The Miracle of Molly

In the Fall of 2000, Denver’s Lisa and Jack Nash genetically engineered a baby in an effort to save their dying little girl. Pastors and pundits said it was the first step down a stem-cell-paved road to Hell. Five years later, the Nashes give us an exclusive look at Heaven.

BY

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**Everyone in the delivery room expected to hear the primal wail of a healthy newborn—that unmistakable sonic boom of a life beginning. Instead, when Molly Rose Nash entered the world on July 4, 1994, she cried a sickly whimper. Already, she was dying.**

She weighed 5 pounds, 2 ounces in the outstretched hands of the immediately concerned obstetrician. Hunched behind the doctor, the new father, Jack Nash, craned his neck to see his daughter; the color drained from his face. Oh my God, he thought. There was a momentary quiet, filled only with the hospital machines' incessant beeping, then all hell broke loose. Nurses ran in and out of the room, yelling about baby Molly's hands and forearm. Someone said something about missing thumbs. Lisa Nash, feet still in the stirrups, struggled to lift herself. She saw bloody sheets but couldn't see her baby. "Where is she?" she shouted. "What's wrong?" Lisa saw the obstetrician's face. At the end of the birthing table, framed by the stirrups, his cheeks were wet with tears.

Lisa is a Neonatal Intensive Care Unit (NICU) nurse; she'd been on hand for thousands of deliveries. She'd seen babies born sick. This time, though, she was the mother and it was her baby—her firstborn. "Where is she?" Lisa shouted again. Out of her sight, behind a wall of nurses, Molly was wiped clean and rushed to the Intensive Care Unit.

Jack and Lisa knew their baby would be small, tiny even—that was plain from the 20-week ultrasounds—but two prenatal tests for chromosomal abnormalities assuaged their fears that the small stature was caused by an illness. The ultrasound tests were also when the Nashes found out they were having a girl. A co-worker gave Jack and Lisa a tiny pink cap to take home. They'd pull it out, rub it between their fingers. They both loved the name Molly. Knowing the sex and name made it all so real. Jack and Lisa couldn't wait to meet their little girl and put that hat on her head. They couldn't wait to be a family.

Now Lisa was on her back in a Rose Medical Center birthing suite, horrified and anxious. Finally, a nurse placed Molly in Lisa's arms. Lisa cooed and held her baby daughter close, studying the round face and tight-knit eyes. With an unsteady hand, Lisa gently unwound the blanket to see the rest of Molly: Her right arm was stunted and bowed, one hand was missing a thumb, and on the other there was a fleshy tab of skin where a thumb failed to root. What Lisa couldn't see was even more heartbreaking: Molly did not have hip sockets, there were two holes in her heart, and she was missing part of her brain.

**The Disease**

"Get the book!" Lisa shouted to someone, anyone in the birthing suite.

She wanted *Smith's Recognizable Patterns of Human Malformation*, the NICU nurse's bible. During Lisa's four years of working at University Hospital, "the book" was the first thing she reached for when a baby was born malformed. Now, knees in the air, Lisa frantically skimmed the pages, looking for Molly's symptoms, seemingly oblivious to her obstetrician seated at the end of the birthing table, stitching her up.

Lisa came across Fanconi anemia (FA), a disease she'd never heard of, and on that page she found a face like Molly's staring back. Same apple-shaped head, same eyes, the same hand and arm abnormalities. FA is a genetic disorder that causes bone marrow failure, leukemia, and usually death in early childhood. Healthy bone marrow creates cells that supply oxygen to the body, fight infection, and clot blood; in the case of FA, cells go awry and leukemia sets in. Not all of the symptoms of FA are so obvious. Some who have it show no outward signs until their bone marrow fails. Relying on mother's intuition and her years of medical expertise, then and there Lisa concluded Molly had FA. When the pediatrician walked into her hospital room, Lisa cut through the niceties: "Molly has Fanconi anemia." The doctor dismissed Lisa's diagnosis. It's extremely rare, he said. He'd never seen a single case.

A bone marrow transplant, in which diseased cells are killed off and replaced with new donor cells, is the only cure for progressive bone marrow failure. But the procedure is risky at best. When Molly Nash was born, the success rate of a transplant from an unrelated donor was a dismal 18 percent. However, under the right circumstances, the success rate for transplants from a brother or sister was as high as 65 percent.

**Experimental Science**

Six potted plants are lined up on a school desk. Three of the plants are struggling to hang on, two are definite goners, and one is downright leafy. It's Jan. 27, 2005, Science Fair night at Belleview Elementary School, and 10-year-old Molly is showing off her entry to her mom and dad. She pushes aside a strand of brown hair with one of her four-fingered hands. Her "special" arm hangs by her side, curved like a hockey stick where it ends a few inches below the elbow. On her wrist is a half-moon-shaped scar—a mark left by a recent, marginally successful attempt to stretch and straighten the bone.

