy Walk. For more information, visit www.fdfds.org, or call 237-1200.

For more resources about Down syndrome, visit the National Down Syndrome Society Web site at www.ndss.org.



Todd feels Karen's contractions during the First Downs for Down Syndrome Buddy Walk on Sept. 10 at Arrowhead Stadium. Karen was determined to finish the one-mile walk, but contractions forced her to drop out early. More than 4,500 people, including 20 of Karen and Todd's family members, walked the one-mile loop, raising more than \$250,000 for Down syndrome support and research. Todd and Karen decorated, above, in anticipation of the new addition to their family.

in the best possible hands



Todd tries to comfort Karen while she is in labor the morning of Sept. 11. Karen was in labor nearly 11 hours before delivering William Charles Tucker Bryant.

Hastily helping Karen into the passenger seat, Todd jumps into the family's charcoal minivan and eases it out of the driveway.

The van's headlights cut through the early-morning darkness as they speed toward Truman Medical Center.

Karen's labor pains are something they both anticipated and feared. They want to meet their son, but his frail gumball-sized heart may not withstand the stress of birth. With each contraction he moves closer to an unpredictable existence.

But by 9 a.m. it's brighter, and friends and family, including Hunter, flood Karen's hospital room.

They talk about the Chiefs' opening game and estimate the baby's weight. One relative reads the baby's horoscope from *The Kansas City Star*.

"What's taking him so long?" Karen's older sister Kelly Williams jokes.

"His own time ...," Karen pants, her words stopped by an eye-bulging contraction.

Dr. Michelle Tolefson, a chief resident who gave birth to her own baby just nine months earlier, moves in and out of the room.



Karen's sister Kelly Williams holds her hand as pastors from Karen's church bless Tucker a few hours after birth.

It's good, she says, that the family has a prenatal diagnosis on their son's condition. This helps not only doctors and nurses but also the family.

"That way it's a joy," she says. "They're not dealing with the grief of not having the baby they expected."

As she talks about what Karen and Todd should anticipate, she is approached by Leah Tucker, Karen's mom.

"I have a concern. I just — is this baby, is he going to be OK?" Leah says. "I mean, with his heart?"

"Well, I can't tell you what's going to happen," Tolefson says quickly. "But what I can tell you is that he's in the best possible hands."

The two talk a bit more, and when Leah turns to leave, she places a shaky hand over the doctor's fingers.

"You want to give them as much reassurance as possible," Tolefson says after Leah walks away. "But you don't know."

When Karen begins pushing at 1:30 p.m., family and friends leave, making room for a battalion of pediatricians and nurses. A score of them, smelling of antiseptic, line the walls and hover near an infant warmer set to the side of the delivery room.

"OK, relax," Tolefson says. "You've got a shot on the next contraction."

"Oh my gosh!" Karen calls out, panting.

William Charles Tucker Bryant enters the world with a gurgled wail.

Doctors whisk him across the room. Five sets of hands surround him.

One holds a stethoscope to his pumping chest.

Karen and Todd watch. And wait.

One doctor nods. Tucker, as they will call him, is healthy enough to be held.

Cradling her son close to her breast, Karen is the first of the family to touch the whimpering newborn. As she pulls him close, Tucker, swaddled tightly in a receiving blanket, opens and closes his filmy, almond-shaped eyes.

"We've been waiting for you," Karen says. "Hi, little baby."

Her smile can be heard in each of her words.

The doctors and nurses who line the room shift nervously as Karen passes Tucker to his father.

"Does he have to go?" Karen asks after a few precious minutes.

"Just a few more seconds," someone answers. "Let Mom hold him again."

Tucker fusses quietly as he's placed back in the crook of his mother's elbow.

"It's OK," Karen whispers, her lips inches from her son's. "It's OK."

Seconds later, nurses rush Tucker down the hallway to the Neonatal Intensive Care Unit, a normal practice for babies with heart defects.



Hunter says goodbye to her newborn brother, Tucker, before he is taken to Children's Mercy Hospital's pediatric intensive-care unit.



Todd watches a medical transport team load his son into an ambulance for the move from Truman Medical Center across the street to Children's Mercy Hospital.



Hunter watches intently as her mother, Karen, gets her first look at Tucker. Tucker will demand much of his mother's attention in the weeks to come, which Karen thinks will be difficult for her attention-hungry 10-year-old daughter.

Todd looks at his wife, giving her a peck on the mouth.

"Good job," he says. "I love you."

After a few minutes, Karen, fidgety, sends Todd down to the NICU to check on the baby. When he opens the door to the unit he squints, startled by the sterile white light.

