Frogheart

Shireen Campbell

Rough Rhymes for Tough Times
Or
Jonathan Gets His Heart Fixed

Edith Rylander

Jonathan Campbell
Could not yet gambol,
But could smile and wiggle,
And was learning to giggle.
He delighted his uncles and aunts
Whenever he had the chance.
And his grandpas and grammas
Thought he was the cat's pajamas,
While Mom and Dad
Doted on the lad.
Apart from the occasional wheeze
He looked healthy as you please.
Then, bang! Came a diagnosis
Of truncus arteriosus.

Said Dr. ———
"I know he looks well,
But, believe me, it's for the best,
If we open up his chest
And patch up his ticker
Before he gets any sicker.
Wednesday morning is the plan,
And Dr. —— is your man."

So before the sunrise
Shireen and Jeremy wiped their eyes,
Hoped for good luck
And carried their baby out to the truck.
He smiled at the nurses, looking very small,
And all those people in uniforms took him off down the hall.

Being a parent is absorbing, being a parent is often great.
But not when your child is in the operating room,
And all you can do is wait.

Then those hours were over, and the word came through,
"Jonathan is in the CVRU,"
And so he was, in his crib, looking nearly invisible,
Under tubes and wires, but alive, and getting well.

His folks are grateful to the doctors and nurses, phlebotomists and
Respiratory therapists.
For the people who brought food and toys and cards, for the long list
Of friends and strangers praying in different ways,
Whose good thoughts carried our hearts through difficult days.

Jonathan Campbell is back in his own abode,
Kicking and smiling, once more the little prince of 2057 Eaton Road,
And the doctors say, "His vascular ring
Don't mean a thing,
And that tracheal malasia
Shouldn't phaze ya,
Hi-tech medicine is our pride and joy,
But now Jonathan just needs to be a little boy,
To play in the morning and laugh in the afternoon,
And we won't have to see him anytime soon."

When Jonathan Paul
Has grown strong and tall
And finds it embarrassing
To talk about that heart thing,
He might enjoy these goofy rhymes
From dangerous times,
Written by Grandma Edie, who knows the heart
Is where miracles start.

A fellow wants to grow up brave and bold,
And not to have had all his adventures when he was three months old,
So let him put the old folks' stories back on the shelf,
And go out and find some excitement for himself.

Three months after he was born, my son was diagnosed with a profound heart defect, truncus arteriosus. In most cases, a child with truncus will die by his or her first birthday if the defect is not surgically corrected. Eight days after the diagnosis, Jonathan had open-heart surgery to lop off a malformed blood vessel, attach a new blood vessel connecting his heart to his pulmonary arteries, and patch a hole between his heart's pumping chambers.

When Jonathan returned home from the hospital, I asked my mother, a poet and essayist, to write something for him and for us. Specifically, I challenged her to write a poem that incorporated the technical terms for his diagnoses. I wanted something fun we could share with the people who had been supportive, something we could give Jonathan when he got older. And, containing the diagnoses in light verse might make them seem less scary and help us end this somber episode. (At that time, I believed we could "end" the story.)

As my mother's poem suggests, Jonathan is "just" a boy who has played in the morning and laughed in the afternoon. He is now nine, with typical nine-year-old pleasures (swimming, playing Wii) and obsessions (all Lego products and fantasy series). He currently sees a pediatric cardiologist once a year, but has had and will need additional open chest surgeries throughout his life, at least for the foreseeable future.

The story that follows explores our family's experiences with the congenital heart defect from diagnosis until the recent past. By writing and releasing our story to the

world, I hope to make ample room for Jonathan to live and write his own stories in the many years to come.

Prologue
The Historical Heart Community

A diagnosis of a serious, potentially life-threatening medical condition in a child can cause parents to feel suddenly isolated, separate from parents whose families are not threatened. Jonathan's diagnosis came as a great shock to my husband and me, and we felt profoundly alone at times even in the midst of loving families and supportive friends. Yet our family is only one of many families who have a child with a serious congenital heart defect, only one of many more who have had a loved one undergo open heart surgery. In 2001, the year of Jonathan's surgery, approximately six hundred ninety thousand open heart procedures were performed in the United States, including half a million bypass surgeries, eighty two thousand valve replacements, and multiple repairs for other conditions, including congenital defects. More than two thousand people received complete heart transplants.

In the past decade, I have grown to accept our family's place within the substantial congenital heart community. Shared experience with serious medical conditions can transcend a host of differences such as age, class, ethnicity, or location. In the first year or two of parenting, however, I found myself more often looking backward, trying to understand our experience within an historic context. What makes open heart surgery possible? When were open heart surgeries first performed? Who were the pioneers (doctors, patients) of the field? If I could answer these questions, I might be able to understand Jonathan's story as part of a much larger story across time and place its deeply personal meaning to our family in context.

