Modern technology can turn 24-week-old fetuses into babies. But the decision to use it is rarely simple. Maybe doctors could save Dylan DeCosta. He wasn't the only one struggling.

‘Does Anyone Here Think This Baby Can Live?’

BY DARCY FREY

At 12:35 on the morning of Friday, March 24, Jennifer DeCosta woke up in her hospital bed from the sound of her own screaming and realized she was about to give birth. Her husband, Kevin, vaulted from his armchair to call the obstetrical nurse. The nurse paged the newborn intensive care unit. Two doctors and two nurses grabbed their red metal resuscitation kits and took off down the stairwell for Jennifer’s room. As often as 10 times a day at the Brigham and Women’s Hospital in downtown Boston, the newborn intensive care team rushes to the delivery of a premature baby. Jennifer’s was the kind they feared the most: a fetus born at the very border of viability — after only five and a half months in utero — when its tenuous ability to live outside the womb could turn out to be a cause for joy or, as easily, a dreadful curse.

The Brigham doctors had tried to prepare the DeCostas for both possibilities when Jennifer first arrived at the hospital three days earlier, having inexplicably gone into labor in her 23d week of pregnancy. Gathering around her bedside like benevolent priests, the doctors told the young couple that, yes, a fetus has been known to live after only 23 weeks’ gestation, but that its chances of surviving without severe abnormalities are vanishingly small; a normal pregnancy, after all, lasts about 40 weeks. The doctors said they wouldn’t know until they actually saw Jennifer’s baby in the delivery room — because maybe it would be closer to 24 weeks old, in which case the odds improved dramatically. But they explained that every borderline infant must be considered something of a medical experiment.

Jennifer is a pretty, spirited 22-year-old with a mop of curly blond hair and wide green eyes. At home in Abington, Mass., taking care of her first child, an 18-month-old daughter named Siarra, Jennifer had seemed mature beyond her years, filled with the uncommon energy and grace it takes to be a good mother. But lying in her hospital bed at Brigham and Women’s, hardly showing in her oversize maternity gown, she looked childlike herself, far too young to be facing such grim prospects for her family.

“I’m trying to prepare myself for every scenario,” she said quietly, watching as the doctors set up their resuscitation equipment. “I guess we won’t know till it comes out.”

“Boy, it makes your life take a total turn,” murmured Kevin, holding his chin in his hand. Suspecting that words alone could not prepare the young couple for what might happen next, the doctors took Kevin on a tour of the newborn intensive care unit, known as the NICU, to which their baby would be rushed if born alive. A 24-year-old security guard, Kevin has all the physical requirements for his line of work: scrappy beard, muscular bearing, small scar

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over his left eye. One can imagine a burglar spotting him on patrol and thinking twice about the heist. But Kevin also possesses a gentle, open manner, and as he stepped into the NICU, his eyes grew wide and he raised his hands to his head, as if he couldn't quite believe the strange landscape he beheld.

The NICU at Brigham and Women's is a long, fluorescent-lit room that stretches the width of the hospital. Built last year to replace obsolete quarters in the hospital basement, it has the sleek, digitalized look of a space lab or, more nearly, a hydroponic tomato nursery — row after row of premature newborns, suspended in a tangle of life-support machinery, poised at the threshold of life. On the unit's periphery are the more stable babies in their plastic isolettes — the "growers and feeders," as they're called — often nestled among stuffed animals, snapshots of older siblings and balloons joyfully announcing, "It's a Girl!"

These are the lucky ones — generally, babies born after 28 weeks' gestation and weighing at least two pounds at birth — who may be going home soon to start their lives. The DeCostas' baby would join the ranks of the unit's borderline population: babies born around 24 weeks, weighing as little as 1 pound 4 ounces, who can be held like a bunch of grapes in a nurse's hand. Their heads are too large for their guant bodies. Their wine-red, translucent skin may be covered with a light coating of fetal hair. Some sleep with their legs by their ears, as if still in the womb. Ten years ago, the smallest of these infants would have been labeled "stillborn" or "premature," wrapped in a blanket and handed over to a mother's loving arms to die. Even now, some babies are just a few days past the age at which they could have been legally aborted as fetuses. And yet here they are, lying froglike and immobile beneath warming lights and plastic tents, attached to pulsing respirators, beeping heart-rate monitors and intravenous lines — a challenge by their very existence to the notion of what is fully human.

Perhaps no area of medicine has made such astonishing advances as neonatology, the study and care of the newborn. Every day, doctors resuscitate the tiniest infants, using oxygen masks and chest compressions, and rush them to the NICU, where the latest technology turns them into "miracle babies," destined to live for 30 years. But occasionally an infant is saved in the delivery room only to face months of painful and costly intensive care, which may simply prolong its dying or — perhaps worse — usher it into a life of devastating handicaps: blindness, chronic lung disease, mental retardation, cerebral palsy. Moreover, the technology is so new that doctors can no longer predict which borderline babies will thrive and which will not. Staring at a 24-week infant in the delivery room, physicians cannot say whether the baby will grow up relatively unscathed — aside from wearing Coke-bottle eyeglasses, perhaps, and struggling with the fastball in Little League — or whether, if rescued with so-called heroic efforts, he will grow up unable to eat, walk or talk while his family must provide lifelong care.

Because of that dreadful uncertainty, some of the Brigham doctors were privately hoping that after Kevin DeCosta saw the NICU in all its awesome and disturbing detail, he and Jennifer would agree on minimal intervention and head off what could become a troubling situation for everyone. "If I were Jennifer, I'd be doing jumping jacks," said one of her doctors, prescribing a miscarriage.

Yet it's one thing for a physician to foresee a potential medical morass, quite another to expect a couple who have nurtured their
dreams of parenthood for more than five months, who have already felt their baby move in utero, who know it's a boy and have even picked out a name for him — Dylan DeCorra — to pass up the chance to save their child. When Kevin returned to his wife's room, he and Jennifer discussed the situation — how prepared they were for the financial and emotional hardships of raising a handicapped son, the toll it might take on their daughter at home — and did what most parents do in their circumstances: prayed that their baby would be that rare 23-week infant who survived in full health or, better yet, that their date of conception was off by a crucial week.

