Mid-Line Failures to Close

Rain is falling hard from the slate December sky, the relentless Nor’easter throwing sheets of icy water against the windshield as we drive steadily along the Rhode Island coast. The tide is high and the storm has dumped so much rain on the ground that the beach between the road and ocean has disappeared, forcing us to drive in a churning mixture of sea and rain water. At times it feels like the car is actually floating, water sloshing against the under carriage. An organ fugue is playing low on the radio, barely audible over the beating of the rain against the windshield and the slapping of the wipers.

There are two of us in the car, me in the passenger seat, and my wife, Ann, behind the wheel. Between us on the console is a small cardboard box containing the ashes of our son, Nikolas, who died two days ago. We do not speak, each of us lost in our own thoughts: thoughts of grief, thoughts of guilt, thoughts of relief. Nikolas was born 8 months earlier with an array of anomalies that the doctors said was a very rare syndrome, occurring only once in every six million births. There was no known cause; “Chalk it up to cosmic rays,” one of the medical team had suggested.

We have been on the road now for several hours, having left our ramshackle graduate-student apartment in New Haven before daybreak. Our destination is not far off, just a few more miles up the coast. It is a special place to us, a rocky promontory thrust into the mouth of Long Island Sound, a bird sanctuary that we discovered summer before last, not by design, but out of impoverishment.

I had just completed my first year of a PhD program at Yale, and Ann, a public-school teacher, was on break. Neither of us was paid over the summer, and by August our meager savings were exhausted. Bored and tired of the oppressive heat and humidity of late summer in southern Connecticut, we used our credit card to gas up and drove north one Sunday to check out the fabled beaches outside New Port. After several hours of driving we had to agree that the pristine beaches did appear wonderful when viewed from the windows of our car. The problem was that parking at the beach required five dollars cash, and after rummaging through the glove compartment, our pockets, and Ann’s purse we were only able to come up with three dollars and 14 cents. Hoping to find less expensive parking, we continued north along the coast until we came across the 300 acre wildlife refuge where we could park our car for free.

The sanctuary was a wild and beautiful place. Its beaches not sandy, but lined with huge gray boulders and slabs of granite over which the ocean waves tumbled and broke like thunder. Getting to the water required a short hike along a stony trail bordered by low thorny thickets and wild rose bushes that – that time of year — were heavy with crimson hips. Ann and I stopped and plucked one of the brilliant fruits from a bush growing next to the trail and broke it open, breathing in its redolence and licking the tangy juice from our fingers.
In addition to the many species of birds that sojourned there, the sanctuary was inhabited by dozens of wild rabbits, New England Cottontails. One hopped along the path just a few feet in front of Ann and me that August afternoon, like a furry tour guide showing us the way to land’s end. Every so often the rabbit stopped and reared up on its haunches, long ears erect, nose in the wind, trying to sense whether danger in the form of a hawk was near. We fell in love with the wildlife sanctuary that afternoon and visited it several more times before Nikolas was born and our lives were turned upside down.

Nobody expects to have a child with serious medical complications. Sure, we are all aware of the possibility, but that is the sort of thing that happens to other people, like earthquakes, floods, and other acts of god. Perhaps we should have started to worry something was wrong when – after 14 hours of labor – the baby refused to enter the birth canal. Eventually they rushed Ann to the operating room for an emergency caesarian and I hurriedly donned disposable scrubs and a face mask to join her there.

I was standing at the head of the operating table trying to soothe Ann who had been given a spinal block. She was alert but understandably exhausted and agitated. The doctors and nurses around us were busy with their tasks, monitoring vital signs and performing the operation. When they at last pulled our son from Ann’s womb, there was an ominous moment of silence as the medical professionals took in the observable signs of the syndrome.

That moment of silence is etched in my brain. It hit me like a physical blow, a gut punch that left me dazed and reeling. In a few seconds my life was violently and forever knocked off one track and on to a very different one.