Molly is waist-high, elfin, and compact. She moves as if her muscles have been starched and often leans a bit to the right to compensate for her deaf left ear. Her gluey complexion is fixed with a happy grin, and her squinty brown eyes convey a warm sincerity. She gestures toward the table with her good arm and explains that she fed each plant a different diet—water, fertilizer and water, vinegar, cola, Pepto-Bismol, or chicken soup—and charted each plant's health.

For every other kid in the room, the science experiment probably amounts to just another classroom activity, but for the Nashes the project is a reminder of Molly's own fight for life and the controversial cutting-edge medicine that saved her. Five years ago, Molly and her mom underwent a series of experimental and excruciating procedures; for the first time in history doctors blended the sciences of in vitro fertilization (IVF), stem cells, and genetic screening—which thrust the Nashes into the spotlight of international news. They were covered, and in many cases condemned, in media ranging from *The New York Times* to the BBC. And Molly came to personify the ongoing medical, ethical, religious, and political debates over genetic testing, "designer babies," and embryonic research.

**Imperfect Pair**

Jack and Lisa knew almost immediately they were meant to be together. Both raised in Denver, they met in the summer of 1984, on a blind date orchestrated by their mothers. The couple fell in love quickly, and rather than break up the romance, Lisa, then a 17-year-old champion synchronized swimmer, gave up a scholarship to Brown University and opted for the University of Colorado. Meanwhile, 19-year-old Jack transferred from Arizona State University back home to Arapahoe Community College. Five years after their first date, the couple wed at BMH Synagogue on July 16, 1989.

But beneath the surface of the Nashes' idyllic union a chromosomal storm was brewing. Each of them had the recessive gene for a deadly disease. If only one of the two newlyweds had this particular DNA the disease would have remained dormant and the couple would have produced a healthy child; however, because both of them possessed this uniquely flawed DNA, there was a strong probability that their child would be born with an almost certainly fatal genetic illness. Jack and Lisa learned all of this 21 days after Molly's first birthday, in July 1995, when she was officially diagnosed with Fanconi anemia.

In the year since her birth, the Nashes had tirelessly researched the disease and contacted the Fanconi Anemia Research Fund in Oregon for direction. Lisa's college courses in molecular and cellular developmental biology and her NICU experience were invaluable when it came to deciphering the science. The more Jack and Lisa learned about FA, the more determined they became to beat it. They postponed having another child. The idea of trying to conceive and perhaps give birth to another child with a death sentence struck the Nashes as cruel and selfish.

So, heading into that official diagnosis in the summer of '95, Lisa and Jack were prepared for grim news, but they were devastated when they learned Molly had the deadliest strand of FA: Type C—the Jewish version. In the general population, 1 in 300 people is a carrier of FA, but among Ashkenazi Jews (those with ancestral ties to Eastern Europe), the odds increase to 1 in about 90. Jack and Lisa are both Ashkenazi Jews. And because both are carriers for the disease, there was a whopping 25 percent chance they would have a baby with FA-Type C. Children afflicted with this variation are born with more birth defects, get sick sooner, and, without a bone marrow transplant, die earlier. Jack and Lisa could expect Molly's bone marrow to begin failing at the age of 3.

Already, in Molly's first year, she'd spent countless days in the hospital. She was born with a platelet count (an indicator of bone marrow health) of just 53,000, when it should have registered 150,000 to 400,000. When Molly was 1 month old, she was fit with a brace to force the development of nonexistent hip sockets. Built like a booster seat, the device applied nine months of constant, grinding pressure on her soft hipbones. Gastrointestinal problems meant she couldn't eat properly. Her weak immune system was barely functioning. At 5 months and weighing only 6 pounds, Molly was hospitalized for strep throat, which is unheard of in babies under the age of 2. At 6 months old, doctors sliced a hole in Molly's stomach for a feeding tube. Each night Jack and Lisa watched Molly's tiny chest rise and fall, praying she would wake the next morning.

Dozens of children ran toward a lake with handmade boats tucked under their arms. Some of them appeared fit, but all were sick and many were dying. A few especially weakened children walked behind. Each child had written a wish on a piece of paper and placed it inside his or her boat. At the lake, they gave their boats a little push and watched them glide away. Jack and Lisa released their vessel along with the others, but Molly was too young—not yet 2—to grasp the significance of letting hope ride.