They asked the Brigham doctors to attend their son's delivery and, if he was born alive, use all their formidable power to save their child's life. "Because everybody deserves a chance," Jennifer said. "And I don't want to live the rest of my life wondering, What if . . . ?"

From time to time, the story of a premature baby makes it out of the pediatric journals and onto the front page — invariably when doctors and parents clash over what to do. Last December, doctors at a hospital in Spokane, Wash., were treating a premature baby with kidney failure and brain damage, decided that aggressive care would only prolong the baby's suffering and moved to withdraw his life support. The parents refused, igniting a wrenching, public battle that ended only when some Oregon physicians, reading about the case in the newspaper, agreed to take over the baby's care. A few months later the roles were reversed when a Michigan man, who asked doctors not to make heroic efforts to save his extremely premature son, was indignant for manslaughter after he unplugged his child from a respirator and allowed him to die; he was acquitted in February.

But those are the notorious cases. Every year, some 30,000 babies are born in the United States more than three months before term, half of whom survive. Which ones receive aggressive treatment and which ones are left to die is decided in the trenches, as it were, by parents and by doctors — all of them exercising nearly divine power over these tiny, vulnerable beings and, in some fashion, over the evolutionary health of the human species, one premature baby at a time.

Almost every hour in the Brigham and Women's newborn intensive care unit, a loud bell sounds, announcing the birth of a new preemie, and a triage team of doctors and nurses runs to the labor-and-delivery floor with their kits. Ten minutes later they're back, wheeling a transport isolette into the NICU with a tiny new patient inside, whereupon the neonatal staff descends on the infant, feverishly trying to repair all the insults that prematurity has foisted upon the child: immature lungs that cannot function without mechanical help; gastrointestinal systems that develop life-threatening infections; fetal heart valves that don't close; retinae that detach, and the most uncertain and potentially drastic consequence of pre-term labor, the possibility that tiny capillaries in the skull will break, leaking blood into the brain.

Presiding over this MASH-like atmosphere is Dr. Steven Ringer, the 42-year-old director of the Brigham NICU. "These babies — they just keep falling from the sky," he said cheerfully as he stood in the NICU one morning, watching his staff gather for their rounds. Bearded and gregarious, Ringer is one of those rare physicians who seem genuinely awed by the power and uncertainty of his work. "Most of our kids come out great — knock on wood," he said, rapping twice on the side of his head. "But when it comes to borderline infants, we never know if we're doing what we think we're doing." He shrugged. "I guess that's what makes this an art, not a science."

Once, Ringer explained, he attended the delivery of a 24-weeker and, after deciding the baby was too small to live, left the mother alone with her dying child. "Twenty minutes later, I get a call from the obstetrical nurse saying: 'Come on down and take a look at your patient, doctor. He's kicking and screaming and doing just fine.' Ringer choked, then grew serious as he described finding himself on the opposite end of the decision as well: using the full neonatal arsenal to rescue babies he was certain would turn out well, only to discover they would suffer from various physical and neurological defects their whole lives. Every day, in fact, Ringer is forced to take such gambles, knowing that if he gets carried away, he may salvage a devastated child that nature never intended to live or, if he plays it safe, he may in effect terminate a life that might otherwise have bloomed. "Frankly," he said, "we're always playing the odds."

In the early years of neonatology, doctors often sidestepped this dilemma by resuscitating every baby, regardless of its prognosis. Indeed, there are legendary stories of physicians intoxicated by their powers — attending the delivery of a 23-week infant, say, and when the baby showed no pulse, slicing open its chest with one stroke of the scalpel and squeezing its tiny heart by hand while the parents looked on in horror.

At Brigham and Women's Hospital, Ringer proceeds far more judiciously, always trying to give the parents the last word in any decision about their child, which has earned him a reputation — rare in this high-tech business — as a sort of old-fashioned family doctor. At times, Ringer has gone well beyond what he considered appropriate care for a borderline infant — in one case, at the father's request, attempting to seal off a hole in a baby's lung with a highly experimental natural glue — because it bought the family time to face the inevitable, knowing they had exhausted every possibility. He has also gone the other way, promising a couple

Top left: A Polaroid of Dylan, taken by a nurse shortly after his birth.
Above: The morning crew of neonatal specialists making rounds.
whose fetus had been diagnosed prenatally with a brain anomaly that he would personally stand in the way of any doctor who tried to resuscitate the baby without their consent.

But much as he considers the entire family to be his patients, Ringer believes that at the moment of birth his allegiance must shift from the parents to the child. "My avowed stance is, before making any decisions, I have to wait and let the baby declare itself — breathe, cry, show signs of life. Maybe it'll come out and surprise us. If he's making a go for it, we'd have to go for it too."

Though he remains mindful of neonatology's potential for abuse, Ringer is, at bottom, confident in his ability to take an extremely premature baby and, as he says affectionately, "make him a keeper." He often tells a story about a resident he once supervised who attended the delivery of a borderliner infant. The obstetrician snipped the umbilical cord, turned and advanced toward the NICU team with a small dark mass in her outstretched hands.

It felt like being at the scene of an accident — seeing a human body so altered from its normal state that you feel the top of your skull lift slightly from the shock of it. He was a mere 10 inches long, weighed 1 pound 4 ounces, and though he possessed the right number of arms, legs, fingers and toes, he was little more than a fetus lying in a puddle of amniotic fluid on the warming table. His oversize head was covered with purplish bruises from the trauma of birth. His skin was plum-dark and gelatinous. And though his face looked like a baby's, his eyes were still fused shut, as if grumbling at the cruelty of being expelled so prematurely from the womb.

Nurse Capistran stuck a rubber bulb in the baby's mouth to suction fluid from his lungs, then Nurse Sheldon towed him off — actions that would trigger a normal infant's first cry and breath. But this marginal organism did not breathe spontaneously. Aside from a few twitchy movements, he lay on the white sheet silent and limp. He looked no more like he belonged in this world than if he breathed through gills.

Ringer, his back to the DeCostas, looked at his colleagues and screwed up his face: this could be a nightmare for everyone. For a moment, it looked as though he was going to turn to Jennifer and Kevin, who were watching with suspended breath, and tell them they had a lovely little boy, perfect in every way, but that, sadly, he was just too small to live. This was not a baby "declaring" itself alive. And yet under the blazing heat lamps, the infant began to move his arms and legs in circular, swimming gestures. No one knew what complications lay ahead, but if there was any chance of saving him, the doctors would have to start now.