The first 24 hours after Nikolas’ birth were nightmarish. Fatigued from lack of sleep and numb from emotional overload, I could barely comprehend the stream of horrific news that the doctors continuously delivered to Ann and me. Nikolas had been born with what was known as Pentalogy of Cantrel, Pentalogy meaning five distinct birth defects and Cantrel being the researcher who first identified them as a syndrome in 1958. The doctors ticked off the five anomalies one by one: an omphalocele (opening in the abdominal wall), a diaphragmatic hernia (hole in the diaphragm), a sternal cleft (shortened sternum), an ectopia cordis (opening in the protective sack around the heart), and a ventricular septal defect (major heart lesion). The medical terminology was strange and unfathomable, but one thing was painfully clear. Our son was not expected to survive more than a day or two, and -- if by chance he did -- then he soon would require several surgeries to repair the diaphragmatic hernia and omphalocele.

It was customary in the hospital to serve new mothers a celebratory dinner after giving birth: a small bottle of sparkling grape juice, a stuffed-game hen, a miniature
birthday cake. The irony of the little feast served in Ann’s room was painful. Nevertheless, we raised plastic cups of sparkling juice and toasted to hope. After she finished the meal, I salvaged the minuscule wish bone from Ann’s plate and offered her one end. “One, two, three,” we counted and each pulled hard. The tiny bone snapped, and left us gaping in stunned disbelief. Tears welled up in Ann’s eyes. The wish bone had broken not into two but three pieces. Ann and I each held empty twigs in our hands: the middle segment with the head of the bone had fallen to the floor.

A tertiary-level neonatal intensive-care unit is an overwhelming and bewildering place to someone viewing it for the first time. It is a large brightly lit room filled with dozens of cribs, warming tables, and sterile glass incubators. Each infant in the ward is literally wired for sound. There are machines surrounding each crib and incubator monitoring its inhabitant’s heart rate, respirations, blood pressure, temperature, and a myriad of other life metrics. There are hundreds of screens, dials, hoses, flashing lights and bubbling canisters.

In sharp contrast with the space-age equipment, the walls of the NICU at Yale New Haven hospital are decorated with large pictures of Disney characters: Pooh and Friends, Snow White and Dwarves, and Uncle Donald with Huey, Dewey, and Louie in tow. There are also numerous rocking chairs scattered throughout the room for the use of family and visitors.

Each infant in the NICU is closely attended by a highly trained nurse. Every so often one of the sensitive machines measuring a baby's vital signs sounds an “out-of-range” alarm, buzzing or beeping accompanied by flashing lights. Most of the time it is a false alarm caused by nothing more than a hiccup. In this case, the attending nurse calls out “Got it,” and resets the alarm. Occasionally, however, one of the infants in the unit “crashes” and one alarm goes off followed by another and another until the machines surrounding the patient are all flashing, buzzing and chiming like an insane pinball arcade. When this happens, staff from all corners of the room come running: nurses, residents, and attending physicians converging on the distressed newborn. The normal steady rhythm of the unit is replaced by an anxious frenetic tempo, precious seconds ticking by while the team diagnoses why the patient is crashing and what can be done to stop it. Most of the time they do stop it with quick wits and judicious intervention, but once in a while the crashing infant does not respond to treatment and the crisis intensifies. At this point, non-medical staff, families and visitors, are asked to leave the room, while the doctors and nurses fight desperately to save their tiny patient. Sometimes they succeed, and sometimes they do not.

The first time Ann and I ventured into the NICU to visit Nikolas, he was crashing hard, surrounded by a grim-faced throng in surgical scrubs. As soon as we identified ourselves as the baby’s parents and asked what the commotion was about, one of the unit’s social workers steered us into a nearby private waiting room and began to prepare us for the worst. But the worst did not happen that day. After 20 nail-biting
minutes the medical team was able to stabilize our son and we were permitted to pull
rocking chairs up beside his hospital crib and to begin the strange and difficult process
of bonding with a child in the NICU.

For the next six weeks, this would be our home for 10 to 12 hours a day, every
day. During much of this time we could not pick up or hold Nikolas because he was
“intubated” (on a ventilator helping him to breathe). We put our fingers in his little
hands where he gripped them tightly; we stroked the bottoms of his tiny feet and
watched his perfect toes curl; and we sang to him. We sang “Puff the Magic Dragon,”
“Me & Bobby McGee,” and “Don’t Think Twice It's All Right.” We sang the summer
camp songs of my youth and the Danish folk songs of Ann’s, and when our repertoires
were exhausted, we brought in song books from home and sang from them.

