

**(1) When the Air Hits Your Brain: Tales of Neurosurgery**  
by Frank Vertosick Jr., M.D.  
New York & London: W.W. Norton, 1996, 2008. 272pp. Paper.  
p. 187-208

(last sentence of Chapter Nine:)

My first assignment was Children's Hospital, where surgery often did not help at all.

**Chapter Ten: Rebecca**

On my return from England, the department assigned me to the division of pediatric neurosurgery at the local children's hospital. The pediatric rotation was unpopular among the neurosurgery residents. Drawing blood from a wailing infant in the middle of the night while the mother screams "You're murdering my baby" was just one reason. The place did have one selling point: it *wasn't* the pain service.

(2) The neurosurgical floor in Children's Hospital was more of a Sesame Street advertisement than a clinical ward. Bert and Ernie stared down from every wall like Muppet versions of Big Brother. In the middle of the ward was the treatment room, where minor procedures were performed. The very name of that place suggested an interrogation chamber. Muppet stuffed animals littered the place, as if they could soothe a child lying strapped to a table awaiting the cold steel of a needle. (3) Once, as I was having a particularly difficult time getting blood from an infant, I kept smacking my head up against a Muppet mobile which was dangling from the light fixture. Driven nearly mad by the infant's screaming, I pulled the contraption from the light, heaved it into the corner of the room, and shouted "Fuck you, Cookie Monster!"

(4) The infamous "swinging chairs," in which infants rocked for hours on end, lined the halls. Nurses had the audacity to call me when one of the pendular infants puked. "Let me put you in a swinging chair for a couple of hours," I would sneer, "and see how much of your lunchtime hoagie *you* keep down."

(5) A child's cry pierces to the bone and aggravates the soul far out of proportion to its decibel level. The crying of a sick child is far worse. Eric put crying into perspective for me: "When you go to draw blood on a two-month-old, remember, he doesn't know it's just a simple procedure. He thinks you're trying to *kill* him! He's going to peg the meter, pull out all the organ stops."

(6) Three weeks into my tour of pediatric duty, I met Rebecca, the only child of a rural couple from out of state. A free clinic had transferred the six-week-old infant to our emergency room that morning for evaluation of her lethargy, vomiting, and failure to gain weight. A CT scan, ordered by the ER pediatrician, revealed a tumor in Rebecca's small brain. As the neurosurgical student on call, I was summoned to admit her for further treatment.

(7) I found Rebecca with her parents in the ER's cast room, a cluttered cubicle used for setting bones and placing plaster casts. The cast room also doubled as the holding area for ER patients awaiting hospital admission. The infant, wearing only a plastic diaper and soiled T-shirt, squirmed in her mother's lap and gummed a pink pacifier.

(8) Both parents sported worn denim clothes and looked to be no older than twenty. Father paced the small room puffing a cigarette, while Mother stared quietly at the floor, her pale face framed by straight, bleached hair.

(9) Rebecca's appearance startled me. Her bulbous, oversized head teetered unsteadily atop a tiny body, the scalp stretched to a porcelain sheen and laced with delicate blue veins. An intravenous line, anchored by a piece of yellow Big Bird tape, dangled from a scalp vein. Her rib cage bulged beneath the parchment skin of her chest. Her eyes deviated so far

downward that only small crescents of her watery-blue irises were visible. The exposed white of her eyes, together with the gaunt, corrugated chest and large head, endowed Rebecca with a pitiful, buglike aspect – typical of untreated infantile hydrocephalus.

(10) Hydrocephalus, Greek for “water brain,” results from a blockage of normal cerebrospinal-fluid flow within the brain. CSF moistens and cushions the gelatinous nervous tissue. One pint of CSF is made in the brain daily, percolating through small chambers and tunnels within the head and spine before flowing back to the brain’s surface, where it is absorbed by large veins.

(11) CSF production is relentless, a faucet with no “off” position. Any obstacle to CSF flow causes fluid accumulation, increasing the pressure on the brain. A variety of diseases cause hydrocephalus. The viscous pus of meningitis, for example, plugs the tiny CSF channels like grease clogging a kitchen trap. Intrauterine infections, including cytomegalovirus and toxoplasmosis, scar the fetal brain’s inner cavities and produce a form of congenital hydrocephalus.