Sheldon leaned over the baby and, placing her stethoscope to his chest, announced quietly, "No heart rate, guys." Ringer fit a plastic mask over the baby's face and, with rhythmic squeezes of a black rubber bag, pumped highly oxygenated air into the infant, hoping to inflate his lungs, which are the last significant organs to develop in utero and, in borderliner babies, cannot stay open unassisted.

"They're very, very still," Ringer reported. Everyone spoke in subdued voices, but the DeCostas could hear every word and Jennifer began to weep with confusion and fear. Kevin, still clutching his wife's hand, leaned over her bed and tried, amid all the huddled bodies, to catch a glimpse of his newborn son.

Even a nonviable baby will sometimes have a heart rate at birth, and in another few seconds Sheldon, still pressing her stethoscope to the baby's chest, announced she was getting an irregular one of 60. Quickly, Ringer pulled the mask away from the baby's face and Preibe leaned over the infant. With the precision of a man building a ship in a bottle, Preibe opened the baby's jaw with one hand and with the other tried to thread a plastic tube down his throat so that oxygen could be pumped straight into his lungs. Because a baby cannot breathe during this procedure, causing his heart to slow, doctors often hold their own breath so that they know when it's time to pull the tube out and try again; otherwise, the intense focus needed to thread the dark, narrow trachea can become hypnotic and
The First Intensive Days

The newborn intensive care unit is medical science’s best attempt to repair the many insults that prematurity foists upon an infant. Respirator and IV catheter tubes deliver oxygen and nutrients (above left), while a thin sheet of plastic wrap keeps fluids from evaporating through the preemie’s membranous skin. Human contact is a treat: parents are encouraged to hold their newborn (above right and right) and nurses bathe early arrivals by hand (below right). Then it’s back into the plastic isolette (below) — warmed by heat lamps, bathed in blue light to treat jaundice: a sterile womb ex utero.

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soon the baby is properly “tubed” and dead. But as Preibe eased
the tube down the baby’s throat, lighting the way with a pen-size
instrument called a laryngoscope, Sheldon kept listening for the
heartbeat, calling out the free-falling numbers into Preibe’s ear:
“Heart rate 60 . . . heart rate 50 . . . heart rate 40.” Sheldon said
urgently. “You have to come out!”

Preibe whipped out the tube. Ringer reached in from the side to
give the baby more oxygen by mask. “He’s five minutes old,”
Capistran announced to the room, a reminder that if a good heart
rate and airway weren’t established very soon, the baby would
suffer irreversible brain damage.

This time Christou tried her hand with the tube and the
laryngoscope. Once again, the baby disappeared beneath a looming
doctor and her instruments of rescue. And once again, Sheldon
called out the decelerating heart rate until it was too dangerous to
go on. Ringer moved in with his bag and mask.

Everyone exchanged nervous looks. Just how far were they
prepared to go to jump-start this tiny life? The baby still had a
heartbeat, but his arms and legs were splayed lifelessly to each side.
The only part of him that moved now was his chest, which heaved
mechanically each time Ringer squeezed the bag. Sheldon listened
with her stethoscope. Then she looked up at Ringer and shook her
head: no heart rate. Jennifer’s view was blocked, but Kevin caught
the gesture. His eyes overflowed with tears and he buried his face
in his hands.

“You’re eight minutes out,” Capistran announced.

“Draw some epinephrine just in case,” Christou called out.
Neonatologists will argue forever about the finer points of their
work, but using epinephrine, a heart-stimulating drug, on a 23-
week-old baby is an aggressive move in anyone’s book. Capistran
turned to his kit. “Epi, one cc,” he called back.

Once again, Christou tried to insert the tube. This time, she
found the baby’s trachea without delay and Ringer was able to
attach his rubber bag to the jetting plastic tube. Now he could
squeeze air directly into the baby’s lungs, hoping to send oxygen
— not a moment too soon — toward the infant’s brain. Sheldon
leaned over, listening with her stethoscope. “I’m not getting
anything,” she reported.

“I can’t get his lungs to expand,” Ringer said, squeezing with
considerable force. Under the heat lamps set up to keep the baby
warm, the doctor’s face was covered with sweat.

“I’m not hearing anything,” Sheldon said again, “just a squeak.”
Ringer squeezed the black rubber bag harder and harder,
approaching air pressures that would either inflate the baby’s lungs
or blow them apart. Then Christou poured the epinephrine down
the baby’s trachea.

“Ten minutes out,” Capistran said, to a new round of
squirmish looks. Later that night, Ringer would say he was
two squeezes away from stopping when Sheldon announced,
somewhat tentatively, “Irregular heart rate.” Ringer shot her a
skeptical look. Sheldon closed her eyes and listened fiercely
with her stethoscope. “Actual beat!” she said with more
certainty.

Ringer kept pumping, judging the condition of the baby’s
lungs by the resistance he felt from the bag. “Lungs opening a
little,” he said.

“Heart rate 80,” Sheldon said. Ringer glanced skyward, whether
out of relief or foreboding was impossible to say. The only sound
in the room now was the rhythmic pumping of the rubber bag and
Kevin and Jennifer’s muffled sobs; the baby himself had yet to make a noise. Sheldon was still bent over, listening to the infant’s chest.

“Still got a heart rate?” Ringer asked. Sheldon nodded: “Above a hundred.” Like a motor that kept turning over and finally caught, the baby’s heart began beating normally. And with his lungs expanding from the force of Ringer’s pumping, oxygen was finally passing into his bloodstream and reaching the cells of his body and brain. Resuscitation appeared to have worked, at least for the time being.

IT TOOK LESS THAN A MINUTE FOR the triage team to wrap the baby in a white blanket, place him in a transport bed to whisk him upstairs while Ringer ran alongside with his black rubber bag, pumping in each breath. As soon as they reached the NICU, a new team of doctors and nurses descended upon the isolette, scooped the baby out, unwrapped his naked body and plugged him into the machinery: respirator, intravenous drip, heart-rate monitor. Within minutes, he was squirming around in a profusion of tubes and wires, and the staff took blood tests and X-rays in a rapid search for the myriad ailments he might develop: hypothermia, from having none of the baby fat that would have grown during this last trimester; fluid loss, from having skin so thin it was actually rubbing off on the nurses’ hands, and, most ominously, the prospect of brain hemorrhages.