It was 1996 and the Nashes were at Camp Sunshine in Maine, where each year FA families gather for a week at the campground in the town of Casco. The children giggle during sleep outs and magic shows and give each other "high fours" on the volleyball court while researchers and other experts hold seminars for parents.

Also attending Camp Sunshine that summer was Dr. John Wagner. Wagner did not watch the children play; he tries to see them only as patients. It's a defense mechanism—while it may mute his joy after the successful surgeries he performs on kids with FA, it also makes the deaths easier to endure. He had treated and performed bone marrow transplants on many of the kids at Camp Sunshine. As the scientific director of clinical research in the Marrow Transplant Program at the University of Minnesota, Wagner has performed more bone marrow transplants on FA patients than any other doctor in the country. If any of the parents asked him to explain what drew him to FA, he would have said simply, "It was a disease that was virtually hopeless." In the FA cases he studied, Wagner recognized that transplants from a related donor—a brother or sister—were critical to success. He teamed up with cutting-edge reproductive geneticist Dr. Mark Hughes, who was director of molecular and human genetics for Georgetown University and worked for the National Institutes of Health. Together, the doctors were thinking of ways to push the envelope of science in an attempt to outsmart natural selection. They wanted to begin genetic screening for the perfect bone marrow donor. The ideal match would be A) a healthy sibling embryo and B) a suitable tissue match.

Wagner understood the risks, for his patients and for himself. He knew that some critics would view the genetic testing as crossing a moral line, but too many kids were dying after transplants. Wagner talked about his perfect-donor scenario during a seminar at Camp Sunshine in the summer of 1996. In the audience, Jack and Lisa grasped hands tightly as Wagner described a series of tests that could dramatically increase the chances that a couple's next child would be healthy and a bone marrow donor. Wagner emphasized these two existing tests had never been used together, but science was moving in that direction. As she listened, Lisa told herself: "I'm going to do this."

The process Wagner described is called Preimplantation Genetic Diagnosis (PGD), and it entailed testing multiple embryos created by in vitro fertilization. One cell of each days-old embryo would be screened for Fanconi anemia's genetic code. Affected embryos would be discarded, while healthy embryos would be further analyzed to see if the tissue type was a match for the patient in need of transplant.

The Nashes considered the fact that the testing involved controversial embryonic research—and would involve discarding diseased embryos. According to the teachings of their Jewish faith, life doesn't begin until 40 days after conception, and the tests would take place after only three or four days. Besides, they thought, if science was offering the promise of a miracle, wasn't that better than standing by and watching their daughter die?

The only alternative to PGD was naturally conceiving a healthy child who was a suitable donor (an 18.8 percent chance). However, only a prenatal test 10 weeks into the pregnancy could check for FA and determine if the fetus was a bone marrow match. For the Nashes, that was irresponsible. After all, couples often aborted upon learning the baby had the disease. The way Jack and Lisa saw it, getting pregnant when there was a 25 percent chance the child would be afflicted with FA was not a gamble they were willing to make. "We didn't want to give a kid a death sentence or have an abortion," Jack says. "For a long time those were our two options." After the seminar, the Nashes fought through the crowd to Wagner and volunteered on the spot.

**Science Sucks**

Months after returning home from Camp Sunshine, the Nashes learned they qualified to be a Wagner and Hughes test case. Things were looking up; Molly's platelets were stable, albeit low, and science seemed to be working in their favor. Lisa entered under the care of the two doctors who had spent months in the laboratory perfecting the tests, but they warned Jack and Lisa that the science was experimental and far from a sure thing.

Molly was 2 and a half when Lisa completed her first round of fertility drugs. Lisa produced multiple eggs that were extracted from her ovaries by needle and fertilized in a petri dish. Three days later, Hughes screened for FA and checked the tissue type. The tests took less than 24 hours. Only one embryo met the criteria: a disease-free bone marrow match for Molly. The embryo was reinserted into Lisa's uterus. Sixteen days passed. The Nashes prayed and hoped and waited, until they received the crushing news that the in vitro was unsuccessful.

Doctors had told the Nashes to expect Molly's bone marrow to malfunction when she was about 3 years old. "Sure enough," Lisa says, "the day Molly turned 3, her platelets started falling and her red blood cells were larger—an indication of bone marrow failure."

