

Love to last a lifetime



At a special prayer service at Olathe Bible Church, as many as 60 people gathered in fellowship with Jessica and Dave Weatherford and their families, including Dave's mother, Kathy (foreground, at left). During a hymn, church members reached out to the couple and prayed for their unborn son, Zeke.

STORY BY LEE HILL KAVANAUGH ★ PHOTOS BY ALLISON LONG
THE KANSAS CITY STAR

Jessica Weatherford lies small and helpless on the operating table, staring at a blue surgical sheet hanging inches from her face.

It blocks her view of the Caesarean operation on the other side, as a doctor delicately reaches for her baby.

A baby Jessica's been waiting for.

A baby she prays will live long enough to hold in her arms.

The physician and his assistant talk quietly as they operate. But Jessica, 29, feels nothing, hears nothing except the banter from her husband, Dave, who is talking because he has to do something.

"This is a lot different from last time, isn't it, Jess? You were out for the other one. ... And gosh, you can see so much this time."

She nearly laughs. Dave, joking with her, just as he always has, just when she needs it the most. Dave, dressed like a surgeon, blue scrubs tight, a white surgical mask blotting out his mustache and goatee. All she can recognize are his brown eyes, the ones that turn up at the corners when he smiles.

Nearly two years earlier, she'd gone through an emergency Caesarean, deep anesthesia and deeper anxiety about the outcome. But it brought forth their

FIRST OF TWO PARTS

baby girl, Victoria "Tori" Ann, now nearly 2.

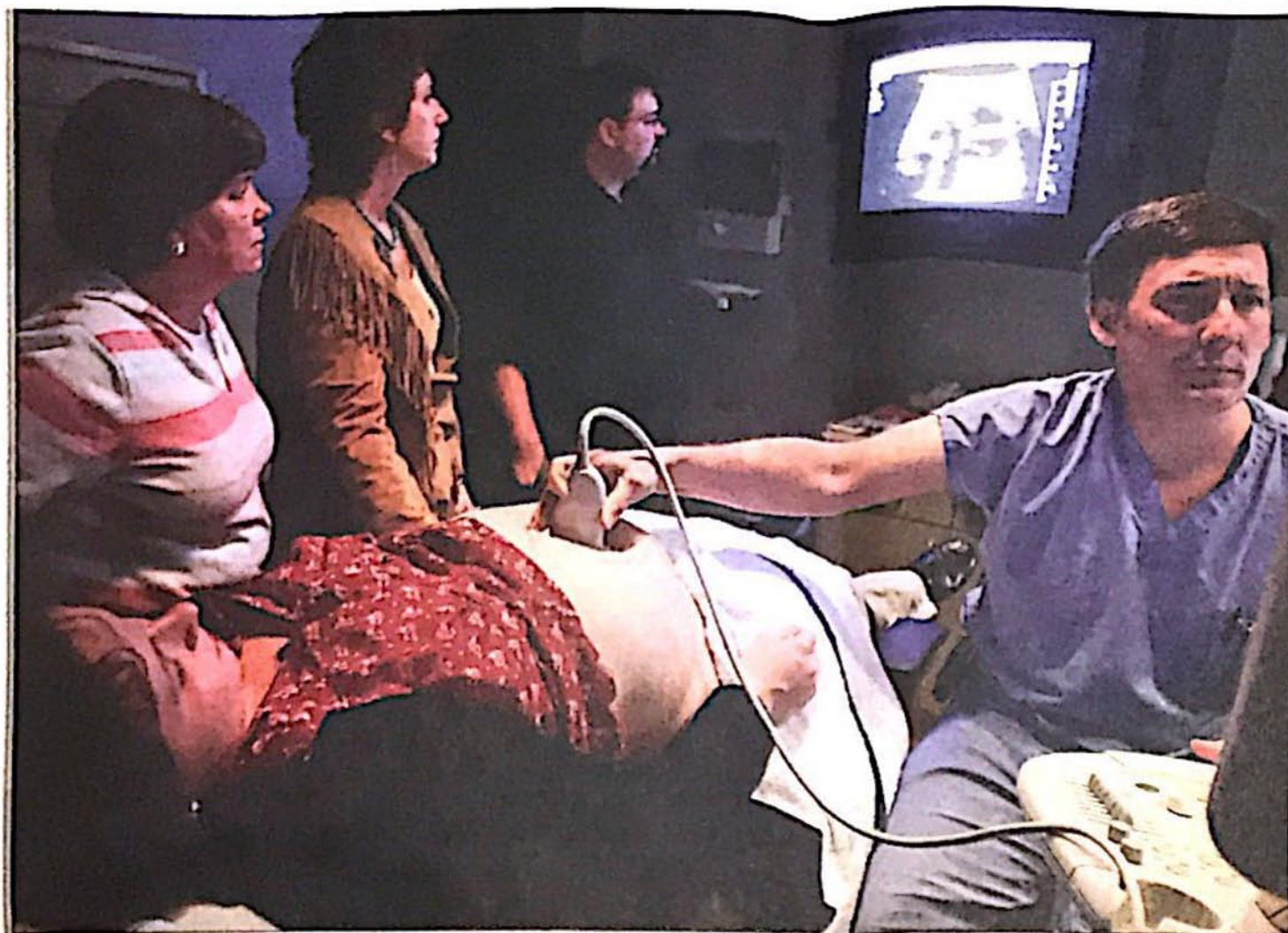
This time, Jessica is awake, the C-section planned, but there is no question about this outcome. Already, planning has begun for their baby's funeral.