During the first few days we spent in the NICU, Ann and I felt out of place, like
strangers in a strange land. After a week or so, however, we began to feel more at
home. What at first had appeared like utter chaos started to take shape as purposeful
patterns and it became clear to us that the unit was a complex highly functional
organization. We, ourselves, learned to read the pulse oximeter and to discern a false
alarm from a crash. We also learned to read our son, to know what made him happy,
when he was hungry, and when he needed pain meds.

Ann’s sister sent Nikolas a wind-up mobile with a circus theme that we erected
over his hospital crib among the plethora of wires and tubes. When we were not
singing, we would wind it up and he would delight in the Calliope tune and the little
characters suspended over him turning in a slow circle. His favorite was a beagle with
floppy ears wearing a clown’s hat and sitting on a large yellow ball. Every time the little
dog came into his field of vision, Nikolas would wave his arms and kick his legs gleefully.

We also became familiar with the human side of the NICU. We learned the
names and medical histories of most of the other infants. We chatted with some of
their parents and became close friends with a couple whose premature son, Zach, was
in an incubator next to Nikolas’ crib.

Zach’s father, Michael, born and raised in the Bronx, had a raucous infectious
laugh. He was an independent truck driver who hauled raw sewage to a treatment
plant for processing. Some of the stories he told made us laugh until tears rolled down
our cheeks: the time he took a corner too sharply and his rig turned over, sending a
smelly tsunami down the street into a line of people waiting to buy lunch at a hotdog
stand; the time he was emptying his tank at the plant and opened the wrong valve, a
high-pressure stream of raw sewage pinning him against a brick wall for several
breathless minutes; the time he brought his strikingly beautiful wife, Fran, to the plant
on a date before they were married and she ran screaming for the door when she saw
the little brown wafers scented like creamsicles rolling off the conveyer belt. “Your shit
is my bread and butter!” Michael liked to say, laughing uproariously. Michael’s
irrepressible sense of humor and ability to laugh in the face of tragedy helped Ann and I through many dark moments in the NICU.

A base-line rhythm of the NICU is the four feeding times punctuating the day at six hour intervals. These are periods when the infants who receive nourishment per os (by mouth) are taken out of their cribs and incubators and given baby bottles. The 8AM, 2PM and 8PM feedings are performed by families and community volunteers, but at 2AM there is typically only staff on the ward.

Nikolas’s fourth surgery had been rough, and Ann and I remained in the NICU very late that night making sure that his recovery went alright. That was how we came to witness a particularly memorable 2AM feeding.

At the appointed hour, a dozen nurses and residents circulated around the room, removing babies from their cribs and sitting down in rocking chairs to feed them bottles of formula. There was a set of identical twins in the unit who had been born prematurely, the Sugs brothers, Melvin Larry and Galvin Gary.

At one point, the resident feeding Melvin Larry held him up to face his twin who was stationed nearby in the lap of another resident. The doctor holding Melvin Larry affected a southern accent. “I do declare brother that yonder Miss Turquoise Amber Sims is the prettiest thing I have ever scene.”

The doctor feeding Galvin Gary held up his Sugs twin in turn and replied in a thick drawl, “Yes brother, Miss Turquoise Amber is my heart’s own delight and I intend to marry her if she will have me.”

“You?” asked Melvin Larry with deepest incredulity. “Why brother, I will have Miss Turquoise Amber as my betrothed, and I will let no-one and nothing stand in my way!”

Then the very pretty red-headed nurse who was feeding Turquoise Amber Sims held her up and did her best southern belle imitation. “Please brothers, do not quarrel so. You are both fine young gentlemen of high repute that any young lady would be proud to call her beaux, but my affections lie elsewhere. I am smitten with the English Gentleman, sir Markis Scott who resides of late in the crib next to mine.”

The doctor feeding the Scott baby next held him up to join the conversation, feigning a stuffy upper-class British accent.

This wimsical soap opera lasted throughout the hour, each member of the staff acting as a ventriloquist, giving voice and character to the infant he or she was feeding at the moment. There were: love triangles, proposals, betrayals, and reprisals.
Ann and I were captivated, hardly believing our eyes and ears. For an hour that night, at 2AM, the supremely professional doctors and nurses of the NICU at Yale New Haven Hospital revealed to us what few outsiders ever got to see, their playful side.