Before the Nashes could repeat the PGD process, Dr. Hughes, whom the Nashes then saw as Molly's only hope, stopped returning their phone calls and e-mails. Months and countless unanswered messages later, some news reached Jack and Lisa: Hughes was being investigated for using federal funds for embryonic research, which would have been illegal according to a 1996 federal law. Hughes—and Molly—were caught in the crosshairs of a politically charged debate and the public's apprehension about embryonic research. When the Nashes finally spoke with Hughes, he informed them that he was off to the private sector and could no longer help. The Nashes' cell samples and corresponding research remained locked in the bowels of Georgetown University, which now wanted nothing to do with Hughes' research, nor anything to do with Molly. In August 1998, Dr. Hughes sent what would be his final e-mail to the Nashes: "I am sorry. Science sucks sometimes. Go on without me."

**At Any Price**

As far as Jack and Lisa were concerned, two-plus years had been wasted while their daughter weakened. Molly's platelets fell to 30,000. The Nashes sought solace in their faith, and the Jewish community rallied around them, holding blood drives at the synagogue and encouraging members to join the National Bone Marrow Registry. With luck the Nashes might find a good enough match—one that would have an 18 percent chance of succeeding. Daily life for the Nashes became a long, vaporous moment in which they tried to keep one eye on the future and the other on Molly's every move.

The extended family spent endless hours together simply celebrating Molly's existence, lavishing love on her. Each day, each step, each laugh, each doll, each bath, each bedtime story was precious, and perhaps Molly's last. Family gatherings were routine rather than rare, with huge home-cooked meals as the centerpiece. And prayer. There was lots of prayer. Lisa, as she says, "never questioned God, never asked 'why me?' I knew He would give me the answers, the solutions." Every Friday when Lisa would light her candles for prayer, Jack would joke that the candles would melt down because she prayed so long.

In October 1998, the Nashes heard of a place they thought might answer those prayers. The Reproductive Genetics Institute, a Chicago-based company, had also been performing PGD. In January, Jack, Lisa, and Molly flew to Chicago and met with Dr. Charles M. Strom, one of the center's geneticists. When they walked into his office, Molly immediately crawled into the big-shouldered Strom's lap. Whereas Dr. Wagner had wanted to keep personal distance between himself and his patients, Strom chuckled as Molly climbed onto him. He asked the family to call him "Buck." In Strom, Lisa saw "a warm smile and a big heart that you can see from outside."

Jack and Lisa explained to Strom that what they wanted was to have a healthy child who would also be a bone marrow donor for Molly. Dr. Strom agreed to take their case. For inspiration, he inked an important date near Molly's 13th birthday on his calendar. "That was the thing for Lisa and me through this," says Strom. "We wanted to dance at Molly's bat mitzvah."

With a renewed sense of hope, Lisa once again began in vitro. This time, of the multiple eggs extracted, Strom located a pair of healthy embryos. Both were tissue matches, and both were implanted. And Lisa got the wonderful news that she was pregnant. Just as Jack and Lisa had begun talking about setting up the nursery down the hall from Molly, Lisa miscarried.

For Jack and Lisa, the loss was unbearable; so, too, was watching their now 5-year-old daughter deal with the side effects of her medication. Molly was taking a synthetic form of the male sex hormone intended to stimulate her blood production. It was a short-term solution that came with a humiliating price. In addition to liver damage, androgen's side effects include pubic hair, muscle definition, and a deepening voice. Molly's body was shoved into adolescent male puberty.

Because of the prayers, because of their family, because their little girl's life was at stake, Jack and Lisa refused to give up. They repeated IVF and PGD in June and again in September to no avail. After the never-ending stress of in vitro fertilization, PGD, and gut-wrenching waiting periods, Lisa and Jack were physically and emotionally depleted. Hope, the Nashes discovered, is a double-edged sword: The powerful emotion sustained them through each day but also deepened their despair with every failed attempt.

All Jack and Lisa had to show for their four IVF attempts was a weakened child and a mountain of bills. Jack's salary as general manager of a Denver hotel did little to make a dent in expenses. Each in vitro, which is not covered by insurance, cost roughly $15,000, plus an additional $6,000 for PDG and HLA testing. And that was on top of Molly's endless medical expenses for procedures and medications. Back in Minnesota, Dr. Wagner was convinced that Molly would soon develop preleukemia. He called off any more IVF attempts—he believed there was simply not enough time. Wagner began to search for an unrelated donor.

**A Very Good Call**

"How do you explain to a 5-year-old she's going to die?" That's the question Lisa asked herself. It's what kept her and Jack going. The Nashes took their case to yet another doctor, William B. Schoolcraft, at the Colorado Center for Reproductive Medicine. Schoolcraft is one of the country's top fertility specialists. One of Schoolcraft's colleagues had developed a process for stabilizing an embryo—growing it longer in the petri dish and giving it much better chance of impregnating.