Their baby boy will not endure beyond Jessica's womb. Zeke, they have named him, short for Ezekiel, meaning God is my strength. Jessica wanted to name him soon after the diagnosis. She wanted him to be as real to the world as he already was to her.

Dave, 35, is her best friend. He has helped carry her grief during this months-long journey. He has shared her laughter, prayers, tears. This has been his walk, too.

SEE ZEKE | A8

ZEKE: Huge consequences result from a tiny genetic error



At Zeke's last ultrasound, attended by physician Louis Ridgeway, Dave and Jessica Weatherford were joined by Dave's mother, Kathy Weatherford (far left), and Jessica's mother, Lori Singleton (second from left). It was the first time that Jessica's mother and mother-in-law had seen the baby.

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The doctor tugs hard and between his hands a tiny head appears, covered in wet curls.

Jessica feels her husband's hand gripping hers. He's as scared as she is.

The operating room is eerily quiet as everyone looks to Zeke.

Jessica has prayed that she will see beauty instead of her son's deformities. She's prayed that the sadness she knows is coming won't rip her heart beyond repair. She's prayed too that maybe God will work a miracle, make Zeke whole and perfect.

But after four months of medical tests, she's not blinded to reality.

She knows that God has already performed one miracle: Zeke is alive.

The choice

Psalm 139, 13-14: "For you created my inmost being; you knit me together in my mother's womb. I praise you because I am fearfully and wonderfully made."

The worst day was Nov. 6.

Jessica remembers her excitement when she finally saw an image of the 20-week fetus inside her. She remembers staring at Dave's face as the sonogram technician, a young woman, smiled when she told them they were having a boy.

A boy!

But the sonogram technician grew quiet as she swirled the wand this way and that on Jessica's belly. She remembers that the technician just ... kept ... looking.

Jessica and Dave were ushered into a waiting room where they spent nearly an hour. When they finally saw the doctor, his face wore the news.

"I'm sorry, he said. There are abnormalities with your baby's brain and abdomen. Problems too great for medical science to fix.

Jessica felt her throat close. Felt the sting of tears, the shudder of a broken heart. In the blink of a routine appointment, their world spun from giddy joy to gut-wrenching sorrow.

The doctor left the couple alone to grieve.

And choose their future.

Jessica had miscarried before, before she gave birth to Tori. The sadness still lingers. One day pregnant, the next day not. No baby. No funeral. No memories, except the day they learned the baby had died.

But this time, she'd been feeling this baby. He felt strong. She'd watched her belly jiggle with the impression of a little foot pushing out. She'd felt him kicking and twisting and reminding her: *I am here!* He had already brought her so much joy.