(12) Rebecca’s hydrocephalus stemmed from a blockage of the fourth ventricle, the main drainage pathway within the brain. A tumor in her cerebellum, the crinkled hindbrain, was the culprit.

(13) Because the mature skull is solid bone, adult-onset hydrocephalus slowly crushes the brain between pressurized fluid and the skull. The infant skull, on the other hand, is pliable, consisting of eggshell-thin plates of bone linked by fibrous fontanelles, or “soft spots.” Designed to expand slowly during normal brain growth, the baby’s skull offers little resistance to unchecked accumulation of CSF. If untreated, infantile hydrocephalus inflates a head to freakish proportions, transforming the brain into a translucent water balloon.

(14) While hydrocephalus remains common in children, modern treatments using surgically implanted plastic shunts have reduced monstrous heads to textbook oddities, although in some rural areas, where access to medical care is limited, advanced cases of hydrocephalus still exist. About once a year, a child with a grotesque head is trundled into our medical center, carried on a wagon or cart like a human watermelon. Children with uncontrolled hydrocephalus look more like Hollywood-created space aliens than human beings, with massive foreheads bulging out over tiny faces.

(15) Hydrocephalus damages brain mechanisms controlling eye movements, deviating the eyes downward. The exaggerated downward gaze is called “sunsetting,” since only the top portions of the irises are visible. The brain’s nausea center, when compressed by hydrocephalus, signals frequent, forceful vomiting, with subsequent dehydration of the patient. In Rebecca’s case, her inability to hold down food spurred her parents to seek medical attention.

(16) Rebecca was not irreversibly deformed, not yet anyway. But she was in serious trouble. I approached her parents, the Hobsons, with my best professional demeanor.

“I’m Dr. Vertosick, Mr. and Mrs. Hobson, from neurosurgery,” I said as I strode into the room, Rebecca’s X-ray jacket under my arm. This introduction garnered only quizzical stares.

(17) “Neurosurgery?” asked Mr. Hobson.

“We’re the brain surgeons,” I continued, hoping to clarify the obviously unfamiliar term “neurosurgeon.” I disliked the label “brain surgeon.” It evoked silly images of Jethro Bodine, bearer of a sixth-grade education.

(18) “Brain surgeon! What do we need a brain surgeon for?” cried the mother. She held Rebecca closer, as if to keep her out of my clutches. This family had no clue – no one had bothered to tell them about the scan.

(19) “Your daughter – Rebecca, is it? – her scan shows a growth, a growth in her brain. That’s why she’s been spitting up all the time.” “Growth” is a good word, much better than “tumor,” or “cancer.”

(20) Dad ground his cigarette under the heel of a weathered boot. “What sort of growth?”  
“A lump, growing in the back of the brain – here,” I explained, touching the velvety nape of Rebecca’s tiny neck, “about the size of a grape.”

Foods are the traditional yardstick for tumors anywhere in the body. “A tumor the size of” a grape, walnut, egg, melon, orange. Although a macabre practice, food comparisons allow a visceral feel for prognosis – someone with a cancerous cantaloupe in their chest isn’t going to live as long as someone with a cancerous pea. Although a “grape-sized” brain tumor doesn’t seem threatening, it’s plenty big enough to kill an infant.

(21) “It may be benign,” I went on, “something we could successfully remove, or it might be something that we... uh, we can’t remove completely.” I can’t bring myself to use the word “malignant.” At least not during the initial confrontation with patients or their parents. People faint from hearing such words. My calm assurances were deceitful. I knew that infants almost never have benign brain tumors.

(22) I coaxed Mrs. Hobson into telling me her baby’s brief history. Born after an uneventful pregnancy, Rebecca was fine for about a week before her vomiting began. A clinic pediatrician in their home state advised changing formulas, thinking the child was developing a food intolerance. This strategy worked for one or two days, but the vomiting soon resumed.