Finally relieved of their triage duties, Ringer and his teammates gathered nearby in a state of manic exhaustion. “Well, we’ll see whether resuscitating was the right choice,” Ringer said, collapsing into a chair and pulling his surgical mask down around his neck. “It’s little, but he looked like a 24-weeker to me and his skin was thicker than I would have thought. Plus, he was pretty frisky. But he’s as young as he can be, plus or minus a few days, given our current technology.”

Phil Casperian was pacing back and forth. “I was thinking we’d all quit down there,” he said. “But then he bounced back.” Not thirty seconds after the “He’s little” pronouncement, the baby was sanguine. One nurse who hadn’t been at the delivery walked past the baby and — appalled by its size and vulnerability to every physical and neurological defect — said to the triage team, “Boy, you guys got faith, don’t you?”

And in truth, the triage members themselves felt ambivalent about what they’d just done. “You feel kind of weird at first,” Casperian said, still walking off his excess energy. “We save these kids. Then some of them get serious head bleeds. But, hey, you gotta do what the parents want, because they’re going to have to live with this for the rest of their goddamned lives. It’s not our job to say, ‘He’s small; screw him; he’s outa here.’”

“Yeah, if you don’t want anything, you shouldn’t come into a facility with a NICU,” Yvonne Sheldon said forcefully. But then her voice lost its edge and she said with considerable sadness, “This is the hardest, hardest thing.”

Ringer sighed and wiped his brow with his surgical mask. “Well, unless it’s crystal clear the baby can’t survive, I think you owe the family the opportunity to know everything was done. But it’s getting harder and harder. I mean, with all this technology, who the hell knows anymore? It came down to a split-second decision: looks like he can make it versus it’s hopeless. I thought this kid had a good chance of being a keeper. But it’s a frightening moment every single time.”

In a few minutes, the first test results came back from the lab. Astonishingly, the baby’s blood gas — the amount of oxygen and acidity in his blood — was almost normal, indicating that, despite the time it took to insert the endotracheal tube, the triage team had performed a successful resuscitation. The chest X-ray was not so good. It revealed that the baby had extremely immature lungs and that the handpumping had torn a small hole in one of them. Moreover, the doctors would have to wait for a head ultrasound to know whether this baby had suffered any brain hemorrhages, though no one could imagine how he might have survived such a traumatic delivery unscathed. In fact, Dylan, now the smallest and sickest patient in the unit, was at risk for every disease and complication in the neonatal textbook. The next 24 hours would be critical. With every second his heart continued to beat, he was exceeding his life expectancy.

At 2:30 A.M., an obstetrical nurse brought Jennifer and Kevin up to the NICU so that they could see their child. All the graphic medical talk ceased and the crowd of doctors and nurses respectfully parted, as the DeCostas, wide-eyed with shock, made their way down the row of infant stations. When Jennifer, in a wheelchair, reached her son’s bedside, her face collapsed. “Oh my God,” she whispered. “He’s so small.”

Kevin peered down at his son, brought both hands to the sides of his face and took two steps back. Thirty minutes after he was born, Dylan DeCosta lay suspended in a sort of artificial womb. His head was pulled to one side by his respirator tube, which was delivering blasts of oxygenated air to his lungs. A catheter, threaded into the umbilical artery, pumped fluids into his body. Heart rate and temperature and oxygen monitors ran to his arms. IVs to his feet. A blue cotton patch lay over his fused eyes against the glare of the warming lamps. And to keep his bodily fluids from evaporating, plastic wrap had been stretched over his bruised, membranous skin.

He was preconscious, of course, and without memory. But there was no doubt he could hear and feel. From time to time, his arm sprang up to pull at the tube in his throat and his legs kicked at the plastic wrap. It was hard not to wonder how he felt: safely in utero one moment and in the brutal grip of all this hardware the next.

“Do you want to touch him?” Jennifer’s nurse asked her. Jennifer opened her mouth to answer, then started to cry. “Here
you go," the nurse said gently, rolling back the plastic wrap. But when Jennifer laid her hand on her son's leg, he instantly curled into a ball, like a small poked with a stick.

"God, I just want to hold him but I can't," Jennifer said, pulling her hand away. "I just want to comfort him, but I can't."

"How about you?" the nurse asked Kevin. "Would you like to touch him?" Kevin, still lingering a few feet from the table, shook his head.

"You sure you don't want to touch him?" Again Kevin shook his head.

"Go on," the nurse said. She reached out, took Kevin's hand in hers and guided it under the plastic wrap. His palm came to rest on his child's soft, bruised hand, and Kevin shut his eyes tight. Maybe Dylan would turn out to be a keeper. Maybe

Just then an alarm went off, and Kevin looked up at Dylan's heart monitor in time to see the spiked green line go flat across the screen.

not. The nurse wanted to make sure that Kevin would know the feel of his child, if only once.

UNTIL THE 1960S, LITTLE COULD BE DONE FOR A PREMATURE BABY — even out weighing as much as three pounds at birth — aside from maintaining its body temperature with an incubator, providing it with extra oxygen, feeding it and, as often as not, watching it die. But several events quickly led to major advances. In 1963, President Kennedy's second son was born at 34 weeks and died two days later of respiratory distress. That, along with studies revealing a disturbingly high infant mortality rate in the United States, raised public consciousness, and Federal financing began flowing to the first NICUs.

The early 1960s's also saw the invention of the mechanical ventilator, as well as the technique of cardiopulmonary resuscitation, and by the end of the decade, 34-weekers were being rescued routinely. Over the years, new forms of technology, like better ventilators and intravenous nutrition, kept arriving, pushing the threshold of viability higher and lower. By the 1980s, 90 percent of infants born at 28 to 31 weeks gestation were being saved.