After carrying him for weeks beneath her heart, she knew he'd stay in her heart forever.

Couldn't the doctor be wrong? Maybe his problems weren't so overwhelming...

But days later, more tests would bring more bad news: His brain wasn't forming properly. His face had deformities: a double cleft lip and problems with his eyes. His heart's veins and arteries were on the wrong sides. An omphalocele — a sack containing half his organs — was growing outside his body.

An amniocentesis confirmed a nonhereditary birth defect: full trisomy 13, a condition of having three copies of chromosome 13.

One extra hiccup of DNA, a genetic error sabotaging a human's destiny.

As the couple drove home, the road at times seemed to disappear behind their tears. Jessica hurt so badly for her little boy, who would never grow up, never even leave the hospital. She asked Dave to stop.

A park bench beckoned. The late autumn sunshine was warm on Jessica's face. She could see the fiery reds and brilliant yellows of fall leaves. The air was sweet with a hint of damp earth.

Dave's arm found its cuddling spot on her shoulder. She nestled against his chest. The couple read Scripture, looking for words that would ease their heartbreak, words that would help them understand.

And the words came. They read about Abraham, who was told to sacrifice his son. They read about Hannah, who had so wanted a child she promised him to God, no matter what. They read about Jesus, God's son who had died for them.

Ending Zeke's life now wouldn't short-cut their sadness. God has a reason and a purpose for this little baby, Jessica told Dave.

She decided that the best gift she could give to her unborn son was to love him until his death, even if the only fullness of his life would be in the soft cushion of her womb.

As long as Zeke lived, they would love him as best they could. Maybe he would go all the way to term. Maybe they could hold him before he died.

Jessica vowed she wouldn't let herself wallow in grief. She would choose to seek joy. Look for it in every kick, every flutter, every wonderful moment.

She knew there would be days and nights when her tears would spill. But she knew faith doesn't mean there is no sorrow; faith helps you through the sorrow.

She wouldn't let the grief tear at the fabric of her five-year marriage with Dave. They weren't superhuman, but they needed to be strong for each other.

They knew most people wouldn't continue a doomed pregnancy. But for them, it was the right choice.

That decision was easy. Living with it would be another matter.

Jessica knew she would need help.

Finding comfort

Two weeks later, a phone rang at a house in Westport.

On the other end, a young woman cried and cried, unable to speak. But this was a phone call Patti Lewis had answered hundreds of times before.

Is your baby sick? Lewis asked. ... It's OK to cry. ... Let yourself cry. ... I'm here. ...

"Everybody cries when they call here," said Lewis, 56, who has helped some 200 families through her non-profit group, Alexandra's House, a perinatal hospice care center.

She opened the house to be a place of caring for families grieving the loss of any infant, be it an unexpected stillborn, a miscarriage, an abortion or an unborn baby the parents know will not survive.

Sometimes people hang up when Lewis answers. Words often escape the grieving parents who find her.

"But they always call me back," she said. "It's just so hard."

She listened to Jessica, an expectant mother struggling to tell a stranger the diagnosis for her son. And Jessica found a soft voice who knew how it felt when dreams collapse.

Within days of her call, Jessica and Dave visited Alexandra's House, walking through its gated archway, past the stone lambs on the lawn.

Lewis walked them through the house, past the front door where a prayer candle flickered. Past the book of life filled with handwritten names of children whose families have sought refuge here. She

showed them the wall of life — photos of babies whose bodies weren't strong enough for this world.

Lewis shared with them how other families loved their babies at death. Told them all the ways they could love Zeke to remember him forever.

She told them it's OK for families to hold their baby, even if the baby has died. She told them it's OK to bathe and kiss and baptize the baby, take photos and dress the baby, make plaster casts of little hands and feet, even take the blanket the baby was wrapped in.

Anything that touches him becomes cherished, she told them.

"It's the only moments they'll have in a lifetime of memory," she said.

She told them she'd help them but would only do as much as they asked.

Jessica and Dave listened to all that she said.

And later that night Jessica wrote in her journal that for the first time in weeks, she felt hope.

Learning, accepting

By January, Jessica and Dave had gone two months with the knowledge that their little boy would not live very long.