(23) After one month of life, Rebecca weighed less than she did at birth. Her head grew large as her body withered. Since Rebecca’s father was unemployed and without health care coverage, they avoided further medical care and tried to correct the problem themselves, feeding the infant herbal teas, whiskey and water, orange drink, ginger ale – anything they thought she might hold down. Nothing worked. When Rebecca grew stuporous from dehydration, the parents finally agreed to come to us for help.

(24) After examining the baby, I mumbled some additional words of encouragement to her shaking parents and left the room to call Dr. Wilson, the attending neurosurgeon on the case.

“It’s the cerebellar mass, lateral, enhancing, about two centimeters,” I told Dr. Wilson over the phone, holding the scan films over my head to illuminate them with the ceiling lights. “Big-time hydrocephalus, huge vents, sunsetting, the works. She’ll need to be done soon.”

(25) “Yeah, sounds like it,” he replied. I could hear him shuffling through some papers. “I have to give a deposition tomorrow, so put her on for Wednesday. We may need the microscope, maybe not...and schedule some brain-stem evoked potentials. How old is she?... Six weeks? Not good, not good. Must be a PNET. PNET stood for primitive neuroectodermal tumor, a tumor of the embryonic tissue which gives rise to the neurons, or nerve cells, of the brain.

(26) I returned to the cast room. Rebecca was crying: not the penetrating wail of a healthy baby, but the weak, catlike meowing of a brain-impaired newborn. Her mother’s eyes were puffy and red as well. Her quaking fingers fumbled to replace Rebecca’s now discarded binky. She must have spent most of the last six weeks trying to settle her starving baby in this way, and the strain of her sleeplessness was palpable.

(27) “I’ll take you up to the neuro floor. Dr. Wilson will be your staff surgeon and he’ll talk with you later. We don’t plan to do with anything more today, other than give her IV fluids and some steroid medication to make her feel better.”

I glanced at my watch: lunchtime. There wasn’t much more I could, or would, tell them at that time. I left them there, alone. Two adolescent parents and their dying child.

(28) *The goals of Rebecca’s surgery* were to relieve her hydrocephalus by removing the obstructing tumor and to confirm the diagnosis of brain cancer. If the hydrocephalus persisted after tumor removal, a permanent shunt would be necessary. The shunt consisted of a thin

plastic tube, inserted just beneath the skin, to redirect excess CSF to the abdominal cavity.

(29) Surgery on an infant brain can be a nightmarish affair. While the adult brain is soft as warm gelatin, the infant brain is even softer. What little rigidity the brain has derives from the tough insulating fat known as myelin. Myelin first appears during the third or fourth month of life, and continues forming until the nervous system reaches full maturity at age twenty-five. A neuroanatomy professor once lamented to me that twenty-one was too young an age to vote, given that the brain wasn't even "done" yet.

(30) At six weeks of age, the unmyelinated brain is thick soup which can be inadvertently vacuumed away by operative suctions. Moreover, nerves the thickness of pencil lead in adults are little more than a spider's web in a baby.

(31) Infant surgery poses other problems. The loss of a thimbleful of blood, not enough to make a decent stain on gauze sponge, sends an infant into shock. Worse still, infants are prone to fatal hypothermia. The operating room must be kept very warm. Even the IV fluids must be at the proper temperature to avoid cooling the infant excessively. The exquisite difficulties of infant surgery have a Darwinian explanation: nature doesn't want sick babies to have surgery, but to be buried. Civilization no longer cares about survival of the fittest, however. We want all our babies to live.

(32) Dr. Wilson and I took Rebecca to the operating room on Wednesday, as planned. After she was anesthetized and a breathing tube was inserted into her throat, she was wrapped in foil to retain her body heat. These foil wraps gave us our affectionate nickname for sick infants: hoagies.

(33) Since her tumor was in the rear portion of her brain, we flipped Rebecca into the prone position, with her face resting on a padded "horseshoe" head holder. In adults, we would use a pin-and-clamp head holder known as the Mayfield device to suspend the head in midair. The horseshoe, on the other hand, is just a modified pillow. In long operations, pressure from the horseshoe breaks down the skin, causing blisters, pressure sores, even permanent facial scarring. The thin infant skull cannot support the Mayfield clamp, however, making the risks of the horseshoe unavoidable.