And by 1990, newborn medicine had been revolutionized yet again when researchers discovered a method for taking the surfactant — a fatty substance that coats the interior cavities of the lungs and prevents them from collapsing — from newborn calves and administering it to premature humans. Surfactant has helped nudge the border of viability down to between 23 and 24 weeks. Below that, babies lack sufficient lung tissue to exchange gases and the rescue of even younger preemies would require some radical new technology, like an artificial placenta. That day may not be far off, however. Recently, scientists experimenting with fetal rats discovered how to oxygenate them underwater. As the Brigham NICU, the staff jokes that it will soon report for work in scuba suits to treat 20-weekers swimming in a giant tank of amniotic fluid.

Dr. Thomas Berger looked as though he'd glimpsed that future when he arrived at the NICU on the morning after Dylan DeCosta's birth and found his tiny new patient on the warming table. The doctor was shaken by what he saw. "I think it's crazy," he muttered. They're more paternalistic" — meaning that doctors will decide on their own whether or not to save a borderline infant. "Prets," he added with an ironic smile, "I'm being taught to respect the parents' wishes."

In fact, it was Berger who had met with Jennifer and Kevin when they first arrived at the Brigham to determine if they wanted aggressive measures taken to save their son's life. Heading toward Jennifer's room that day, Berger was frank about his own opinion — "I wish they'd say, 'Do nothing,' if this were my child, that's what I would say" — and equally frank about his obligation to give them medical advice and nothing more.

But determining the parents' wishes was one thing: assuming responsibility for the small human form on the warming table was another. As the daytime staff of nurses and respiratory therapists gathered near Dylan's bedside to check out the new preemie, Berger said softly, "Guys — what are we doing here?"

"I agree," said Gabrielle Harrison, who was Dylan's new nurse and, like Berger, seeing her patient for the first time. "I have a real problem with the ethics of this. This kid wouldn't be viable in any other hospital. Even if this baby survives, to give a severely handicapped child to very young parents of limited means — there are serious health consequences to this."

Usually the NICU assigns borderline infants to nurses who enjoy the technical challenges of their care, such as threading IV's into veins no thicker than a hair. Harrison was not one of them, preferring to work with families on long-range planning. "We need to think ahead, make some decisions before there's a crisis," she said. "If this kid blows a pneumothorax — a hole in the lung — we'll say, 'We've gone this far already, we've got to go on.'" And we'll put in a chest tube. Frankly, I think we've gone too far already."

Just then Ringer, going into his 24th hour of on-call duty and clutching a tall cup of coffee as if he might drop to the floor without it, approached the group. "How much did he weigh at birth?" Berger asked him with an edge to his voice. He and Ringer are the closest of colleagues, but they never shy from a good disagreement, especially if they believe their patient will benefit from the debate.

"Six hundred grams," Ringer replied, taking a long, thirsty
Dylan challenged his doctors to use their machinery with wisdom and mercy. Indeed, every hour he lived was a test of the social contract the human community makes with its most vulnerable members.

As the steady white noise generated by all the medical machinery, amid the constant flow of doctors and nurses moving around the infant's bedside, it can seem startling when a parent comes into the NICU. With IV's doing the work of breast-feeding, islet cells displacing a mother's arms, who needs parents?

Some new mothers and fathers adjust quickly, keeping journals of their baby's respirator settings as if documenting their child's first steps. Others teach themselves the NICU jargon to keep up with the doctors. "Olivia got a little bradycardia, had some decelerations, but they went up on her mean pressure and she came out of it," one eager new father says, meaning his baby had some breathing difficulty and needed more support from her ventilator. The NICU staff, ever-conscious of technology's alienating presence, invites parents to lend a hand with baths and diapering. And in the last few years, they have encouraged parents to "kangaroo" — a technique, first developed in South American hospitals without isollettes, in which a premature baby is placed against a parent's bare chest to maintain the infant's body temperature. But many parents, at least in those first few days after the birth of their critically ill child, walk around the NICU like lost souls or like civilians stumbling onto a high-security army base without authorization.

That was how Kevin DeCosta looked on the morning Berger and Ringer discussed his baby's prognosis in the NICU. Intimidated by the physicians' presence, Kevin hung back a few feet, hardly noticeable in the blue scrubs he wore in lieu of clean clothes. As soon as Ringer and Berger moved on, Kevin approached the warming table, frowning at first, as if he expected to come upon an empty sheet, then smiling with joy and relief when he discovered his baby was still alive, kicking and kicking beneath the plastic wrap.

"He's a spunky little thing, isn't he?" Kevin said. Already Kevin was working to meet the demands of fatherhood, taking pride in..."
DYLAN'S STORY

whatever small steps his son could make. "I was scared to touch him last night; I was afraid I'd hurt him. But look at this: he's kicking up a storm." Kevin threw a few punches, in celebration of his son's visible will to live. "I have a good feeling in my heart about this. I just know he's going to pull through."

Hearing this, Nurse Harrison walked over to introduce herself. "So how's he doing?" Kevin asked. "Is it 50-50 now?"

"Well, we're really going minute by minute now," Harrison replied soberly. She explained the problems with Dylan's blood pressure and lungs, but moved quickly from the baby's medical status to the broader picture Kevin and Jennifer were facing if their child were to survive, if Dylan grew up in a near-vegetative state requiring lifelong institutional care.

Just a few yards away and Kevin looked up at Dylan's heart rate monitor in time to see the spiky green line go flat across the screen. Kevin gasped. Harrison leaned over to silence the alarm, then reached beneath the plastic wrap to re-attach the heart monitor, which had fallen off the baby's chest.

Kevin was still waiting for his heart to stop pounding when Jennifer walked into the unit, wearing a hospital gown and socks. Like her husband, Jennifer eased her way slowly toward Dylan's bedside, but discovering her baby alive did not erase the look of sorrow from her face. Overwhelmed by their situation, Kevin and Jennifer seemed to have divided duties to help them cope: his was to protect the flame of hope, hers to remain realistic.

"Will they take a picture of him for us, just so I have one?" Jennifer asked the nurse. She stayed by her son's bedside for a few minutes, as construed as a visitor at the zoo; then, unable to bear her helplessness a minute longer, she went back to her room. Kevin lingered by Dylan's bedside, keeping vigil. In a few minutes, a young resident came by to read some numbers on the baby's respirator.