They had informed family, friends, neighbors. Their church, Olathe Bible Church, held a prayer service for them and Zeke. They had switched physicians, seeking out medical professionals who supported their decision to go to term.

Zeke's due date was five weeks away. On this day Jessica waited at her doctor's office in Overland Park for Lewis to join her for a routine appointment. She sat in a corner, away from the mothers-to-be, a sea of blossoming bellies.

Despite everything she knew, Jessica was happy. Her brunette curls were wrapped in a lacy black scarf. Her face glowed, with just a sneeze of freckles across her nose and cheeks.

For weeks she had avoided contact with other pregnant moms. She



PHOTOS BY ALLISON LONG | THE KANSAS CITY STAR



AT LEFT: As Zeke's delivery date approached, Dave and Jessica Weatherford had grown accustomed to hearing about Zeke's health issues. But as they awaited an appointment with physician R. Tony Moulton, their faces reflected a sad inevitability.

ABOVE: Six days before Zeke's birth, Jessica laughed with Patti Lewis, founder of Alexandra's House. Even as Jessica was ready to be through being pregnant, she also faced up to the sad fact that Zeke's birthday would also be his last day on Earth.

didn't want to ruin anyone's joy telling them about her situation. For her, there would be no prenatal aquatic class — too much sharing. No magazines about pregnancy — too painful. While other moms-to-be shopped for baby clothes, Jessica searched for just one outfit for her baby.

A special outfit to bury him in.

When Lewis arrived, Jessica told her about finally venturing into a Babies R Us with Dave just two nights before. They wandered the aisles looking at layettes and onesies and tiny T-shirts.

Both parents barely made it out of the store before beginning to cry.

"We weren't ready for that yet," Jessica said. "But we will be."

Every prenatal appointment reminds her of reality, especially the Level II ultrasounds that show clearly the many problems her little boy has.

Just for this day, no ultrasound. Just a normal prenatal appointment where she will be weighed, have her tummy measured and listen to Zeke's heart.

"It's so comforting to hear that," she said.

Inside the office, certified midwife Patti West breezed in and asked Jessica how she'd been.

Jessica patted her belly, talked about a few aches and pains, then opened her notebook, the one where she logged the medical terms that changed her life, the one she kept to remind her what questions to ask.

West listened without interruption as Jessica told her about her fa-

SEE DECISIONS | A9

FROM AB

tigue, some odd cravings, how she knew she needed to eat more protein and drink more water, maybe not so near bedtime.

West measured Jessica's belly.

"Perfect. ... Your weight is perfect. A 3-pound gain."

She swabbed Jessica's abdomen with a blue goo and held a Doppler to it.

Thump-thump. Thump-thump. Thump-thump.

The sound of Zeke's life filled the room.

To Jessica, it was the best music in her world.

"Nice and strong," West said, smiling at her patient. West focused on what was right with Zeke, not what was wrong.

Then she asked the question, the one Jessica had been dreading: Had she decided on a vaginal birth or a Caesarean?

Jessica's face grew dark. She'd dreamed so much of having a natural childbirth. Because she'd already had one C-section with Tori, she knew that having another would mean any future babies would also have to be C-sections.

Yet another dream slipping from her grasp.

West spoke in her gentlest voice: "Because of his special condition, a Caesarean might be best, because it would give you more time to enjoy your son."

Jessica began to sob. Lewis patted her back.

Jessica told West she was leaning toward a C-section but wanted time to think.

West nodded and told her she was doing great in her pregnancy. No complications in her health. Good news that Jessica could focus on this day.