(34) Skin ulceration during prolonged operations is just one example of how anesthesia differs from sleep. During sleep, we change positions every hour, protecting each body area from prolonged pressure. When injured by a contorted position, a limb becomes painful and numb, forcing us to move or even awaken. During brain operations, such sudden movements could cause the surgeon to slip, with devastating results. For safety, the patient must be kept absolutely motionless for hours.

(35) For long operations, we position patients with extreme care, filling the eyes with ointment, padding nerves, covering intravenous tubes with soft foam.

After the baby was positioned to our satisfaction, I began shaving her downy hair, using a straight razor. This resident's job took as much skill as the surgery itself. Rebecca's scalp was just a few millimeters thick – a careless swipe and the blade could cut to the bone.

(36) Dr. Wilson counted any nicks made during shaving. He charged us a quarter a nick, paid as one lump sum into the resident's research fund at the end of our rotation. Rebecca's head shave cost me a dollar, but I made no major razor blunders.

We would be working near Rebecca's brain stem, the upper part of her spinal cord. The brain stem, the brain's chief switchboard, is easily damaged. To monitor its function during surgery, we would use Rebecca's sense of hearing.

(37) Sounds are transmitted from the hearing nerves into the brain via the brain stem. Thus, hearing can be used as a barometer of brain stem injury. Of course, infants, anesthetized or awake, cannot tell the surgeon whether they can hear, so hearing must be checked electronically.

(38) To do this, small earphones emitting sharp clicking noises are taped to the patient's

ears. Sound transmitted from the ear into the brain stem travel upward into the cerebrum, the “thinking” part of the brain. By attaching electrodes to the scalp overlying the hearing regions of the cerebrum, neurophysiologists can detect the subtle brain waves that occur when signals carrying the clicks arrive in our consciousness – even if we are asleep or anesthetized. Using an operating room computer, the neurophysiologist calculates the time interval for the clicking noise to go from ear to cerebrum. Too long a transit time means that surgical injury has occurred to the brain stem or auditory nerves.

(39) Our neurophysiologist for the day was Bob, a small, bearded man with a Ph.D. in electrical engineering, as well as an MD – and a ponytail. He looked like he’d just walked out of the 1960s. During the surgery he sat on his stool, gazing at a fluorescent computer screen filled with white waveforms. His warnings would give us time to adjust anything that might be injuring the brain stem before the injury became permanent.

(40) We retired to the scrub sink as Bob finished sewing his electrodes into Rebecca’s scalp and placing earphones into her small ears. We lathered our arms and hands in silence. I gazed through the OR window at the surgical tech as she painted Rebecca’s misshapen head with the gooey orange Betadine. Only weeks into my rotation on this service and I already hated pediatric neurosurgery. Before each case, my mind conjured up laughing babies cuddled by their kindly grandfathers. Everybody’s little bundles of joy. None of them belonged here.

(41) Fifteen minutes later, Dr. Wilson sank his number 15 knife blade into Rebecca’s scalp. The room filled with the high-pitched wailing of the suctions. As he opened a four-inch incision down the midline of Rebecca’s head, I quickly placed plastic clips over the skin edges to halt the oozing. An electric knife stripped the neck muscles away from the underlying skull and cervical vertebrae. The muscle sizzled from the heat, flooding the room with the acrid smell of burning human flesh, an odor that has caused more than a few medical students to swoon. With the bone exposed, a steel Weitlaner clamp spread the wound open.

(42) We drilled small holes into Rebecca’s thin skull and used heavy scissors to open a bony window into the cerebellar region. The glistening white dura mater pulsated through the skull defect we had fashioned.

(43) Before incising the dura and exposing the cerebellum, we drilled another small hole just slightly higher than our bone window and inserted in a temporary drainage tube into the distended spinal-fluid sacs. Clear fluid spurting from the tube under pressure as I passed it into the brain. We were finally ready to expose the brain. We paused as the circulating nurse put on our loupes, custom-made eyeglasses with telescopic lenses that provide a threefold magnification of vision.