"So is he going to be O.K.?" Kevin asked hopefully.

Every doctor who treats a critically ill baby reads a narrow course between the obligation not to withhold information from parents and the desire not to be cruel. But if not is not something the doctor makes happen in a medical school.

"Well, he's at a very high risk for blowing a hole in his lungs," the resident told Kevin, unleashing a torrent of medical information in an attempt to candid but sounding merely brusque. "And our interventions may make it worse. And he's still not peeing, which means he's going to start puffing up with fluid overload —"

"The way they pee at that age!" Kevin interrupted, trying to keep up.

"Oh, yes."

"Then he will," Kevin said firmly.

The resident scarcely paused. "Well, we have only one more medication we can use after this and that's pretty last-ditch." Kevin had never been given such a bleak assessment and his face flushed with anger. "If things don't turn around," the resident added, "we'll be forced to make a decision to do more or do less. At a certain point, it may not be worth it."

"What do you mean, worth it?" Kevin said incredulously, rising from his chair. "From whose perspective?"

"Well, the harm of intervention may outweigh the benefits," the resident replied, as if quoting her medical textbook. Then, trying to soften her tone, she added, "Maybe you didn't even think he'd get this far."

"If did," Kevin, inches from the young resident, glowered at her.

"Well, you have a lot of faith. That's good. To help you stay strong. I'm not sure I have the same amount of faith."

The resident smiled and moved away. Kevin backedpedaled from Dylan's bedside, reeling from the force of her rough candor.

"What did she say? She doesn't have any faith? She should have a little faith. I've got to keep my faith. That's all I've got going for me. He's got to fight," Kevin brought his fist to his mouth. "Maybe I'm not prepared to lose him."

Then he shook his head, furious that he'd succumbed to such pessimism. "I can't give up on him."

"Look at him: he's alive!" He walked up to Dylan's bedside, gripping the table so hard his knuckles turned white. "I just hope he pees."

ASIDE FROM PUTTING ICE ON A BRUISE, ALMOST NO MEDICAL intervention is free of adverse side effects. And the history of neonatology is filled with episodes of much-heralded treatments that turned out to have disastrous consequences. In the 1940's, for example, before the invention of respirators, doctors treated babies with breathing difficulties by piping 100 percent oxygen into their sealed isolators. The oxygen therapy made their patients nice and pink. A few years later, it was discovered that such prolonged, high concentrations of oxygen had damaged the retinas of thousands of babies; by the 1960's, this was the leading cause of blindness in children. Modern respirators allow for precise oxygen and air-pressure settings and cause significantly fewer side effects. But any baby that requires mechanical ventilation for more than a few days is at risk of developing chronic lung disease, as its pulmonary tissue becomes scarred. Like everything in the NICU, it's a cost-benefit game: without the respirator, the baby will die; with it, the baby's rate of recovery must offset the damage done.

All day long, the doctors and nurses watched to see how Dylan's lungs, as thin as cheesecloth, would handle the repeated, mechanical stress of the respirator. Sometime that afternoon, one of his alarms went off again, this time for real. Suddenly the oxygen in the baby's blood plummeted. While a respiratory therapist quickly unplugged the infant from the ventilator and began pumping oxygen in with the black rubber bag, Berger ran over and held a blue light, called a transilluminator, against the baby's thin chest wall to see if one of his lungs had developed another hole — Ringer's sign from God. But Dylan didn't appear to have either an air leak or a collapsed lung. Which left only one other explanation for the alarm: his lungs were simply falling apart from the constant banging of the respirator.

Berger ran to a nearby conference room and waved Ringer out of a meeting. "DeCosta is desaturating," he reported. "We don't see any free air. Should we put him on the oscillator?"

Ringer grimaced at the thought of it. The high-frequency oscillator is the NICU's newest respirator, perhaps the most state-of-the-art machine in the unit. Instead of delivering a normal rate of, say, 30 breaths per minute, the oscillator vibrates a baby's chest with up to 900 tiny puffs of air per minute, which keeps the infant's lungs constantly inflated, yet does so far more gently than a conventional ventilator. It is a scarce resource, however — a $20,000 machine, of which the hospital owns only two. The doctors usually use the oscillator to treat healthier

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The DeCostas and Dylan in a Poleraid taken by a nurse.
bqes who must recover from an injured lung. now they would be using it to maintain a tiny infant. some thought should never have been resuscitated in the first place. If two new patients with better prognosis needed an oscillator — a not unlikely scenario, given the pace at which babies arrive in the NICU — putting Dylan on it could seem an extravagant use of technology, a case of doctors losing sight of the ends for which their machines were devised simply because they had the means to use them.

“Have you thought about it?”

Berger asked.

“Not really, replied firmly, then as quickly he added, ‘Would you?”

The two of them had to smile, this was precisely the debate they had hoped to avoid.

“Well, I don’t know,” Berger said. “If he needs the oscillator, I don’t think it’s going to work.

“Well, I’m not sure I view it as a different level of care,” Ringer shrugged.

“We could give it a shot.”

“It may be better for the parents anyway,” Ringer reasoned, “to say, ‘We’ll try one last thing.’”

Ringer, too, seemed to need some hard evidence before giving up. By the time the doctor reached Dylan’s bedside, Gabrielle Harrison and three other nurses were vehemently debating Dylan’s current treatment, frustrated by what they saw as a half-way course between Berger’s reticence to prescribe too many painful interventions and Ringer’s desire to give it the best shot they could.

Either let’s do a full-court press and put him on the oscillator,” one nurse said angrily, “or let’s back off and let nature take its course.”

“Do you know how much we’re spending a day on this kid?” another nurse said with equal conviction. “Do you know how much postnatal care, how many school lunches or immunization shots you could give with that money?”

Hospital care for a premature baby costs, on average, $60,000 compared with $2,800 for a healthy full-term baby, not to mention the enormous cost of years of rehabilitation programs. But once doctors have embarked on an aggressive course, cost alone seems an inhumane reason to stop.

Ringer listened to the debate. It’s bordering on an odd extraordinaire measure to use the oscillator,” he said. “We could easily do it in the line right here.” But then he paused and looked down at Dylan. They had brought him into the world, how did they now refuse him the best treatment available? “Or, we could say, all these lines are artificial and they’re there just to make up what we feel better, so why not go whole hog?”