Under Schoolcraft's care (and with Dr. "Buck" waiting in the wings to perform the PGD and tissue testing), Lisa endured in vitro for the fifth time in almost three years. A round of "big gun" fertility drugs helped Lisa produce 24 eggs, almost three times as many as she had previously. Half of the embryos were healthy, but only one had the winning combination of no FA and a bone marrow match. On Dec. 10, 1999, Schoolcraft implanted the single embryo. This, the Nashes thought, was their last shot.

Two weeks later, on Christmas Eve, as Molly received a blood transfusion at Children's Hospital, Lisa's cell phone rang. It was Schoolcraft's secretary calling. A voice on the other end said, "Lisa, you're pregnant." She'd heard that before.

**On Target**

Lisa turned into the parking lot of the Target store as if she were driving a NASCAR race. Molly, exhausted from the transfusion, was in the backseat underneath winter layers—scarf, woolen cap, and green surgical mask. The mask was necessary to protect Molly from inhaling common germs that were potentially fatal for her.

Lisa jerked her Suburban into the first open spot she found. She was halfway out the door before she cut the engine. Seizing Molly's 5-year-old hand, she marched into the madness: Christmas carols on repeat, blinking lights, too many last-minute shoppers. Dodging the mobs with teetering carts, Lisa bought five boxes of e.p.t. pregnancy tests and ran to the restroom.

Still wrapped in the scarf and hat, Molly leaned against the bathroom wall sucking air through the surgical mask. In the next stall, Lisa ripped open the e.p.t. boxes. Hands shaking, she fanned out five white sticks and followed the directions. "Mol, you OK?" Lisa called. One, two, three, four, five.... They all had blue plus signs. My God, Lisa thought, I'm pregnant; they weren't lying. She burst from the stall, gathered Molly in her arms, and dialed Jack on the cell phone.

**Down the Drain**

On a January morning, seven months before her August due date, Lisa stood in her shower, under the warm water, gently rubbing her belly and smiling at the thought of having two healthy children. The agony was instantaneous. Pain seared through her abdomen, and blood suddenly rushed down her legs. The shower drain was awash in crimson red. Lisa crawled from the shower and collapsed onto the bathroom floor. She dialed Schoolcraft's office and was told to come in immediately. When Dr. Buck in Chicago heard what had happened, he said only one word: "Fuck."

In the examining room Lisa could not bear to look at the ultrasound monitor. She knew what was happening. She knew the baby was gone—and so was Molly's last chance. Two children. And then there were none. Schoolcraft informed the Nashes that the placenta had torn away from the uterine wall, leaving a hole that was bigger than the baby. Schoolcraft found a faint heartbeat. He sent Lisa home and prescribed a strict dose of bed rest. She was allowed one shower a week and three daily trips to the bathroom. Back home on bed rest, Lisa lay with Molly curled beside her.

Molly's blood count was grim. Her 5-year-old body was gray, lethargic, and feeble. When every other little girl in her ballet class was learning new dance steps, Molly struggled to walk. She was blood-transfusion- dependent. She endured frequent needle sticks so nurses could keep tabs on her falling blood counts. The steroids that once boosted her marrow were useless now. Doctors tested her bone marrow every six months for preleukemic cells. The agonizing test, which punches through the pelvic bone to extract the thick, red liquid, was sometimes preformed without anesthesia. Those were especially bad days. But even on good days, Molly had had enough of needle sticks, IVs, and hospitals. Each appointment was an exhausting battle—Molly's will against the nurses'. She would put up a good fight, crossing her arms firmly over her chest and fixing steely eyes on those who dared to come close. She threatened to bite. Inevitably, Molly would lose the standoff and dissolve into a hysterical tantrum. In May 2000, 20 out of 20 bone marrow cells tested showed signs of preleukemia—Molly's bone marrow had all but shut down.

Jack and Lisa couldn't just sit around and wait. They had to live all they could with Molly. In May, they took a family trip to Disney World. Molly had always wanted to go. They were reserving the trip for after the transplant, a celebratory time, but now who knew if there would be a tomorrow, let alone a transplant. Jack rented an electric scooter for Lisa. There they were: the dying child, her bedridden, pregnant mother, and the father walking a step behind and trying to keep it together. Lisa and Jack did their best not to let Molly see their tears. They snapped picture after picture.

One month later, in June, the Nashes flew to Minnesota to retest Molly's marrow. There was a glimmer of good news: The preleukemic cells had not progressed, meaning Molly would likely make it through Lisa's delivery and until the transplant without developing leukemia. But 6-year-old Molly's platelets were virtually nonexistent. When Molly's skin was punctured her blood dribbled out purple.