(44) Dr. Wilson grasped the dura with a long forceps and nicked it with a pointed knife until the pinkish cerebellar surface peeked through. We enlarged the dural opening with fine tipped scissors, stopping intermittently to place silver clips across small venous channels.

“Evoked potentials have improved,” Bob said softly from behind the wires that engulfed him like technicolor linguini. By letting off CFS with the drainage tube, we had relieved some of the existing pressure on Rebecca’s brain stem. This improvement was to be short-lived.

(45) Rebecca’s tumor showed itself as we peeled the dura away from the left side of her cerebellum. Firmer than the surrounding brain tissue, the mass was a darker pink, almost purple in areas. The dura stuck to it, and tiny rivulets of blood began streaming from the tumor’s raw surface as we stripped the dura away using a metal dissector.

(46) “Cottonoids up, please.” The scrub nurse brought up a gleaming steel basin full of white cotton squares of various sizes. To each square was attached a long green string. These cottonoid patties stopped our suctions from plunging into the soft brain, like snow shoes which keep feet from sinking into snow. The strings allowed the patties to be identified and removed before the case ended.

(47) Dr. Wilson encircled the tumor with half-inch patties, holding the cottonoids with a

forceps in his right hand while using a suction tip in his left hand to push the cotton squares between the tumor and the normal brain. He began developing the “plane” between tumor and cerebellum. In benign tumors, a clear plane exists and the tumor can often be popped out using this encircling technique.

(48) In malignant tumors, however, the cancer invades deeply into normal tissue, obscuring the plane between tumor and brain. Such was the case here. As we tried to separate the tumor away from the brain, the purplish lump disintegrated and the bleeding increased. A small piece of the friable mass was handed off to the circulating nurse in a small plastic cup for a “frozen section.” The pathologist would freeze the tumor and examine it under a microscope to assess malignancy.

(49) The patties were now soaked with blood and the wound swam in the growing ooze. We aspirated the tumor with our suctions in the vain hope that removing it would slow the hemorrhage. Unfortunately, this maneuver only created a deeper hole from which the red blood continued to pour. I glanced at the heart monitor. Rebecca’s heart rate climbed steadily, a sign of her persistent blood loss.

(50) The nurse-anesthetist called for the anesthesiologist to return to the room.

“Trouble?” Doctor Wilson asked.

“Her pressure’s dropping a bit.”

“Do we have blood in the room?”

“No.”

“Get some,” he said sternly while shoving a large ball of cotton wadding into the bleeding brain wound, “and start warming it.” The bleeding was getting ahead of us.

(51) “Evoked potentials, two milliseconds out on the left,” chimed Bob. The hearing impulses from the left ear were taking longer to reach the upper brain regions, the first warning of brain injury.

The surgeon shook his head. “Shit.”

(52) Although the large packing slowed the bleeding, the pressure on the brain stem was unacceptable. If we took out the packing Rebecca might bleed to death; leave it in and the brain stem might be damaged, causing permanent deafness or paralysis.

“Fuck the evoked potentials. I’m leaving this pack in for a while, until they get some blood into her,” Dr. Wilson whispered to me. Several minutes went by.

“Where’s my blood?” Dr. Wilson grew restless.

(53) “Potentials out four milliseconds on the left and the waveform is flattening,” intoned Bob, a voice of doom in the corner, “and the right is now out one millisecond.” The brain stem cried to Bob’s computers, pleading for relief. Dr. Wilson sighed and pulled the cotton wadding from the hole. The bleeding resumed, but more slowly. I grasped the bipolar coagulator, a long forceps hooked to a battery pack which is used to coagulate small blood vessels with heat, and attacked those bleeding arteries I could identify in the soupy tumor bed.

(54) The OR door swung open and a small, squat man dressed in white paper coveralls entered the room. The pathologist.

Dr. Wilson greeted him. “What do you have for me?”

“It’s pleomorphic, highly cellular, aggressive... a PNET, most likely.”

“Yeah, that’s what we thought.”

“Looks like you’re up to your ass in alligators!” The pathologist’s grin shone clearly from beneath his surgical mask as he glanced at the tangled mass of cottonoid strings spewing from the bloody cranial wound.