“Well,” replied the first nurse, “everything we’re doing is experimental, given his age. And if the oscillator would be worth it, we should use it. Because if we keep this up, we’ll probably blow a hole.”

Ringer rubbed the heels of his palms into his eyes. “Well, I don’t know the right answer. But there’s only one way to find out. Let’s put him on. Then we’ll know. Tom will be ticked off, but the hell with it.”

Now and then, the stress of treating critically ill babies wears down everyone’s civility and the staff finds itself at each other’s throats. That wasn’t exactly one of those times. Still, Ringer’s policy of consensus decision-making not only meant that each doctor and nurse was free to speak his or her mind but that each was in some fashion responsible.

“It’s this overwhelming power we have over the baby’s life,” one nurse said. “Frankly, it scares the hell out of me.”

As she spoke, a respiratory therapist unplugged Dylan from the conventional vent and attached his tube to the oscillator. Going full-blast, the new machine sounded like an industrial-strength air-conditioner and shook the baby’s chest with the force of its rapid-fire breaths. The doctors were now at the very edge of what they could do to this baby — both technically and conscientiously — in order to save him. Berger stood off to the side, watching the transfer.

“Well, I’ve got to admit, it’s amazing that we have the equipment that can support life at this age,” he said, removing his glasses to rub his eyes, he started to look as tired as Ringer. “But I just don’t know whether we’re doing anything a service the child or the parents. And if we consider this the appropriate decision, without a week, then when are the times where it’s too much? We go on until the babies break. Are we not to make the decision ever? Until the baby just falls apart and his heart stops? There’s got to be another way.”

“DECIDING WHEN IT IS NO longer justifiable or humane to artificially sustain a patient’s life has become modern medicine’s most agonizing ethical predicament. And making the decision to withdraw care is exasperatingly harder when the patient is a baby. Infants cannot speak for themselves, either to ask for help or to protest painful procedures. In some ways, neonatology resembles veterinary medicine, since doctors have so little human interaction with their patients. It takes me a while to get attached to them,” one Brigham doctor remarked candidly. “Sometimes they seem almost like physiologic machines that we can keep going.”

Nurses, on the other hand, do not enjoy the same psychological distance from their patients. They are the ones who must thread IV’s into a baby’s veins, prick his skin to draw blood, place scopes against an infant’s chest and leave a tiny bruise; they are the ones who know by the way a baby’s blood pressure jumps and his skin changes color when he is in pain. Dylan’s nurse on his second day of life was a passionate, talkative woman named Diane Regan. Regan works only a few days a month in the Brigham NICU, spending the rest of her time caring for former preemies at their homes because she says, “I want to see what the impact is of all this high technology.”

For 20 minutes, Regan gripped Dylan’s heel, which was no bigger than the tip of her pinkie, and tried to squeeze three drops of blood from it. “O.K., lovebug, I’m going to leave you alone in two minutes,” she said, pricking his skin at the baby tried to kick free. But Dylan had been subjected to so many blood tests already — and only possessed about two ounces of blood in his entire circulatory system — that he had almost nothing left to give. Again Regan pricked him and again he kicked. “I know, I know, it’s wickedness. I keep saying I’m done and I’m not, Handstome.”

When she pricked him yet again, Dylan’s heart raced and his blood-oxygen plummeted. “Oh my, you’re too little for this world, aren’t you?” she said sadly. “This is like skydiving for you. Getting
Dylan
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A few hours earlier, his kidneys could not keep pace with all the fluids. Nor could his skin prevent the fluids from evaporating. In fact, what skin Dylan started with at birth was now breaking down as the doctors and nurses handled him. As soon as the staff attended to one problem, another emerged, and then another. They simply could not keep up.

As Barfield spoke, Berger stood by, shaking his head and looking as if he might walk away in disgust. Finally he could bear it no longer.

"Can I just ask," he said in a pugent tone, "is there anyone here who thinks this baby isn't going to die?"

An awkward silence fell as the doctors glanced at each other.

"Well, I told the parents he was the sickest baby in the unit," Barfield replied, annoyed at the interruption.

"Dad is still optimistic. Mom understands the implications."

"This is starting to fall into the category of heroic work," Truji said.

"Starting to?" Berger laughed.

"Look, I think we're getting into a worse and worse situation."

"I agree," Truji said. "But it's hard for the parents to see a piece, moving baby and accept that. If we had an ultrasound that showed a head bleed, that would be more concrete to them."

Secretly, the doctors had hoped a massive hemorrhage would provide a clear exit to this torment — for the baby, the parents, the doctors. But yesterday, the ultrasound had come back normal, in this, as in all things, Dylan had refused to make things easy.

Parad seemed equally reluctant to pull the tube just yet. "Well," he said, "the baby's still got an O.K. heart rate, an O.K. oxygen saturation."

"But that's looking at numbers," Berger said, his voice rising. "Step back for a second. Are you seriously expecting it to survive?"

"Well, saying it probably won't survive is a gut feeling," Parad replied. "What is it based on? If we keep treating him for another day or two and we maximize every setting, every dosage and the baby is still getting worse, then we'll know for sure." Berger was shaking his head again. "And it'll be more easier to tell the parents it didn't work. Hard numbers and time will help."

"But we're there right now," Berger cried, fully unhinged. "And if we don't stop now, we're just waiting for brain bleeds or the heart to slow down. Maybe the parents need that, but this baby doesn't."

But just then Diane Ragan walked up to the doctors with the results of the blood gas she had labored so hard to get. "Well, you've got your numbers," she said grimly. "They suck."

Across from the NICU reception desk was a lovely solarium, its glass walls looking out on the church steeples and red-brick row houses of Boston's Mission Hill district. To come here from the NICU on a sunny spring day is to remember that, though it seems otherwise to most parents, the world does encompass more than the confines of the hospital. The solarium is the place where the doctors and nurses often take parents for what they ruefully call the Big Talk.

"So how are you guys feeling?" Berger asked to Kevin and Jennifer as they took seats in the solarium 36 hours into their child's life.