After 44 days, six operations, and more crashes than I care to remember, the powers-that-be declared Nikolas fit to graduate from the NICU and at last to go home with Ann and myself. That was a triumphant afternoon, a sweet moment of miraculous victory. The infant expected to die within hours of his birth had – by the skill of his medical team and virtue of his own life force – eluded the jaws of death and was coming home with us, home to fill the empty crib I had assembled the week before he was born, home to the nursery Ann had painted blue when we first learned we would have a boy, home to midnight feedings, diaper changes, and afternoon walks in the park. Of course, it was not a normal homecoming and far from a normal situation. Nikolas was medically fragile and keeping his condition stable required a great deal of vigilance. We had to equip the nursery with air conditioning; we had to feed him formula through a tube that we learned to insert through his nose; and we had to give him six separate medicines throughout the day, red and blue serums that had to be refrigerated, a suspension in a green bottle that had to be shaken first, a purple elixir that had to be given every six hours, a thick brown liquid to be given once a day but not at the same time as the red or yellow medicines. We also had to make weekly visits to the pediatric cardiology clinic. In spite of this, the ensuing three months seemed tranquil after the tumult of the NICU.

Nikolas, who had gained no weight in the hospital because of his frequent operations, began to grow rapidly at home. Our parents came to visit, flying cross-country to see the grandchild they feared they might never meet. Our friends, who had supported us so stalwartly through our time in the NICU, now stopped by the apartment to congratulate us. And our Golden Retriever, who we had worried might not approve of a new baby in the house, took up her self-appointed station, a watch dog, sleeping nightly under Nikolas’s crib.

For three months we enjoyed a halcyon summer, watching our son grow and attain developmental milestones, holding his head up. Gaining control of his hands, and smiling. In spite of the hardship he had experienced, Nikolas was a cheerful baby with a sunny disposition, his face constantly adorned with a radiant toothless grin. He was also a beautiful child, strawberry blond hair, lively dark brown eyes, fine features, and pale complexion. Ann was careful to dress him in blue whenever we took Nikolas out of the house because people were otherwise apt to mistake his pretty features as feminine.

The city of New Haven celebrated its 350th birthday that Fourth of July with a massive firework display, launched from atop the 366 foot bluff known as East Rock. As the pyrotechnic extravaganza filled the night sky with shimmering star bursts and sparkling curtains of light, Ann and I clinked together cold bottles of beer and drank a toast in honor of our own private celebration.
July ultimately gave way to August, and as August drew on, early signs of autumn began to appear, shorter days, cooler nights, and yellow tinged leaves in the Elms. Alas, as summer faded, so did our carefree days. There came a night late in August when Ann went to give Nikolas his midnight feeding and found him seriously oxygen deprived, listless with a dusky blue complexion. We rushed him to the emergency room where he was given supplemental oxygen and admitted to the hospital for observation. He was released to go home after 2 days, but this same scenario repeated itself three more times over the next few weeks. In fact, our midnight trips to the ER became routinized: I would call ahead to the hospital to tell them we were coming so that they could prepare a crib with an oxygen head box; Ann would grab the diaper bag, her purse and the car keys; and we would dash off, tearing pell-mell through the deserted late-night streets in our Japanese hatchback.

After our fourth visit to the ER, the doctors concluded that Nikolas was a victim of his own success. He had grown so fast over the summer that he had literally outpaced his delicate respiratory system. It was determined that he would need constant supplemental oxygen for the foreseeable future. We were shown how to tape a nasal cannula under his nose and were set up with weekly oxygen deliveries. The man who made the deliveries, Steve, must have been a football player earlier in life. He jogged effortlessly up the two flights of steps to our flat with a gigantic tank of liquid oxygen in his arms. Steve showed us how to use a valve on the big tank to fill a small portable one that we could use to take Nikolas out of the house. The small tank hung from a shoulder strap and was itself quite heavy and awkward, especially because the wearer also had to carry the baby. By far the worst feature of the portable tank was that when it was bumped or shaken it made a deafening screeching sound, something like the squeal of tires skidding on pavement or the cry of an angry panther.