(55) “It’s a wet son of bitch, all right,” replied Dr. Wilson as he turned back to the wound, “but we’ll manage.”

“I’m sure you will, John,” the pathologist said over his shoulder as he headed for the door, “but cases like these remind me of why I only deal with dead people.”

(56) We fell into a silent routine, sucking away bits of the tumor, stopping the bleeding, then removing more tumor. The gutted cerebellum collapsed on itself. I held it away with thin copper “brain ribbons” as Dr. Wilson chased the tumor further and further into the depths of Rebecca’s head. Downward into disaster.

(57) Rebecca had a cancerous brain tumor. The standard methods of dealing with cancer, radiation and chemotherapy, cannot be used in infants. Radiation therapy would destroy the developing brain cells and guarantee that Rebecca would be vegetative before she reached one year of age. The single weapon we could fire at this tumor was our surgery. Removing as much tumor as we could was her only, albeit slim and very risky, chance of meaningful survival. Rebecca became hypotensive and hypothermic, her heart flipped in and out of ventricular tachycardia (one step removed from full cardiac arrest), and yet we pressed on.

(58) “Oh, damn!” Dr. Wilson finally exclaimed as he halted the tumor resection. I peered into the hole left vacant by the excised tumor. At the bottom, spinal fluid welled up and diaphanous strands of severed nerves floated in the watery pool like miniscule bits of white seaweed. He had gone completely through the cerebellum and into the space surrounding the brain stem, where vital cranial nerves exit on their way to the ears, face, and throat. Some of the nerves were destroyed, meaning that Rebecca might not hear, swallow, or breathe after surgery. The aggressive tumor resection was a gamble which we had lost.

(59) The left evoked potentials are out completely,” Bob said, his computers verifying the damage we could see with our eyes. The hearing nerve was transected on the left side.

(60) Dr. Wilson put a cotton ball into the tumor bed and squinted at the CET scan hanging on a view box across the room, trying to compose himself. He was motionless for a long time. I have since come to know the agony of those minutes which follow hurting someone badly in the operating room. In those moments, the fear of confronting the family, the panicked thoughts of changing careers, visions of lawyers – all dance through the mind in a flash.

(61) “Surgicel.” He finally stirred and called for the fine cellulose mesh used to fill the tumor bed. Done. Tumor remained in the cerebellum, but Wilson had lost his stomach for this case. With an incompletely resected PNET and several damaged cranial nerves, Rebecca was officially unsalvageable. Outside the OR, in a smoke-filled room, Rebecca’s parents and grandparents waited for good news that would never come. There would be no prom for Rebecca. We packed the brain with wads of surgicel and sutured the dura closed without speaking another word.

(62) *We took Rebecca* to the recovery room still asleep and on a ventilator. She made a few decerebrate movements with her arms and confirmed our worst fear: we had damaged the stem. Decerebration, a rigid posture of the limbs, indicates a living, but dysfunctional, brain stem.

(63) We called the family into a more private conference room, away from the crowded OR waiting area. I sat in a corner of the room as Dr. Wilson explained the situation to Rebecca’s parents and maternal grandparents. Unlike television, where people take bad news with explosive histrionics, such news in real life produces only a shocked silence. Families erect a shield of denial almost immediately.

(64) “Rebecca has a deadly form of brain cancer called primitive neuroectodermal tumor,” the neurosurgeon calmly explained, “a name I know you won’t remember. Bottom line? It cannot be totally removed and we have no further treatments we can give her because she is a baby.”

“How does a baby get cancer?” asked her grandmother with an almost cynical tone.

“They’re born with it,” Dr. Wilson continued. “Cancer is not uncommon in infants and children.”

“Will she be a retard?” said the mother. “Can she go to a normal school like other children?”

(65) The grandparents shifted uncomfortably in their seats. Although uneducated, they grasped the reality of the situation far better than their daughter. Dr. Wilson leaned close to Mrs. Hobson’s face and placed his hand on her arm.

“Janet,” he said in a soft but firm tone as he gazed directly into her eyes and prepared to drop the bomb. “Rebecca is not going to school. Rebecca is not going to have a first birthday party. Rebecca is not leaving this hospital. Rebecca is going to die. Probably very soon.”