**Practice Makes Perfect**

Dr. Buck hurried through the maternity ward, mentally checking off which rooms he'd already visited. He poked his head into another doorway and asked another pregnant woman if he could come in. He explained the situation—Molly's situation—to the expectant mother, and made his request: See, Buck would say, there was this mom, Lisa, and she was due at the end of August, and when she gave birth he'd need to collect her umbilical cord blood to use for a critical transplant.

For Molly, and for many bone marrow transplant recipients, the normally discarded umbilical cord and placenta are lifelines. Cord blood, the blood that remains in the placenta and umbilical cord after birth, is rich with blood stem cells—"adult" blood stem cells. Adult stem cells are produced in the organs and tissues of the fully developed human body, unlike embryonic stem cells, which, in a controversial procedure, are extracted from and thereby destroy embryos. During a bone marrow transplant, adult stem cells are transplanted into the patient, where, if all goes well, they take root and produce blood cells and marrow.

Problem is, Buck sheepishly told the expectant moms on the ward, he had never actually collected cord blood before, and only had one shot to get it right. He figured a little practice would be good. So, would the soon-to-be mother donate her placenta and umbilical cord to the cause. Yes? Thank you, ma'am. He moved on to the next room.

**"Here Are Your Babies"**

On August 29, 2000, 56 hours after inducing Lisa, an obstetrician swiped a scalpel across Lisa's midsection, reached in, and lifted the head of a beautiful baby boy. A proud, primal howl of a healthy newborn filled the room.

Nurses worked in unison, clipping the umbilical cord, checking vitals, washing and wrapping the baby in a white blanket with pink and blue stripes. The air was thick with celebration and urgency.

Lisa's placenta was gathered and placed upside down in a sling with the limp umbilical cord hanging down, and the blood slowly trickled into a blood-bank bag. Dr. Buck, flanked by a representative of the Bonfils Blood Center, milked the placenta as though he were draining a flask of the finest wine. He retrieved a half-liter-half a soda bottle's worth.

"Does someone have the cord blood?" Lisa shouted, straining to see. "Does someone have the goddamn cord blood?" Buck turned to Lisa, holding in his arms her newborn son and the bag of blood. "Here are your babies," he said resting them both on her chest.

In the midst of the organized chaos, time slowed. Jack and Lisa looked from their baby to the bag of fluid. In an instant, the cord blood was lifted from Lisa's chest. It had to be packaged for transport. Jack's dad would hand-deliver the precious cargo to Dr. Wagner, who would perform the transplant in Minnesota.

**Solution in the System**

It was below zero that day in the Twin Cities when the first of five days' worth of chemotherapy began dripping into Molly's central line. The chemo would annihilate whatever was left of Molly's bone marrow. As the solution worked through her system, Molly remarked that it tasted like metal. After chemo, Molly was radiated and wheeled back into her room, looking red and swollen as if she'd been baked in the microwave.

At 1:20 p.m. on Tuesday, Sept. 26, 2000, a nurse walked into Molly's room carrying a bag of her new brother's blood. A rabbi joined the family to bless Molly's "new life." While the slow, syrupy-thick drip began, Molly's family sang happy birthday—what everyone hoped would be the beginning of the rest of her life—and snapped pictures. Molly's baby brother, not even a month old, sat on her lap.

Jack could smell the blood. It smelled like creamed corn. Looking on, the mother in Lisa thought, "You expect thunder and lightning and miracles." But the nurse in her saw it was only a bag attached to a central line. The Nashes watched the clock. The transfusion—so many years in the making—lasted just 25 minutes. The family ate forkfuls of cake emblazoned with "Happy Transplant Day." Molly looked no different. No thunder. No lightning.

The Nashes prayed that the blood stem cells would find their way home to the empty bone marrow cavities. If all went well, the cells would set up shop and begin producing normal cells within weeks. Until then, blood transfusions, potent antibiotics, and a healthy dose of luck would keep Molly from falling ill. Wagner would monitor her blood counts with daily labs. And for days, that was how it went.

Some days Molly felt OK, others she shivered and sweat under the thin hospital sheets. Several days after transplant, chemotherapy's side effects wreaked havoc. She threw up, developed painful mouth ulcers, and could barely swallow with mucus glands that had dried up like raisins. One day, while lying in bed, Molly pulled off part of her tongue as if it were a piece of bark. Large tufts of Molly's hair fell out and clumped on her pillow. Lisa shaved Molly's head smooth. She looked like every other kid on the transplant ward. Nine out of 14 kids on the ward died.