A nurse guards the unit, and for the first time there is hesitation in Todd's typically robust voice.

"I'm here to see my son," he says. "My son."

Back in the delivery room, Karen talks excitedly to family and friends. The baby seemed healthy, his flesh the color of a blooming carnation.

Several family members ask Karen whether they can hold the newborn before a transport team takes him to Children's Mercy Hospital for assessment.

"Well, they can't bring him in here and not let us hold him," Karen's sister Kelly answers with a smile.

But when Tucker returns, alarm spreads through the room, stifling the eager chatter.

Tucker, now chalky white, lies still inside a device that looks like an oversized cooler. Dime-sized electrodes cling to his chest. A thick plastic flap separates him from his family.

This is reality.

And it comes too soon for Karen.

As pastors from her church pray over the baby, she weeps silently, making no move to wipe away her grief.

The transport team leaves, and Karen, unhappily restricted to her hospital bed, sends Todd with their son.

"Take care of him," she says as she kisses her husband goodbye.

When Todd enters his son's room in the Children's Mercy Pediatric Intensive Care Unit, a cardiologist is performing an echocardiogram of Tucker's heart. A screen next to Tucker's plastic bassinet shows the heart's moving valves and pumping muscles.

When the doctor moves away for a moment, Todd steps close to admire his son's tiny cheeks, still waxy from birth.

"They're so fat," he whispers, sliding his finger down a jaw line that closely resembles his own.

When the cardiologist finishes the exam, he invites Todd into a small conference room. Inside, Todd, without the support of his family or the hand of his wife, learns his son's chances of survival.

And when he leaves the room minutes later, two tears cling to his cheek.

"That's a lot of information," he says.

Before Todd can face his family, gathered in the waiting room, he slips into the men's restroom.

Inside, a single sob escapes.

the claws of denial

Sitting in one of only two chairs in Tucker's room, Karen, still wrapped in her hospital gown, rocks from side to side in a quick, uneasy manner.

Dark lines beneath her eyes reveal a level of exhaustion that goes beyond physical discomfort.

Throughout the night after Tucker's birth, Karen called the PICU twice just to hear from nurses that her baby was OK.

She doesn't know what color his almond-shaped eyes are, and she can't hold him in her arms.

But today, at least, she's by his side.

Before Karen and Todd move into a small conference room to converse with Dr. Stephen Kaine about Tucker's heart defects, Karen covers her son with a blue blanket from home. She slips the edge, lined with bouncing dogs, underneath his feet.

Kaine, Tucker's cardiologist, is a tall and sturdy man. Age has made the top of his head slick while covering his face with a full beard. His voice is soothing, but what he has to say is not.

As they sit around a small table, Kaine uses diagrams to explain the anatomy of Tucker's heart.

Among other problems, Tucker's left ventricle, the pumping chamber that moves blood to the body, is dangerously small.

At this point, the only thing moving blood away from his lungs is a fetal vein, which typically closes after birth.

Doctors are keeping it open and Tucker alive with medication.

Tucker is doing well now, Kaine explains, but his condition will quickly deteriorate. The options are stark.

Karen and Todd can take Tucker home to die peacefully, or they can choose a three-step surgical process called the Norwood procedure. The first step would be risky open-heart surgery that would take place sometime in the next few weeks.



Dr. Stephen Kaine discusses treatment options with Karen and Todd Bryant a day after Tucker's delivery. Among other problems, the doctor tells Karen and Todd that their son's left ventricle is so small it is pumping virtually no blood to his body. Below, after deciding to go ahead with the open-heart procedure on the newborn with Down syndrome, Karen and Todd hold each other in Tucker's PICU room.

"Yesterday I told Todd that the risk of dying with this procedure is about 30 percent," Kaine says. "My role is to give you information, to tell you what the options are and then to support your decision for what's best for your family and your baby."

Todd digs a Kleenex from the box left purposely on the table. He hands one to his wife.

As they weep quietly, Kaine looks through his folded hands at the speckled blue carpeting below.

"You think by checking out the rest of his body that he stands a pretty good chance?" Todd asks.

Unable to give false hope, Kaine explains that babies with Down syndrome often have more difficulty with surgery than other children.

"We have patients who do well; they fly right

through, and we have patients who don't do as well, who may even die on the day of surgery," Kaine says. "But risk is unavoidable. And without treatment he won't survive."

Those last three words smack Karen and Todd in the face. They stare, shocked momentarily, as though all the other warnings didn't quite make it through. But the simplicity of the doctor's final statement unhooks the claws of denial.