(66) “No, no, you’re wrong, she’s a strong little girl. I know. She kicked like a mule in my stomach...” She started to cry harder and put her head down on the room’s circular conference table. “...She has such pretty blue eyes...Momma, tell me my little girl won’t die.”

(67) Rebecca’s father sat in the corner opposite to me. He was hunched over, elbows on knees, smoke trailing from a cigarette in his left hand. He looked down at the floor and never spoke. The room fell into an eerie silence broken only by the occasional soft sobs of Rebecca’s mother.

(68) “We’ll talk more later.” Dr. Wilson bolted up and started to exit the room, with me close behind. The grandfather followed me out the door while the grandmother stayed behind to comfort her daughter.

“Doc, can I talk with you?”

We closed the conference room door and moved out of earshot down the hall.

(69) “How long does she have?”

“That’s difficult to say... A few months...,” replied Dr. Wilson. “She isn’t fully awake yet from surgery, but I’m afraid she may be badly hurt. There is a chance she might have some paralysis or that she might not wake up at all.”

(70) “Can we take her home? This is such a long drive and the poor kids don’t even have their own car.”

“I don’t think she’ll ever be able to go home. We might transfer her to a hospital in your own state, but since she’s on medical assistance now and we began treating her here, they may not pay to take her back. Sounds cruel, I know, but she may be stuck here until she dies.”

(71) The old man lowered his head to hide the tears welling in his eyes. “What should we do?”

“Janet may not have formed a truly strong attachment to her child yet. Your daughter is young, she has a lot of time to forget and have another child. My suggestion is that you go home. If you don’t come back, we’ll understand.”

“Don’t come back?”

“This baby has no future. Why watch her suffer and die? Go home.”

(72) *Rebecca eventually did awaken*, but was virtually quadriplegic, with only weak movements of her arms and no movements in her legs. Her swallowing was impaired. She gagged and choked during feeding. Over the ensuing weeks, we inserted a tracheostomy in her neck, a permanent feeding tube into her stomach, and a shunt into her brain.

(73) While Rebecca’s mother visited her occasionally, she could never hold her, never feed her. She couldn’t bear to watch as the nurses snaked thin tubes into her baby’s tracheostomy to suction away the infant formula overflowing into her lungs. Because the tracheostomy entered below the vocal cords, Rebecca could make no sounds. Her gaping mouth cried in ghostly silence.

(74) Finally, the family heeded Dr. Wilson’s advice. One day Rebecca’s mother stopped coming. Rebecca became the ward of the fifth-floor neuro team. Nurses rotated frequently, to avoid feeling too motherly to the child with no future. Even Dr. Wilson quit making regular



rounds on her. She was fed, bathed, and turned. She was given a radio and the ubiquitous Sesame Street mobile to be hung over her crib. (75) Her life became a routine of detached custodial care. She was now a drift in the world, cut free of permanent human bonds, kept at arm's length by those afraid to see children linger. Yet, for some strange reason, I still visited her every day.

Rebecca Hobson responded to the world that had greeted her with an immediate death sentence. She refused to die. At least for a good deal longer than anyone believed possible.

**(76) Months passed.** Rebecca developed a round face, dimples, and a full head of curly hair. She smiled and made feeble swats at her mobile. Though she still could not swallow well enough to be free of the feeding tube, nor breathe well enough to be rid of a ventilator, she became a person. The scrawny infant that had frightened me in the ER grew to be a beautiful baby.

(77) Rounds became playtime. I shook a rattle or her stuffed rabbit, the sole gift from her mother, as I listened to the litany of blood work and vital signs registered for the day. I harbored a nagging worry that Rebecca wasn't going to die fast enough, that she was going to grow to be several years old and fully aware of the world before she had to leave it.

(78) Ethicists and cost cutters argue that placing a pillow over her tracheostomy would be the best thing we could do for Rebecca – and for society. Rebecca's hospital costs now topped half a million dollars, a steep price to pay for a baby with a terminal disease. Her death would be brutal, most likely from pneumonia. The ethicists and cost cutters might change their minds, however, if they saw Rebecca. Although imprisoned in a hospital bed, she did not look like she longed for death as she grinned at her rabbit.