**A Beautiful Day**

Each letter in the Hebrew "alefbet" is assigned a numerical value, and the Hebrew word for life, "chai," adds up to 18. Eighteen days after the transplant, Molly rose from her bed, gingerly twirled around the room, and said, "Mommy, do you want to dance?"

**Controversy**

On Jan. 4, 2001, when Molly Rose Nash returned home to Colorado, the Nashes found themselves in the midst of a media storm. It began even before their genetically screened baby's stem cells dripped into Molly's veins. Six days before the transplant, as Jack and Lisa cradled their new son and stroked Molly's hand, CBS News posed the question: "Genetically improved children—an ethical issue?" The story detailed the measures employed by the Nash family and went on to report that the American Association for the Advancement of Science believed "it is dangerous and irresponsible for scientists to experiment with genetic changes that will affect future generations of humans, even if the goal is to cure disease...."

Jack and Lisa were hounded with requests for interviews. It seemed everyone wanted to photograph Molly with her newborn brother. The Nashes used the hospital's underground tunnels to come and go. News organizations including CNN, *The New York Times*, *U.S. News & World Report*, and the British Broadcasting Corporation teased provocative headlines. The headline in the *British Medical Journal* read "'Designer Baby' Cures Sister." *The Washington Post*'s headline was "Test-Tube Baby Born to Save Ill Sister." The issues were raised: For the first time ever, in vitro fertilization combined with genetic testing had created a perfectly matched donor. Science, it seemed, had just moved a step closer to Aldous Huxley's *Brave New World*, where humans are engineered rather than born. Suddenly, the Nashes were the poster family for the divisive debate.

Dr. Wagner, Molly's transplant doctor, hardly sees the Nash case as tipping the scale toward scientific utopia, yet he does consider it to be a monumental medical moment. "The international response was almost unprecedented," he says. "But that was a mixture of what was going on: There's a child who had a life-threatening condition, time was running out, and we created a donor," he says.

The Nashes' healthy embryos were preserved, not destroyed. Yet some of their critics, actually many of their critics, insisted that the Nashes had been cavalier with the embryos, with life itself. A Christian Life Resources article titled "Babies a la Carte: Good Intentions & the Road to Hell," condemned Jack and Lisa for using in vitro fertilization and creating what it believed was an abundance of embryos for the sole purpose of selecting just one: "[Molly's brother] was a means—valuable only insofar as he carried the right genetic material. And if he hadn't, he would have been rejected—like the other 14 discarded embryos," wrote Charles Colson, a Christian leader and former special counsel to President Richard Nixon.

"To argue that 'surplus' embryos may be thrown away in any case," went an article in James Dobson's *Focus on the Family* magazine, "arrogantly glosses over the fact that embryos are living human beings, created in the image of God, and deserving protection." Father Joseph Howard, director of the American Bioethics Advisory Commission, railed against the Nashes' use of "unethical science," where, as he put it, "The price of treating the sick must not be paid by killing innocent human beings."

Even as *The Washington Post* cited the benefits of genetic testing (such as wiping lethal genetic disorders from future generations), many media pundits faulted the Nashes for ripping open a Pandora's box: If they were already selecting healthy embryos and screening for tissue type, how far was science from creating designer babies?

The responsibility falls squarely on the shoulders of society, says Dr. Schoolcraft, Lisa Nash's fertility specialist. "As long as the community is still responsible enough to use [genetic testing], a superbaby won't happen." These days, PGD can screen for 30 to 40 diseases and is commonly requested by parents terrified of passing along a devastating disease such as cystic fibrosis, muscular dystrophy, or Tay-Sachs.

In *Christianity Today*, Ben Mitchell, a senior fellow at Illinois' Center for Bioethics and Human Dignity, has expressed his concern over the "almost grotesque precedent" set by the Nashes. "Instead of saying that each person is an end unto themselves, this case says that people can be used as a means to the end.... You are having a child expressly to serve the needs of another child." The BBC and the medical website WebMD were among the news sources that posed the question, "Did they choose to have a healthy baby because they wanted another child, or because they wanted a source to help cure their daughter?"

For the most part, Jack and Lisa ignored the press and concentrated on saving their daughter. "All of our attention was wrapped around Molly," Lisa says. "Everything else was white noise. I wasn't focusing on people tearing me apart. My concern was taking care of Molly and giving her brother some semblance of a normal newborn life."

Lisa, who now is in her late 30s, is of average height and build, with a thin, youthful face and dark, curly hair that requires little maintenance, which is a good thing. Like most moms, Lisa puts her family's concerns ahead of her own. There's not a lot of time for primping. The only visible hint that Lisa has endured such an ordeal is in her eyes: They're dark and intense; they're the eyes of a lioness protecting her cubs.