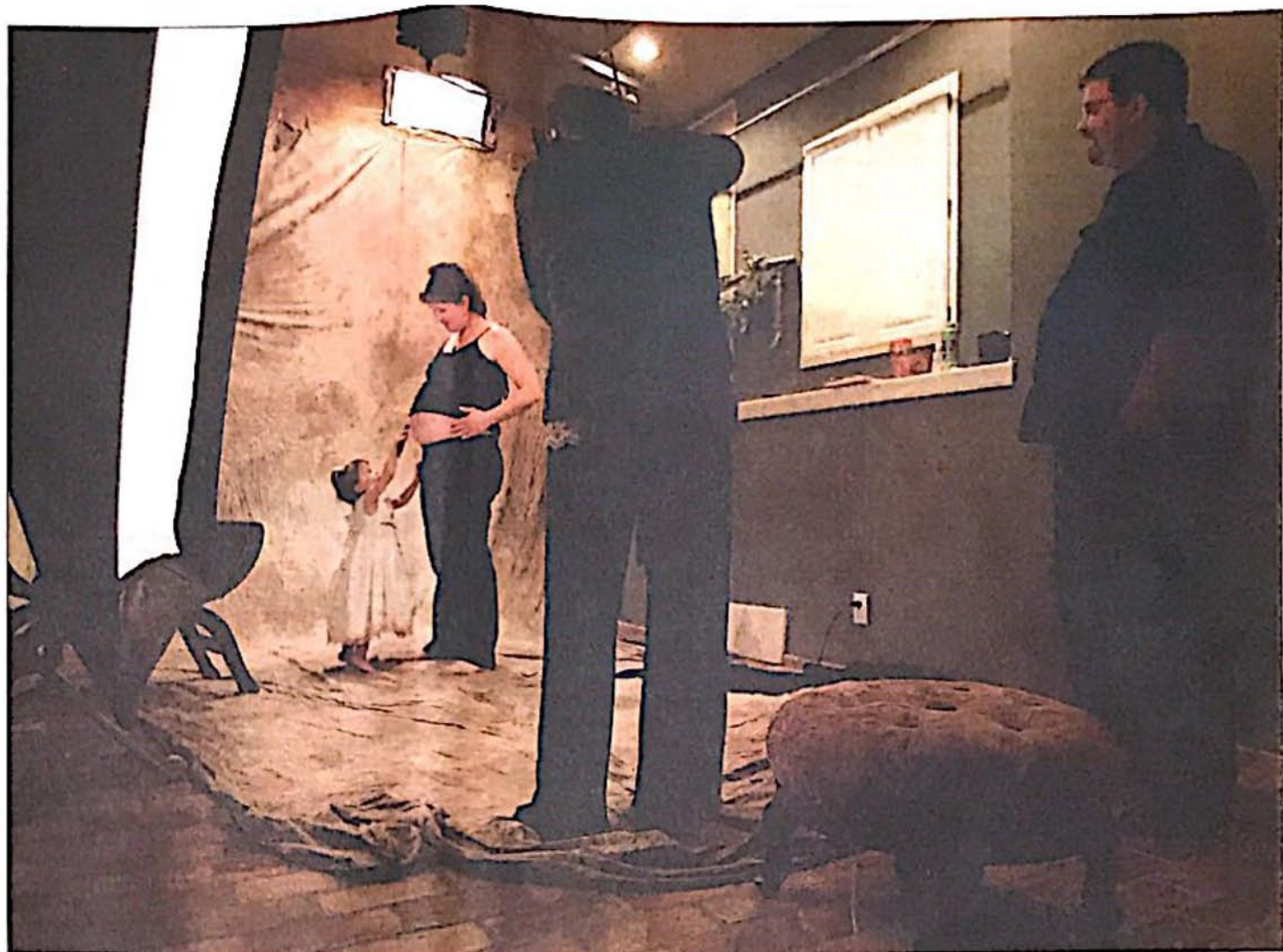
Outside the office, Jessica inhaled and sighed. "Yup, that was hard. The tears come so unexpected and so easily sometimes."

Lewis reminded her how much she was learning and preparing for Zeke. She told her some facts about babies who die shortly after birth.

"They remain soft for hours ... they look like they're sleeping."

She reminded Jessica that a birth plan would help control who would be in the delivery room and how they wanted Zeke's final moments to be.

DECISIONS: 'Think about ... how strong you've been'



PHOTOS BY ALLISON LONG | THE KANSAS CITY STAR

At a photo session with Angie Bocquin, who works with Now I Lay Me Down To Sleep, a nonprofit network of photographers, Tori Weatherford reached for her mother's belly and the brother whom she would never know. Tori is almost 2 years old.