(79) Even after I left Children's Hospital to return to the adult service, I would sneak back on my rare quiet nights on call to check on Rebecca. She lasted nine months, a year. She began mouthing words and spending time in a little swinging chair, rocking back and forth with blue plastic oxygen hoses swaying at her side. Her mobile grew faded and worn, her stuffed rabbit stained with pureed food. Her family, although informed of her progress, did not waver in their decision to treat her as already dead.

**(80) After my pediatrics rotation was over,** I was assigned to the VA hospital for six months and lost track of Rebecca, who is now nearing eighteen months of age. One evening, as I was having dinner in the hospital cafeteria, I spied Eric, the current chief resident at Children's. I asked him if Rebecca was still the same.

(81) "No, she's finally started to crump. We think her tumor is recurring."

"Have you scanned her?"

"Why the hell would we do that? Are we going to operate on her again?"

He was right. This terminal slide was what we had all been waiting for since her first operation. Still, the news disappointed me.

(82) I was going to head home, but I instead wandered down to the fifth floor to see Rebecca again. I hadn't seen her for the past six months and was curious to see how she looked, what she could do.

It was evening when I arrived. The floor was quiet. I waved at some familiar faces at the nurses' station and walked quietly down to Rebecca's room at the far end of the hall. I stopped and looked in the window before entering the room.

(83) The mobile was gone and the radio had been replaced by a television set with the volume turned down. The set flickered silent images of a *MASH* episode. The ventilator clicked and hissed a slow rhythm.

Rebecca blankly stared at the screen, her face paler and thinner than I remembered, her lids heavy. Dark circles underlined her sunken eyes, which were beginning to deviate

downward again. The left corner of her mouth drooped from increasing facial paralysis, the dimples victim to her resurrected malignancy.

(84) I stepped in front of the bed and peered down at the tiny face, which looked back at me. She paused, then broke into a crooked grin. Her eyes widened and she gleefully twisted her head and struggled to lift her paralyzed arms to embrace me, happy to see one of her few friends.

(85) That moment remains clear and frozen in my mind to the day, more than any other moment in my clinical experience. Although in the years that followed I would take care of thousands of patients, marry, and have two daughters of my own, I may never be as important to anyone as I was to Rebecca that night. As I had gone about my own life, I remained special to this pathetic child imprisoned in her hospital crib.

(86) I spent a long time with Rebecca and her rabbit that night. Ten days later she died. The rabbit was buried with her.

*The nurses called me* to the neuro floor a month after Rebecca's death. Her family had sent a gift to the floor and they wanted me to see it: a porcelain statue of a laughing girl. At the base of the figurine sat a small brass plaque, inscribed with the words "In memory of Rebecca."

(87) I am not particularly religious. In fact, the birth of children bearing cancers I find difficult to reconcile with a merciful God. Nevertheless, there must be someplace where Rebecca now laughs in the bright sunshine, finally free of her ventilator and gastrostomy.

My façade of surgical psychopathy cracking to pieces, I left the floor and walked away from Children's Hospital.

Never to return.

Photos of babies with hydrocephaly:

<http://cricketcriscione.theworldrace.org/blogphotos/theworldrace/cricketcriscione/43940147.jpg>

<http://www.eyepathologist.com/disease.asp?IDNUM=352950>

[http://upload.wikimedia.org/wikipedia/commons/thumb/6/6e/Hutchinson-Gilford\\_Progeria\\_Syndrome.png/743px-Hutchinson-Gilford\\_Progeria\\_Syndrome.png](http://upload.wikimedia.org/wikipedia/commons/thumb/6/6e/Hutchinson-Gilford_Progeria_Syndrome.png/743px-Hutchinson-Gilford_Progeria_Syndrome.png)

Fourth ventricle:

[http://www.medical-look.com/human\\_anatomy/organs/Ventricles\\_of\\_the\\_brain.html](http://www.medical-look.com/human_anatomy/organs/Ventricles_of_the_brain.html)