"Lost," Kevin replied. Since Dylan's birth, Kevin had become the spokesman for the couple — in large part because Jennifer found it too painful to articulate what she knew from the outset were exceedingly slim odds. With every hour that Dylan lived, however, Kevin grew more attached to his son.

To persuade the DeCostas that withdrawing Dylan's life support was the right thing to do would, of course, and the dreams that began when Jennifer's pregnancy was first confirmed months ago and make them feel that they were betraying their child, whose future, whose very innocence, they alone held in trust. They wouldn't even have the comfort, as the children of a terminally ill parent do, of saying that old man Dylan lived a full 75 years and now it's time to say goodbye.

"Dylan's chilling his chart in his lap, set quietly for several moments. Then he said, "Well, we can look at the lungs first," and brought Kevin and Jennifer back through all the treatment decisions. "Dylan has to the oscillator, picking up signs of lung injury, giving the baby more and more oxygen until the doctors had reached 30 percent. "I'm afraid there's no room to go from here," Berger said.

The doctors were playing the same end game trying to improve Dylan's blood pressure. "But it's showing no sign of improvement," Berger continued, and "we can't step up the support anymore."

Jennifer was staring glascily into space. Kevin kept his forearm on his knees, gazing at the floor.

"He may hang in there for hours or even days," Berger went on, in a voice so soft he was practically whispering. "But I'm very concerned that's in his best interest."

Few of the DeCostas' friends or relatives understood what was happening to them — why Jennifer went into preterm labor, why they couldn't save their baby. The couple had shared their anguish only with the NICU staff. Berger seemed to have the most in mind when he said "I mean, Dylan sure tried. So did we. And so did you as parents. I think you've been great parents. You wanted to know if there was a chance, even a tiny chance, but I think you don't want him to suffer, and that's great too."

Finally Kevin looked up. "The fact that he's kicking and fighting — isn't that good?"

"Well, that's one interpretation," Berger answered solemnly. "Or you could say that he's telling us: I'm not feeling well. Don't do this to me."

"His words were so sparse that Kevin and Jennifer both winced. But Berger, now that he'd gotten to the heart of it, pressed on. "We're giving him some pain medication, but I don't think he's very comfortable."

Kevin and Jennifer began to cry. "Sometimes we have babies in pain and they get better and it's worth it. But if we cause pain and somebody has virtually no chance of getting out of this unit, I know you don't want that. I feel we've tried very, very hard, but we're recognizing it's not going to work. And it could change any minute."

"For the better?" Kevin asked.

"For the worse."

"Is there any chance?"

"Well," Berger said, "it's not 100 percent certain. Nothing in medicine is 100 percent certain. But there are miracle babies," Kevin said, his voice lifting as if in question. But he had heard enough now to answer himself. "Well, if there's really no chance, we don't want him to suffer any more" Jennifer nodded and reached for Kevin's hand. "So what do you do?"

"Well, we change our goal from survival to making him feel as comfortable as possible," Berger replied. "We give him a high dose of painkiller, we cut him off all the equipment and we let him be with his parents." Berger gave a few more details for how to prepare it would go. Then, sensing they would do well to be alone, he excused himself and went back into the NICU.

I T OUGHT I D A T TH E N A P L R A M A TUR E baby died in a hospital, doctors would have written the end of sight, offered their condolences in one breath and in the next assured the parents they could have another child. Everyone tried to erase the memory of the infant as surely as if it had been a miscarriage. And 10 years ago, a miscarriage is what Dylan DeCosta would have been. During the day and a half he spent in the NICU, he never cried, never nursed at his mother's breast, never breathed on his own, never even opened his eyes.

Yet the awesome power of modern medical technology had made this baby a fleeting creature of the world and, by doing so, put him at the center of dozens of other lives. Lying on the warming table, he had appealed by his very existence to his parents' love, calling on them to imagine his future and afford him a safekeeping until all hope was lost. Wholly dependent on artificial support, he challenged his doctors to use their machinary with wisdom and mercy, a reminder that with the power to give him life also came the terrible responsibility of knowing when to end it. Indeed, every hour that Dylan DeCosta lived was a test of the social contract the human community makes with itself to care for its most vulnerable members.

And so it was with no small ceremony that Dylan's short, fraught life came to a close. Kevin and Jennifer, eyes shining and exhausted, walked back into the unit. Nurses took several Polaroids of the couple leaning over their baby's bedside. Kevin removed his necklace and placed it by his son's head. Jennifer

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soon as Dylan was completely untethered, Nurse Regan wrapped him in a blanket and handed him to Jennifer. The first time she held her child in her arms was the instant he died.

A FEW HOURS LATER, the DeCostas gathered their possessions from Jennifer's room and came by the NICU to say goodbye. Dr. Berger and Nurse Regan took them into one of the family rooms and presented them with a small satin-covered box containing pictures of Dylan, his footprints, a lock of his hair and his birth certificate — part of the process the NICU social workers have devised to help parents grieve, to acknowledge that they did have a baby, however briefly.

"He was a little life that just arrived too soon," Regan said, handing them the box.

"It's weird," Kevin said. "If someone asked, 'How many kids do you have?' I wouldn't say I had a son. But he was born." Kevin looked through the Polaroids and started to cry. "And he was beautiful." Jennifer put her arm around his shoulder and said, "We did the right thing."

"I know," he said. Kevin had feared that he might simply run away at the moment Dylan was taken off the respirator. But in fact he cradled his son in his arms for almost half an hour at the end. "It felt good to hold him. He was finally at peace."

Ringer was off duty when Dylan died, but Berger called him at home to tell him of the decision, with which Ringer concurred. A few days later, he was back on call, thankful at least that the DeCostas seemed to have survived their ordeal intact and that physicians and family were able to agree on the final course of action.

"Of course, you get these twinges," Ringer said. "At one point, that baby barely needed any extra oxygen support. How could he not survive?" Ringer smiled and took a swig of his morning coffee. "Each time a new baby comes along, I think the same thing: I'm going to get this one through. And we do — even against all odds. That's the motivation for this business, after all. To save them, to not let them go."

He gestured to his new patient, another borderline infant now being installed on the same warming table where Dylan DeCosta had lain. "Here we are, back in business. This one is likely to have a happy outcome. And what's the difference?" He shrugged. "A couple of ounces maybe, and one week of gestation."

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