Over the summer and fall, we became even closer with Michael and Fran whose son, Zach, had graduated from the NICU at about the same time as Nikolas. We would often go to their house on Friday evenings for dinner: Fran’s eggplant parmesan was superlative and Michael’s stories and jokes were always entertaining. In early October we were invited to Zach’s Christening at a local Catholic church. Four baptisms were to be performed that afternoon and the church was packed with reverent parishioners. We arrived late (as people with babies often do) and looked around the dimly lit room for an open place to sit, finally spotting one in the middle of a pew near the back. As I sidled past the people sitting near the isle with Nikolas in my arms, I stumbled over somebody’s foot and banged the portable oxygen tank hard against the back of the adjacent pew. The tranquility of the church was instantly disrupted by the horrific screeching of the tank that went on and on and on. Ann and I were mortified, our faces reddening as everyone turned to see what was making the unholy noise. When the squalling finally stopped, an uncomfortable moment of silence followed. Then Michael’s raspy voice boomed across the sanctuary, “What’s the matter Curt, are you possessed or something?” Next, he began to laugh, and – as usual – everyone laughed along with him, including Ann and I.
As autumn wore on, Nikolas condition continued to deteriorate. Before long we not only had an oxygen tank in the nursery but a pulse oximeter and a suction pump as well. As the parents of chronically ill children typically do, We became adept at various medical procedures. We learned to perform a therapy known as Percussion and Postural Drainage (PPD), thumping gently on Nikolas chest and rib cage to clear his lungs of mucus, removing it from the back of his throat with the suction pump. We would often wake in the middle of the night to the alarm of the pulse oximeter, warning us that Nikolas’ sats were dangerously low and that we needed to turn up the oxygen flow from the big tank. Our apartment, our days, and our lives became filled with a dizzying cavalcade of syringes, tubing, surgical tape, and bottle upon bottle of medicine. Nikolas, who had always been cheerful in spite of his condition no longer had the energy to smile, though his ebony eyes still sparkled.

There came a night in late November, a cold starless night when we were woken as so many times before by the beeping of the pulse oximeter alarm. This time, however, turning up the oxygen did not return Nikolas's condition to an acceptable level. We did a round of PPD and suction, but this only made matters worse. Nikolas was fighting for each breath and his color was approaching that of new denim. Instinctively, I reached for the phone to inform the hospital we were on the way, but then I stopped and looked at Ann who was already packing the diaper bag. I swallowed hard and asked her -- and myself I suppose -- a very tough question.

“What will they do for him at the hospital?”

Ann was puzzled. “What do you mean?” she asked.

“I guess,” I said carefully, “that first they will put him in a head box and give him albuterol, but if that doesn’t work, they will want to intubate him.”

Ann looked at me, understanding dawning in her eyes, “I see,” she said. “And if he is put on a ventilator, then he might never come off.”

During our six weeks in the NICU, Ann and I had observed many tragic situations: babies born with serious birth defects, babies born three months prematurely weighing less than two pounds, babies born with their mothers’ addiction to heroin or cocaine. The most tragic cases -- to our minds -- however, were the infants who spent their entire time on earth drugged and intubated, lingering some times for weeks or months before finally passing away. There was no discernable joy in those little lives, just prolonged suffering and drawn out death. We did not want that for Nikolas. Like most parents, we would have done anything to protect our child, giving up our own lives to save his if necessary. But that option was not available to us. All we could do was choose what we believed to be the best course of action to honor the little life that providence had put so tenuously in our hands.
It was not easy to meet the incredulous eyes of the young resident in the ER – a stranger to us – and tell him that we would not consent to have Nikolas admitted to the hospital without a written order that he would not be intubated.

“You realize,” asked the young doctor somewhat defiantly, “that means your son might die?”

“Yes,” Ann and I replied together, flanking either side of the hospital crib where Nikolas continued to struggle for breath under an oxygen head box.

“I see,” said the resident, glaring at us as if we were the sort of nut-job parents who would refuse to permit their child to be treated with penicillin. He turned on his heel and walk briskly from the tiny room in the ER where we were stationed.

We feared that he had gone to fetch security guards who would unceremoniously escort us from the hospital, leaving our son in the competent care of the rational medical establishment. When the young resident returned, however, he was accompanied by the attending physician, a seasoned war horse of the emergency room that we knew well and respected. He recognized us immediately and crossed the tiny room with his hand extended in greeting.