Together, without looking at each other, the new parents reach the same conclusion.

"Gotta," Todd begins.

Karen joins in.

"Gotta do it," they say in unison.

"He came into this world for a reason," Karen continues. "We just have to keep him here."



all they'll have of Tucker

When the couple arrives home the next night, leaving their baby at the hospital, both pace through the house looking for something they can't describe.

"It's like part of you is missing," Karen says. "He's not in my belly, and he's not here with us. You kind of wonder, 'What do we do now?'"

They face days of waiting, caught in a trap of emotions.

Tucker's surgery could kill him. Or save him.

The next few days, they fall into an uneasy routine. As planned, Todd returns to work. Karen keeps a daily vigil at the hospital, clipping her son's nails and surrounding him with toys from home.

Tucker, who rarely cries, spends most of his days sleeping. The PICU nurses comment about his bravery when they take blood for various tests, even as the baby's tiny hands and feet turn black and blue from the needle pricks.

Four days after his birth, Karen holds her baby once again.

Nervous, Todd lifts Tucker from his bassinet, holding him like a moving box full of breakables.

He places Tucker in her arms, slipping four sets of wires, each monitoring a different vital sign, underneath the arm of the rocking chair.

Once he's safe in her lap, stress slides off Karen's cheeks, and a warm, pink flush becomes her.

Tucker's heart rate, previously racing at 169, glides downward.

"Hey, little boy," she coos, barely rocking in the wooden chair.

152 beats per minute.

Both Karen and Todd cherish these quiet times. Because of the risky surgery to come, they realize these moments may be all they'll have of Tucker.

"There's his eyes," she says, getting a rare glimpse.



Karen and Todd look at a Children's Mercy room service menu. Karen often ordered food from the service while Tucker was in the PICU.

"Hi, my baby."

Tucker looks into Karen's face, focusing his dark blue eyes. As he closes them contentedly, his tongue lolls outside his mouth.

145 beats per minute.

"Some babies, when they get in their mother's arms, they just relax," says LeeAnn Brasier, PICU nurse. "They're comforted."

Tucker's tiny fingers hug one of his mom's knuckles.

142 beats per minute.

His oxygenation level, which is sometimes in the low 60s, rises to 91 percent, similar to that of a healthy newborn.

As Karen whispers to the baby and Todd stands over them protectively, the beeping of machines and the shuffling of nurses drift into the background.

And there's peace.

trying to say goodbye

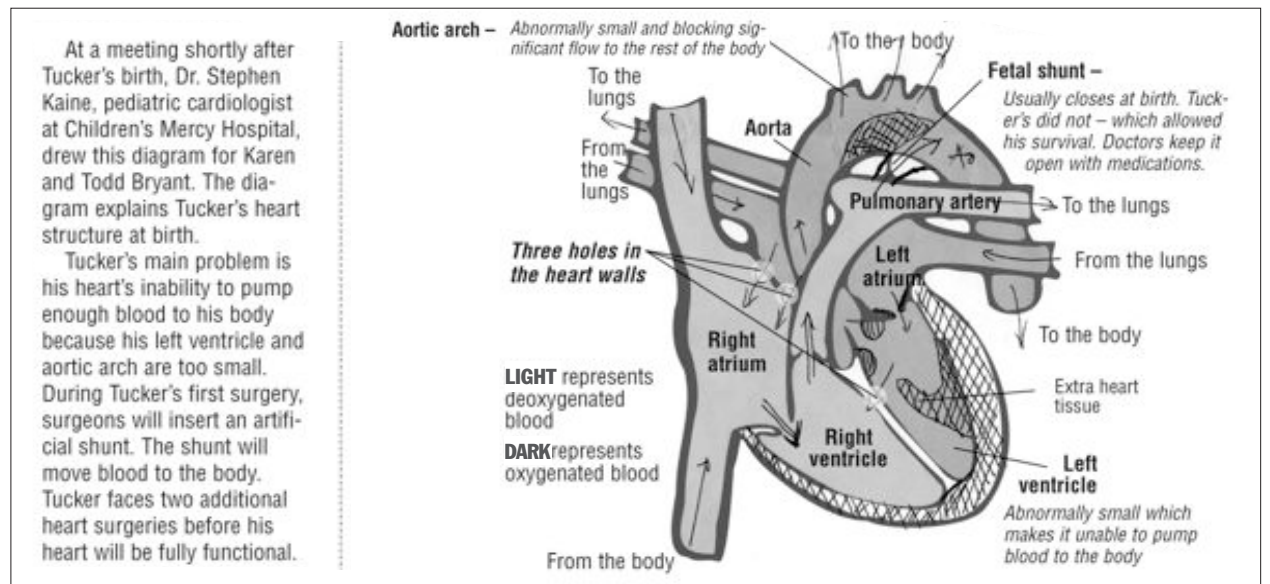
On the morning of surgery, the curtains of Tucker's room are drawn tightly closed. A single light wraps the family in a soft cocoon. Todd and Karen hunch over Tucker silently, holding him, caressing his feet and running their fingers down his velvety cheeks.