Jessica and Dave come from large families. They didn't want to exclude anyone from the birth, but they knew many of their siblings probably would be uncomfortable.

Lewis urged Jessica to talk with her family and tell them it's OK to cuddle a dead baby. It's also OK not to.

Lewis told Jessica about the arrangements that a hospital could make for mothers whose infants die, like moving her into a room on a different floor, away from other mothers and their babies. When leaving the hospital she could go out a different door, so she wouldn't have to see another new mom cuddling her baby.

Jessica nodded. She marked it all in her notebook, the one that made her feel as if she had some control in her life.

She nodded and nodded. Lewis asked what worried her the most.

Jessica didn't hesitate: She was sad that Tori wouldn't know her little brother, that his memory would be lost to her because she's so little.

"We'll tell her about him," Lewis said. "We'll tell her how she loved him so she'll know. ... Sometimes, siblings make a drawing for their little siblings. And we can place it in the casket with them."

Jessica nodded again. So many decisions to make, and time was running out.

Celebrating Zeke

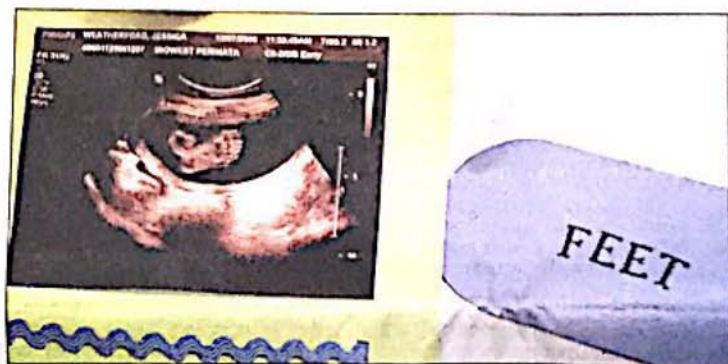
"Tori, give baby Zeke a kiss. Give him a kiss."

Three adults were trying to talk little Tori into kissing Jessica's belly. But right now Tori was more interested in eating a raisin.

When Jessica first heard about a photographer who would take photos of a dead baby, she remembered her reaction: "How weird."

Still, Patti Lewis had witnessed these photo sessions, hours after the death of a baby. The photos from Now I Lay Me Down To Sleep, a nonprofit network of photographers, are heirloom quality, she told Jessica. Babies who look purple can be made to look pink. Babies whose faces are different can have close-ups of one perfect hand or toe.

Angie Bocquin, an Olathe photographer who works with Now I Lay Me Down to Sleep, provides her services for free to families losing an infant. She offered to take maternity photos of the Weatherfords.



Instead of a baby shower, family and friends held a scrapbooking session for Jessica. The scrapbook included Zeke's ultrasound photos, above, Jessica's diary entries and snapshots.



Zeke's one and only outfit awaited his arrival at the Weatherfords' home.

Jessica decided to do it, if only for another chance to celebrate something good with Zeke: the pregnancy. But now she very much felt like a fat, unsexy, bloat-prone pregnant woman — not someone ready to look beautiful for a camera.

Bocquin knows how to bring out the best in couples. She showed Jessica and Dave photos of a husband caressing his wife, her pregnant belly highlighted, bare skin peeking out from behind a black veil.

Jessica giggled.

"I'm not sure I'm comfortable doing that," she said.

"You don't have to show anything you're not comfortable doing," Bocquin said. "We can do whatever you like. We'll just play."

Jessica disappeared into the bathroom, changing into a black tank top, adjusting the black veil like a skirt, swiping on a touch of lipstick.

Feeling awkward, Dave let Bocquin pose his hands on Jessica's belly. His smile was forced, his face sweaty.

But Bocquin was patient.

She moved to the right, then to the left, her camera clicking.

"Think about how much you've been through together," she said. "How strong you've been."

Click. Click. Click.

"Jessica, look up at him," she said. "Give him a kiss."

Click. Click. Click.