“What seems to be the trouble with our little friend this time?” he asked.

Ann and I explained the situation as we understood it, including our fear that if intubated, Nikolas would never come off the ventilator. The doctor carefully examined Nikolas for several minutes, checking his vital signs and his chart. Then he looked up at us.

“I think you are right,” he said. “if we put Nikolas on a ventilator, it seems likely we will have difficulty weaning him off it again. We can, however, give him medicine to help his breathing and keep him comfortable. If you will agree to have Nikolas admitted to the hospital, I will write the order that he not be intubated.”

Nikolas was admitted to the Pediatric Intensive Care Unit and assigned a specialized nurse to monitor his condition continuously. Ann and I parked chairs on either side of his hospital crib and began a marathon vigil. Nikolas’s breathing had become labored and ragged and he had fallen into what the doctors told us was CO2 narcosis, a state of unconsciousness resulting from respiratory failure. We hovered over him all through the night, fearing that each breath he took might be his last. We held his little hands and stroked his sweat drenched forehead- sometimes speaking to him in low voices, but mostly just watching and waiting, silently repeating desperate mantras of hope. Around 6AM Nikolas’s condition took a turn for the better. He began to
breathe easier and his O2 sats inched into the 90s. A day later, he was released to return home, having cheated death one last time.

But it was only two weeks later when Ann and I were woken once again to the now dreaded alarm of the pulse oximeter. We rushed to Nikolas’ room to find him blue and breathless. This time we phoned our pediatrician, Cidney, a wonderful unflappable human being who had been a source of wisdom and emotional strength to us.

An hour later, Cidney stopped by our apartment on the way to his office. He examined Nikolas with his stethoscope for a long time. Finally he set it aside and just looked down at his little patient for several minutes. Then he turned to Ann and me and said words we did not want to hear, but knew to be true.

“I believe that Nikolas has entered a terminal phase of his illness. His impaired respiratory system simply cannot keep up.”

We asked Cidney if we should take Nikolas to the hospital.

“That is up to you,” he replied. “I can give you medicine to keep him comfortable here at home and I will come whenever you call me. There is nothing they can do for him at the hospital that we cannot do for him here. So, it’s entirely your decision.”

My eyes met Ann’s, instantly registering unspoken agreement. “We will keep him home with us,” I told Cidney. “We have seen enough of the hospital.”

That was two days earlier, and now, after a long slow drive through the storm, Ann and I are finally arriving at the wildlife sanctuary. We pull into the deserted parking lot during a lull in the rain. Climbing out of the car, we button our coats against the cold and begin to trudge along the stony path toward the coastline where we can already hear the roar of the wind-whipped sea. I am carrying the box with Nikolas’s ashes and Ann is carrying a spray of small white roses. In a few minutes we reach the shore. The tide is high and huge frothy waves are crashing against the rocks, sending plumes of icy sea water a dozen or so feet into the air. We pick our way gingerly over the slippery granite boulders until at last we are standing at the end of a narrow spit, surrounded on three sides by the raging ocean. We sing a Danish lullaby as we cast ashes and flowers into the surf. When we finish, we remain standing there empty handed, uncertain of what to do next and unwilling to leave this now sacred place. We stand for a long time, silent and motionless, as if we have become part of the landscape, grey statues, set on grey rock, surrounded by grey water...

Then, at last, the spell is broken. From high above we hear a doleful keening, a piercing cry rising over the roar of wind and sea. Looking up, we see the silhouette of a small falcon circling over us, framed against the stormy sky. I am not a superstitious
person and do not typically believe in omens or signs, and yet I know without doubt that the Peregrine is there to tell Ann and I that it is time to go home and to begin the next chapter of our lives.

Two years later our daughter will be born. A year after that, I will have graduated from Yale and we would move to Texas where I would begin my academic career. Two more sons will follow, and time will speed past in a blur of bedtime stories, Saturday morning soccer games, and trips to the ice cream shop. But, whenever someone happens to ask about the small silhouette of a falcon tattooed on my right shoulder, I smile reflectively for a moment and say, “It’s a long story – maybe I’ll tell it to you over a beer some time.”