They are trying to leave this moment feeling complete. Trying to transfer some of their strength to Tucker's tiny body and, with the 30 percent chance that he won't make it hovering in their minds, they are trying to say goodbye.

"You don't know if you're going to see those eyes again," Karen says.

Todd puts it more bluntly. "You don't know if you're going to see him alive."

Tucker, only 17 days old, is uncharacteristically alert. He looks oddly wise, staring at his parents almost as if he understands the reason for their tears.



At nearly 8 a.m., a nurse enters and the hurried atmosphere of the PICU intrudes, bringing the couple back into the moment.

"Is it time to go?" Karen asks, knowing the answer.

"It's about time," a nurse responds as more people fill the room.

"It will be OK," Todd mouths to his wife.

Karen returns Tucker to his plastic cradle, and they both lean over him, whispering encouraging words only he can hear.

As the nurses wheel Tucker to the operating room, Karen and Todd can't watch. They step back and wrap themselves in a tight embrace.

Todd's arms, around Karen's rib cage, shake with her gasps.

"Be strong," Todd whispers. "Be strong."

By 9:20 a.m., surgeons make the first incision into Tucker's milky white skin. Then they break open his rib cage and begin repairing his frail heart.

an agonizing wait



Dr. James O'Brien, left, and his pediatric surgical team begin operating on 17-day-old Tucker Sept. 28 at Children's Mercy Hospital. The day after surgery, Karen and a nurse, right, pay close attention to the monitors hooked up to Tucker, which read his vitals. The newborn was sedated for days after surgery.

In a brightly colored waiting room at Children's Mercy, Karen and Todd join hands with 12 loved ones to pray for their son's life.

"Father, we love this child even if he is not perfect," says David Tucker, Karen's dad. "We pray that you give him strength to survive surgery."

They say "amen" and take a seat in the waiting room's array of stiff-backed chairs.

Tucker's fate is out of their hands.

Upstairs in the stark operating room, doctors place Tucker on a bypass machine to pump his blood. Behind them, black words on a white board outline the procedure. Soft rock, including the Doobie Brothers and Dire Straits, provides a mellow soundtrack.

Downstairs in the waiting room, squealing cartoons on a big-screen TV grate the family's nerves. After one update from the surgical nurse, Todd starts wiggling in his chair. Soon, the group, most wearing T-shirts from the First Downs for Down syndrome Buddy Walk, spreads out. Hunter and members of Todd's family play a card game. Todd and a longtime friend roam the halls.

Karen, the only one who doesn't leave the waiting room, doesn't say much. She mostly stares, her eyes looking past the here and now.

Just before lunch, a surgical nurse tells Karen and Todd the next step will be to take Tucker off the bypass machine. She'll return soon to tell them how Tucker's repaired heart handles the rush of blood.

It's an agonizing wait.

Two hours pass.

"Here she comes," someone says, noticing the surgical nurse stepping off the elevator.

Everyone pauses. Leah, Karen's mom, stops midway through turning a page in her book.

The nurse, still wearing her blue surgical cap, strides toward the group.

"I'm smiling," she says, sticking her fingers into her dimples.

Karen's hand, clutching a napkin from lunch, shoots to her face. Todd's mouth drops open.

"He came right off bypass," the nurse says.

"Oh thank God," Karen says, the words tumbling out of her mouth.

Karen and Todd, still seated, clutch each other in an awkward embrace. Karen's shoulders, bent forward in a shallow

arc, shake silently.

The rest of the family stares.

"He's definitely a trooper," someone says.

"Made of stone, man," adds Carla Travis, Karen's best friend. "Just like his mom."

For a moment, they exhale all their worries.

But the relief is short-lived.

By 3 p.m., doctors move Tucker back to the PICU.

The next 48 hours are critical, the surgeon tells them. Karen and Todd spend the early-morning hours crammed into a twin bed at the hospital's Ronald McDonald house.