She laughed when they laughed. She complimented Dave. He was having fun. The couple's arms entwined. Dave relaxed. This time when he smiled, two dimples popped out.

Jessica seemed to bloom.

A glorious session — except for Tori. She wasn't interested in anything except the toys in the prop room.

Then Dave discovered that a raisin would balance on top of Jessica's belly.

"Tori, get the raisin. ... What is that? Is that where Baby Zeke is? ... Kiss Baby Zeke. ... Tori, kiss baby Zeke."

She looked at the raisin. She looked at Jessica. Almost in slow motion, she gave a tiny kiss to her mommy's belly.

Click. Click. Click.

Zeke's party

Jessica and Dave's parents cried when they heard about their grandson. Dave's mother, Kathy Weatherford, who had borne 10 children, took the news so hard she had a mild heart attack shortly afterward.

But the person who felt the pain the sharpest was Jessica's twin, Jacquelyn Thompson.

The two sisters, born just minutes apart, grew up as best buddies, finishing each other's sentences, running cross country together at Gardner Edgerton High School, each "just hoping not to finish last," Thompson said.

They graduated in 1996. Jessica was the valedictorian. Jacquelyn, the salutatorian.

"I remember hurting because she was hurting," Thompson said about the day Jessica told her. And the thought of holding a dead baby wasn't a pleasant one to Jacquelyn.

"But how could I not be there?" Jacquelyn asked. "Jessica needs me."

"At first, this was all about Jessica's pain. ... But now it's about loving him, providing for him the best way they can."

Little Zeke, she said, "has already touched so many more lives in his short life than some people do in a lifetime. ... He's become a lot more real to everyone. The neat thing about this pregnancy is seeing the people come together because of Zeke."

Jessica told Jacquelyn how she was seeking joy, choosing to see the happiness. Jacquelyn and other family and friends followed Jessica's pregnancy by reading her journals on Caringbridge.org, a Web site that

people use to communicate to others the ups and downs of a health crisis. Hundreds of friends and strangers had already sent Jessica e-mails.

Jessica was saving everything, and it was growing into a nice pile of paper.

And that gave Jacquelyn an idea: a scrapbooking party would celebrate Zeke.

"It's not like you can throw a baby shower for someone who knows their baby is going to die," she said.

One Saturday afternoon, a dozen friends showed up at Jessica's house, armed with colored papers and embellishments, glue and glitter, sayings and cutouts, and lots of brownies and cookies. Jacquelyn assigned everyone a job.



As the guests at the scrapbooking party began to leave, Zeke began kicking so hard that Jessica Weatherford had to share the moment with her twin sister, Jacquelyn Thompson. "Oh, he's kicking. With both feet. Feel that?" Jessica said, laughing.

For four hours the group organized Zeke's ultrasound photos, Jessica's diary entries and snapshots. One page displayed three black-and-white ultrasounds framed with blue rickrack. Another highlighted a diary entry and a Bible verse. Yet another showed the stark science of abnormal chromosomes that dictated Zeke's future.

The 30-page book of memories was a gift that overwhelmed Jessica.

At the end of the party, just when people were leaving, Zeke began kicking so hard that she grabbed Jacquelyn's hand to share the moment.

"Oh, he's kicking. With both feet. Feel that?"

Thompson couldn't believe it, a tiny knocking so hard against her hand. Her nephew.

It made her laugh and laugh.

But just steps away hung the clothes Zeke would be buried in, a tiny blue-striped outfit embroidered with the words Sweet Baby Boy.

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ABOUT THIS STORY

Every year, thousands of parents in the U.S. learn that genetic disorders will end their babies' lives within days, hours or even minutes of birth. The Weatherfords' story illustrates a growing trend in the way families deal with the knowledge their babies will die. Although it is not a choice most parents make, the idea of carrying these babies to term has gained acceptance. More families are turning to perinatal hospice programs for help. The Weatherfords agreed to let *The Star* follow them through the process in the hope that their story might help other families.