Jack's eyes have the twinkle of a playful joker. He is the softer yin to Lisa's yang. Also in his early 40s, with graying hair, he's more inclined than his wife to smile. It seems that Jack and Lisa's marriage is a partnership. One minute, he's following her lead, and the next he's charting the course. But when it comes to Molly, it's Lisa who does the talking, with Jack filling in some details and, when the mood becomes too intense, lightening the conversation with dry humor. Perhaps it's Lisa's maternal instinct or the NICU nurse in her, but she's the one who has the photographic memory of Molly's life. She's the one who can recall her daughter's blood count on any given morning.

The Nashes can't understand why people question their motives and self-righteously deconstruct their private lives. Never mind the arrogance of some Christian pundits who, when preaching against the PGD process and the decisions the Nashes have made, discount the fact that the Nashes are Jewish. And according to Jewish law, as Lisa and Jack see it, the faithful are commanded to do whatever is necessary, with the exception of committing murder or adultery, to preserve life. "We wanted a healthy child," Lisa says. "We wanted a child who would not suffer the way Molly suffered. And we made a decision for our family, not for the world to take issue. In my shoes, you would have done the same thing."

**Goodnight**

She's fighting the needle again. It's Feb. 22, 2005, and Molly is in the hematology department of Children's Hospital. She's got her arms locked tightly around her purple sweater. She fidgets in the chair, shuffles her feet, and commands the nurse not to probe her special arm for veins. Molly glares at her dad, as if the blood test is his fault.

Dr. Hayes, the hematologist, delivers good news: Molly's platelets register a very healthy 395,000, a level that's held steady for four and a half years. The bone marrow is functioning normally. This September marks the landmark fifth anniversary of the transplant and by most standards Molly is a normal fifth-grader. In school, she likes math and science, and she would have gotten a perfect score on a recent spelling test if she hadn't misspelled the word "animal." She experiments with makeup, burns up the phone lines, and listens to ear-splitting music—The Black-Eyed Peas, Outkast, and 'N Sync thump through her bedroom walls. She's 10 and a half going on 13.

Dr. Hayes, taking Molly's blood pressure, asks how her brother's doing. Molly replies, "Annoying." Molly's dad rolls his eyes and chuckles. When Lisa was pregnant, she and Jack went round and round about boy names but nothing stuck—until one night Lisa woke up abruptly. It was so obvious. The name had been right in front of them all the time. It was right there in Genesis: *So the Lord, God, caused a deep sleep to fall upon the man, and while he slept took one of his ribs and closed up its place with flesh; and the rib which the Lord God had taken from the man made into a woman and brought her to the man. Then the man said, 'This at last is bone of my bones and flesh of my flesh....'*

Adam turns 5 at the end of August. He and his big sister, Molly, bicker and bait each other like typical siblings. Yet there are times, usually when Jack and Lisa aren't watching, that Molly gently pushes Adam on the backyard swing and coddles him when he trips in the grass. Molly's careful to be a good big sister to Adam and 2-year-old Delaine. The newest addition to the Nash family was also conceived through in vitro with one of the healthy preserved embryos. "We were twice blessed by PGD," Lisa says. "Without this technique, it could have been just Jack and me looking at pictures on the wall."

Molly is still fragile; the transplant cured her of bone marrow failure, but Fanconi anemia is permanent. Like many with the disease, she receives nourishment through a feeding tube. Although she can eat on her own, Molly never experiences hunger. At dinner she unwinds a California roll and chews a few grains of rice or pushes the contents of her plate around in circles. The exception is curly fries—of which she'll eat four or five. At meal times and at bedtime, she's plugged into a bag of formula that fills her stomach bit by bit. For now, Molly's prognosis is good. But those with FA rarely have a worry-free life. Molly has 35 to 40 doctor appointments annually. She has regular screenings for solid-tumor cancers. Jack and Lisa are always on high alert—a common cold in the Nash family could have dire consequences for Molly.

Each night before bed, Molly bounces into her room and finds a million ways to procrastinate—she plays on the computer, organizes her book bag, shows off her collection of snow globes. Moments before she slips beneath the sheets, Jack or Lisa strap her torso into a brace designed to counteract the scoliosis that curves her spine. "It squishes me—sometimes it's hard to breathe," she says, pretending to gasp for breath. When Molly gets in bed, Lisa plugs in her "button" and a machine begins regulating the slow drip of nutrient-dense formula with a blinking red light and a measured beep.

"Goodnight, Mommy," Molly says.

"Good night, Molly, we love you."

*Amanda M. Faison is 5280's Senior Editor.*