Karen and Todd, still seated, clutch each other in an awkward embrace. Karen's shoulders, bent forward in a shallow arc, shake silently.

a roller coaster

The next morning, Tucker's ribs, still cracked open, are covered by white gauze so thin it pulsates with each beat of his heart. Fluid the color of pink Kool-Aid slips through tubes snaking out of his chest.

Otherwise, he's still.

Karen hovers over his hospital basinet.

An attending physician stops in Tucker's room about 8 a.m. with a team of interns trailing him. The doc-

tor explains Tucker's recent surgery and the complications he faces.

Tucker's left foot is several degrees colder than his right, which might mean a blood clot. He also has yet to produce any urine, which could be a problem with kidney function.

After checking his vitals, the doctor asks whether Karen has any questions.

"So we've just got to get him to pee," Karen says, her voice raising slightly.

"Oh, we will," the doctor says, confident. "We have our ways."

The next two days, Tucker responds to treatment, and doctors feel comfortable closing his chest.

He progresses, but as the weeks go by, hospital life wears on the family.

They receive their first hospital bill, totaling nearly a quarter of a million dollars. Not sure of what portion they will be responsible for, Karen begins making almost daily

phone calls to their insurance companies.

And while Karen can't imagine spending her days anywhere but the hospital, Todd has a hard time sitting there.

"You can only take so much of them poking and prodding him," Todd says. "Before you know it, you feel like you're going crazy."

He begins painting their house, putting his stress into slanted swipes of olive paint.



Though Tucker is unable to ingest Karen's breast-milk, she continues to pump while he is in the hospital, left. Below left, Karen and her sister Amy Tucker tackle a long-overdue deep cleaning Oct. 6 at the Bryants' home. Karen said she hoped to rid the house of every speck of dust before bringing Tucker home. At the hospital, Tucker's move from the PICU on the second floor was a big step forward for the family. During their time on the fourth floor, nurses taught the family how to care for Tucker when he left for home. Tucker, below right, looks around his fourth-floor room at Children's Mercy Hospital nearly six weeks after his surgery.



we're home

Six weeks after surgery, doctors tell Karen and Todd they can take their son home. Despite a partially collapsed lung, tonight will be Tucker's last in the hospital.

After a CPR class the day before Tucker's homecoming, Karen hurries to his hospital room, where Todd is learning how to use a heart-rate and oxygenation monitor.

Because Tucker's heart still requires two surgeries, his vital signs must be monitored carefully. A normal newborn would have an oxygenation rate of at least 95 percent; the technician sets an alarm on Tucker's monitor to sound at 70 percent.

Seconds after Karen wraps the sensor around his foot, Tucker's oxygenation rate dips to 57 percent. The machine begins to beep noisily, giving them the first taste of a sound that will drive them crazy the next few months.

Karen tosses herself onto the hospital room's long padded bench. Stacked behind her on the ledge, three books, "Common Threads: Celebrating Life With Down syndrome," "Babies With Down syndrome" and "Super Search and Find 7," represent part of the evening's entertainment.

"It's going to be a long night," Karen says.

Karen and Todd need to spend Tucker's last night in the hospital in his room, caring for him without help.

The night brings only a few hours of sleep and a new level of nervousness.

"I'm terrified," Karen says the next day as they pack. "We're responsible for him now — if he lives or dies."

As they leave the hospital, Karen and Todd walk down a narrow hallway with poster-sized photos of children whose names Hunter can recite from memory.

Near the end, they pass a photo of Seth, a little boy with Down syndrome who died before he reached his first birthday. Before Tucker's birth, Karen examined the picture of the baby carefully, trying to see her son in Seth's wide grin and large eyes.

Now, Karen says, she sees the Down syndrome characteristics in her son. His eyes are slanted, she says. And the back of his head slopes.



Nearly 2 months old, Tucker gets his first look at the family dogs Harley and Lucky. Todd relished showing his son around the house after they arrived at home, even stopping by the front door to let Tucker feel the warmth of the sunshine. While at a stoplight, Karen, below, checks Tucker's oxygenation levels on their way home from the hospital. With only four weeks before she returns to work, Karen said, she worries about being able to care for Tucker.

But Todd doesn't see it.

"Maybe it's because I'm his father," Todd says. "But I just don't."

When they reach the front door of the hospital, Tucker inhales his first breath of air not filtered by the protective hospital environment. The smell of car exhaust and cigarette smoke swirls with a toasty aroma of fallen leaves.

Any infection, Karen thinks, could make him sick. So she rushes her 2-month-old baby to their minivan parked in the hospital's colorful circle drive.