To report "Zeke's Gift," Lee Hill Kavanaugh spent hours at the Weatherfords' house, reading Jessica's online journal, attending their church, going to a prayer service for them, witnessing Jessica's doctor appointments, and interviewing family and friends. She saw every aspect of Zeke's birth and death and heard every key conversation. Few scenes were reconstructed, and those that were resulted from careful interviews with all key participants. No dialogue appears within quotation marks unless Kavanaugh heard the conversation herself.

Today: Even on the darkest of days, the Weatherfords still find joy.

Monday: Zeke brings many gifts to his parents — the caring of strangers, the love of family and friends, the strengthening of their faith — but they learn the greatest gift is time with their son.

Thanks to Alexandra's House, no family need grieve alone



ALLISON LONG | THE KANSAS CITY STAR

Photos of some of the more than 200 babies that Patti Lewis has been involved with line the stairway at Alexandra's House. Alexandra, Lewis' niece, suffered from a rare genetic disease. Alexandra's six-fingered handprint is the organization's logo.

The founder, who once shunned sick babies, discovered her calling after a niece died.

By LEE HILL KAVANAUGH
The Kansas City Star

Patti Lewis knows the pain and loneliness of grieving for an infant.

She lived through it with her niece, Alexandra.

Alex was born Dec. 12, 1994, with a rare genetic condition that ended her life after 45 days.

Forty-five days and nights that changed Lewis' life.

Lewis and her family were afraid to sleep during Alex's short life. They worried that Alex might die in the night, alone.

And alone is how the family felt.

Isolated, angry, scared. All the emotions that a dying baby brings, but without anyone who seemed to understand.

Lewis watched as Alex struggled to breathe. For hours she rocked Alex in her arms late at night, weeping because "I couldn't buy her anything, or feed her anything. ... All I could do was love her."

Lewis identified a hole in medical and social service support for families with terminally ill babies.

She knew before Alex died that she wanted to do something more with her life. She knew that her family would have found comfort had they met someone who had lived through such an experience, someone who could have listened or just shared stories about other families that had endured the same loss.

More than anything, she knows that it is families who give meaning to these babies' short lives.

"(This work) was definitely a calling," she says.

Lewis has been at the forefront of bereavement care for dying infants and their families. Today dozens of perinatal hospice care programs are operating across the country.

For more than a decade Lewis worked as a cardiology nurse, first at St. Luke's Hospital, then at KU Medical Center. She shunned working with sick babies.

"It was always too sad for me," she says, grinning at the irony.

In 1997, after learning how to put together such a program, she opened Alexandra's House, a nonprofit organization that is not affiliated with any hospital or doctor's office. It's supported entirely by donations from the community, and all its services to families are free.

The work consumes her, de-

manding that she be available day and night, facing all kinds of emotions from parents and other family members struggling with grief and loss.

She prays that others with the same calling will eventually join her, to share the workload. Volunteers are also always appreciated, she says.

To her, helping these families is a sacred task.

She comforts and counsels moms-to-be as if she were their own mother, but also their nurse/counselor/girlfriend.

She attends doctor appointments with them. She holds a parent's hand if they need it during an ultrasound. She prays with them. Visits them in the hospital, calls them as the birth date approaches, often just to listen. Helps them write a birth plan. Helps them plan the funeral.

Families can live at Alexandra's House the last month if their homes are too far from their hospital.

Sometimes the upstairs loft at the house becomes a chapel for a visitation or funeral. Alexandra's House will even pay for a baby's headstone.

Lewis follows through with families for three years, connecting them with other mothers and fathers who suffered such losses, making sure grief support and counseling are in place for the family — and members of the extended family — who may be struggling.

Her calm spirit and empathy soothe hurting families. With Lewis, they do not have to grieve alone.

That grief can be as strong as contractions, Lewis says. "I tell them that if this were a gaping wound, they would be given medicine to take the pain away. Nothing can take this pain away when it comes."

Each mother who suffers this loss will have moments when she cries out, overcome with everything. The fathers suffer, too.

"They all do," Lewis says.

But denying the sadness causes problems later, sometimes many years later, she's learned.

She also knows that grieving now helps families for the rest of their lives.

"Families can be healed. I know it, I've seen it. Avoiding the pain won't make it go away."

She has watched the transformation in lives. "I've seen the best in humanity."