Beaming, Todd kisses Karen before loading up his truck with blankets, medicine and baby toys. Her face lightens with a smile.

When they arrive at their home just

after lunchtime, Karen hurries Tucker inside and sets his car seat on the wood coffee table.

"Hi, baby," she says, pulling him out. "Guess what. We're home!"

"You want to have a look around?" Todd asks.

First Todd carries Tucker through the dining room to the back door. On the other side, the couple's dogs, Harley, a monstrous Great Dane, and Lucky, a schnauzer, press their noses against the screen.

"These are the dogs," Todd says, cradling Tucker in his left arm.

"Todd Douglas!" Karen shouts from the living room.

"I'm just showing him around," Todd says. "Can't I do that?"

But he moves away, instead taking

Tucker to the front door, where the afternoon sun warms the cool November air.

"You haven't seen much of that," Todd says of the sunlight.

"What a pretty day," Karen mutters as she organizes Tucker's eight medications. "The perfect day to come home."

An hour later, seated cross-legged on the multicolored living room rug, Karen stares at Tucker.

Quiet in his infant swing, he looks back blankly.

"I'm plugging him in," Karen tells Todd as she wraps a sensor around Tucker's foot.

He has an 87 percent oxygenation rate, much higher than normal. But Karen still worries.

"Eh. You believe it when it's low, but you don't believe it when it's high," Todd says, waving an open hand at her dismissively.

Karen scowls and adjusts the sensor. The alarm sounds loudly, signaling a dip in Tucker's vital signs.

"That's what you wanted," Todd says, already exasperated with the beeping.

"Don't be like that," Karen shoots back.

Todd, still wearing his hospital visitor's sticker, shuffles from the room.

When he returns minutes later, the monitor is silent.

"Told you it wasn't working," she said, in a mocking tone. "But you thought, 'Paranoid!'"

He laughs along with her. Soon Todd heads outside to finish painting the house, and Karen settles into their teal armchair. Tucker, in her arms, is having lunch through a feeding tube down his nose.

Because of the long hours she spent at the hospital, Karen has memorized all of Tucker's medicines. She knows how he likes to be held and how to get his heart rate up.

And when Todd does something differently than she would, she jumps in to take over.

"It's something I need to watch," she says, yawning. "Because he needs to feel like he's a part of this also."



the moon rocket ride



Karen breathes a sigh of relief when Dr. Stephen Kaine informs her and Todd that Tucker's progress at 3 months and 2 days is good after being in the hospital the first eight weeks of his life. Below, concerned about recent blood in Tucker's stools, Karen tries contacting nurses and doctors familiar with Tucker to see whether he should be brought to the hospital. After a few more days in the hospital, they learn the problem was related to an allergic reaction to Karen's breast milk.

Afternoon extends into evening, and life is suddenly delightfully normal.

Karen, Todd, Hunter and Tucker, each in their pajamas, cuddle up to watch "Bewitched" and snack on popcorn. Todd and Hunter take turns holding Tucker until the movie credits roll.

When Tucker's voice raises into the typical newborn wail, Karen resists the urge to jump up from her chair.

By 9:30, Tucker's eyes slide shut.

Karen and Todd lay him in his crib, whispering good night. They linger there in the dark, quietly holding hands.

Above Tucker's crib on walls the color of sunshine, a moon smiles down on the quiet scene. Also on the poster, the words, "The Moon Rocket Ride," suddenly have meaning for Karen.

"We're on our own little ride," she says later that night.

During the next few weeks, they change diapers and learn how to reinsert a feeding tube. Between their two insurance companies, most of their

\$500,000 hospital bill will be paid for, but they begin to budget for Tucker's expensive specialized formula.

They listen eagerly as Tucker begins to babble at 3 months.

And just before midnight on New Year's Eve, counting down in their living room with friends, Karen and Todd raise glasses of sparkling grape juice to 2006.

They toast to a year they hope will be uneventful, despite weekly physical and occupational therapy visits to ensure their 4-month-old's development.

They toast to health in the face of his second heart surgery scheduled for early April.

They toast to a lifetime of joys and challenges dealing with Down syndrome.

But before they drink, Karen and Todd tap their plastic cups against Tucker's formula.

Looking up from the teal armchair, the baby's rosy lips curl into the hint of a smile.



epilogue

Since the new year began, the Bryant family has continued life without a reporter and photojournalist following their every move.

Hunter has adeptly fallen into the role of big sister. She cares for, protects and supports her younger brother. The fifth-grader recently celebrated her 11th birthday.

Tucker, now 7 months old, continues to grow and put on weight, to the delight of his family and doctors. His occupational therapy visits are paying off: He vocalizes often and rolls over on his own. A few trips back to Children's Mercy have caused minor setbacks, and Tucker is awaiting his second open-heart surgery, scheduled for mid-May.

Since Tucker's homecoming, Karen and Todd have perfected a routine that allows them to care for Tucker without the help of a baby sitter. Karen's mother, Leah, and other family members and friends help with Tucker when needed. And though the constant stream of doctor visits, brief hospital stays and other family activities have kept the couple busy, they've delighted in learning about their son's personality and how he fits into their lives. They say Tucker teaches them something about life and about themselves almost every day.



Since arriving home Nov. 7, Tucker has been readmitted to Children's Mercy Hospital several times. Between these visits, occupational and physical therapists have assisted with his development.



An occupational therapist rolls Tucker to help him become accustomed to the movement. By the time he was 6 months old, Tucker could roll over on his own.

about the journalists

Betsy Lee is a health news and feature reporter for the St. Joseph News-Press.

A native of Lawrence, Kan., Lee earned a bachelor's degree in journalism from Northwest Missouri State University and pursued graduate journalism studies at the University of North Texas.

While in Texas, she freelanced for the Dallas Morning News' health section. Her post-collegiate experience also included serving as a young journalism fellow at the Poynter Institute for Media Studies. Before joining the News-Press, Lee worked at The Examiner in Independence.

Lee pursued the Bryants' story after learning through the Greater Kansas City Down Syndrome Guild that nine out of 10 pregnant women who learn their children will be born with Down syndrome choose to have abortions.

"I was intrigued," Lee said. "I wanted to find out what motivates those families that choose to have a baby with Down syndrome. And I wondered how that choice affected their lives."

The guild put Lee in touch with Todd and Karen Bryant, who decided to share their story because they



thought it might make the world a better place for their son and others with Down syndrome.

"The Bryants never asked us to leave," Lee said. "We truly worked with them as partners to produce the most enlightening story possible."

Betsy Lee can be reached at betsylee@npgco.com.

Matt Frye is a photojournalist with Sun Tribune Newspapers.

A native of Blair, Neb., he graduated from Northwest Missouri State University with a bachelor's degree in journalism and a minor in visual journalism. He's also studied photojournalism at the University of North Texas. Frye has interned at the St. Joseph News-Press and freelanced for the Dallas Morning News and USA Today. He is one of 32 journalists chosen nationwide to attend this summer's Poynter Institute for Media Studies six-week summer fellowship for recent college graduates in St. Petersburg, Fla.

Having "worked wonderfully" with writer Betsy Lee on several projects in college, Frye said he was excited when Sun Tribune Newspapers Photo Editor Christina Daugherty asked whether he'd be interested in chronicling the Bryants' story.

"This story is one of the few opportunities I feel I've had to really educate a readership," he said. "I hope the time we spent documenting the Bryants' lives and the access they and hospital professionals allowed us increase tolerance in local communities."

Frye said he had been changed by the time he'd invested in the family's life.

"I better understand why someone



in the Bryants' situation would allow a couple of strangers into their home and share such intimate times with them and the community," he said. "They felt they had a story to share, which could benefit others in their situation. I hope Betsy and I accomplished that."

Matt Frye can be reached at mfrye@npgco.com.

The copy editing and design work of Paige Worthy, photo editing of Christina Daugherty, and editorial oversight of Amy Schmitz and Amy Keizer contributed to the realization of this special project of Sun Tribune Newspapers. George Stanton of the St. Joseph News-Press, another News-Press & Gazette Co. publication, contributed graphics to the project. Natalie Shelton wrote Lee's and Frye's profiles, and Brenda Ahearn photographed them.

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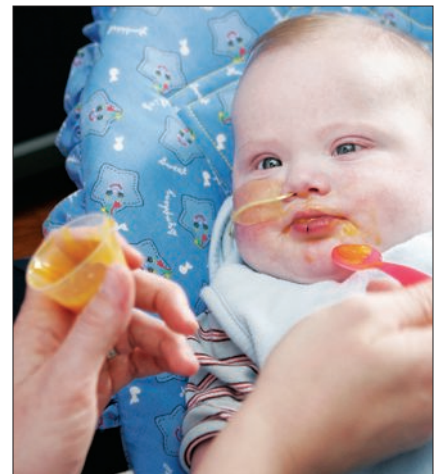
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2005	P4051	Infiniti G35	Black	22K	Lthr, sunroof	Was \$30,998	\$28,998	2003	P4070	Infiniti 35	Sand	45K	Lthr, sunroof, cold weather pkg	\$20,998
2005	P4067	Infiniti Q45	D. Plat	21K	Lthr, sunroof, navigation	Was \$40,998	\$28,998	2003	P4088	Infiniti M45	Silver	24K	Lthr, sunroof	\$24,998
2005	P4066	Infiniti QX56	Black	12K	Lthr, snrf, navigation, DVD	Was \$47,998	\$45,998	2003	9712A	Lexus GX470	Dk. Blue	42K	Lthr, sunroof	\$33,998
2004	P4040	Infiniti G35	Black	25K	XM, lthr, sunroof	Was \$29,998	\$27,998	2003	9749A	Nissan 350Z	Black	30K	Auto	\$25,998
2004	9744A	Infiniti G35 Coupe	Red	26K	Auto, lthr, sunroof, premium	Was \$32,998	\$30,998	2003	100	Lexus E300	Silver		Lthr, sunroof, CD	\$24,998
2004	9846A	Nissan Maxima SL	Maroon	42K	Lthr, sunroof	Was \$24,998	\$22,998	2002	8996A	Infiniti 35	Silver	48K	Lthr, sunroof, CD	Was \$20,998 \$18,998
2004	P4030	Saab 9 3	Black	27K	Auto, lthr	Was \$18,698	\$15,885	2002	9900A	Infiniti 35	White	59K	Lthr	Was \$19,998 \$17,998
2004	9516A	Volvo S-40	Gray	20K	Lthr, snroof, windows/locks	Was \$25,998	\$23,998	2002	P4048	Infiniti 35	White	49K	Lthr, snrf, cold wthr, Gold Pkg	Was \$20,998 \$18,998
2003	9964A	Cadillac CTS	Dk blue	38K	Auto, lthr, sunroof	Was \$26,998	\$23,998	2002	P4064	Infiniti 35	A. Bronze	46K	Lthr, sunroof, CD	\$18,998
2003	9918A	Honda CR-V	Brown	37K	AWD, auto, win/locks, snrf	Was \$20,998	\$18,998	2002	P3999A	Infiniti QX4	Jade	52K	Lthr, sunroof	Was \$26,998 \$23,998
2003	9942A	Infiniti FX35	D. Graph	48K	AWD, lthr, sunroof, navigation		\$29,998	2002	P4035	Infiniti QX4	Jade	33K	Lthr, snrf, cold weather pkg	Was \$26,998 \$23,998
2003	9538AB	Infiniti G35	Silver	57K	Lthr, sunroof		\$21,998	2002	P4036	Infiniti QX4	White	46K	Disc, lthr, snrf, cold wthr pkg	Was \$26,998 \$23,998
2003	9579A	Infiniti G35	D. Plat	53K	Disc, Premium	Was \$25,998	\$23,998	2002	9884A	Mercedes E320	Black	36K	Leather, sunroof, 4-Matic	Was \$26,998 \$24,998
2003	9636A	Infiniti G35	Emerald	68K	Lthr, sunroof	Was \$20,998	\$18,998	2002	9726A	Mercedes E430	Silver	30K	Leather, sunroof, auto	Was \$37,998 \$28,998
2003	9753A	Infiniti G35	White	62K	Lthr, sunroof, windows/locks	Was \$23,998	\$21,998	2002	P4008	Mercedes S430	Silver	30K	Lthr, loaded, nav, moonroof	Was \$37,998 \$23,998
2003	9963A	Infiniti G35	D. Plat.	37K	Certified, lthr, sunroof	Was \$26,998	\$24,998	2001	9236A	Toyota Tundra	Green	46K	Limited, 4s4, leather	\$18,998

back to daily life



Karen feeds Tucker apricots, above, for the first time. Though he never learned to bottle feed, Tucker took to eating baby food easily, surprising the physical therapists. Dr. Merlin Butler of the Children's Mercy Hospital Down Syndrome Clinic says babies with Down syndrome can struggle to develop the sucking instinct that other babies have at birth. At left, the night of Tucker's homecoming, life suddenly feels normal again for the Bryants as they watch the movie "Bewitched."



Todd, above, relaxes with Tucker shortly after his homecoming. A First Steps physical therapist, known to the family as Miss Allison, left, comforts Tucker as he sits in a plastic chair during therapy. Spending time in the chair will help Tucker learn how to sit up by himself faster.

"He came into this world for a reason. We just have to keep him here."

Karen Bryant