Answering the first question was simple. Open heart surgery became possible and then routine after the development of one device —the cardiopulmonary bypass machine, generally called the heart-lung machine—which oxygenates and circulates blood while the heart is stopped and provides surgeons a clear, unmoving organ on which to operate for extended periods of time. Prior to the 1950s, when heart-lung machines were first used successfully on humans, people with malformed hearts, obstructed arteries, and failing valves died.

Intrigued by the information I found, I kept digging and discovered that the history of the heart lung machine is complex. It includes collaborations between scientists

and industrialists, considerable experimentation with animal subjects, and operations that hooked two people together into one circulatory body. Medical historians even debate who should be given the most credit for inventing the first functional machine. What isn't debatable is the love and desperation that drove parents to submit young children to early open heart surgery, the determination, coupled with ambition, compassion, and curiosity, that drove the pioneers of open heart surgery to their work. The story of our family's experience that I share in the chapters to follow should be understood in this larger context.

Though medical historians disagree about who should be given what credit for the invention of the heart-lung machine, by most accounts, the story begins in October 1930, when Harvard research fellow and physician John Gibbon sat with a patient who had developed a huge pulmonary clot after routine gallbladder removal. As he recorded her fading vitals through the night, Gibbon kept thinking how her condition "could surely be improved" "if only he had some machine to remove carbon dioxide from her blood and oxygenate it for her. Subsequently, Gibbon and his research assistant Mary (who later became his wife) began work on the first heart-lung machine. They designed a rotating cylinder over which blood would run, then descend. Through this movement, the blood lost carbon dioxide and gained oxygen.

Once developed, the device seemed to function correctly, and the Gibbons needed to try it on living bodies. With no supply of animals for medical testing, the Gibbons would go out into the Boston night to catch stray cats. By 1937, Gibbon had used the machine to perform the work of a cat's heart and lungs temporarily. Most of his test animals died from blood clots and blood-foreign surface interactions. He continued to test the machine on animals, and the clotting complication lessened thanks to heparin, an anticoagulant that prevents blood clots, which became available in a safe and relatively inexpensive form in the later 1930s. In 1939, Gibbon reported to the American Association of Thoracic Surgery that he had achieved total cardio-pulmonary bypass on multiple cats that withstood the procedure in good health. In 1941, Gibbon's oxygenator had become big enough to test on large dogs.

Gibbon's research stalled when he enlisted during World War Two. Upon his return to civilian life, Gibbon was appointed Professor of Surgery and Director of Surgical Research at Jefferson Medical College in Philadelphia. One of his medical students was engaged to a woman whose

family knew Thomas Watson, the chairman of IBM. Having read Gibbon's publications, Watson wanted to support the heart-lung machine research. In 1946, Gibbon and Watson met to discuss the possibilities. Gibbon agreed to accept support, though he stipulated that money could be made by neither party. A team of IBM engineers helped Gibbon design a machine that reduced blood clotting, kept air out of the circulatory system, and maintained constant blood flow. This complex new machine dramatically improved mortality rates in experimental dogs, from 80% down to 10%.

Yet early attempts to operate on human hearts with this type of bypass machine failed. While Gibbon and his team were still perfecting their design, University of Minnesota surgeon Clarence Dennis worked with blueprints he had obtained from Gibbon to design and modify a similar heart-lung machine. In April 1951, a UM team attempted to use the Gibbon-inspired machine on a dying six-year-old girl. Once they opened her heart, they realized that she had been misdiagnosed, and they were unable to save her. (At mid-century, doctors had no reliable diagnostic methods of confirming heart defects, such as the echocardiogram. Early attempts at open heart surgery were often doomed because of misdiagnosis.) On May 31, the University of Minnesota tried again, this time on a two-year-old girl. Her diagnosis had been correct, and Dennis and his team closed her atrial septal defect (ASD). Yet after the closure, one of the people running the machine made a horrible mistake and pumped her full of air, killing her.

The next year, back in Philadelphia, Gibbon was ready to test his heart-lung machine. His first patient, a fifteen-month old girl, did not survive surgery, primarily because she had been misdiagnosed. A month later, in March, a fellow physician convinced Gibbon to use the machine and assist in surgery on a desperately ill forty-one-year-old man. The patient's heart, grossly enlarged and weak, stopped during surgery and couldn't be restarted. Twenty years of research had yielded no success.

In addition to blood oxygenation devices, mid-century researchers pursued other strategies to aid open heart surgery, such as the potential benefits of hypothermia. Causing hypothermia in a surgical patient was counter to contemporary medical practice, which held that low body temperatures were lethal. For example, accident victims were warmed after surgery with hot water bottles. But Canadian doctor Bill Bigelow had observed that hibernating animals survived frigid Canadian winters, partially because their metabolisms slowed sufficiently to keep them alive without food for months. Bodies also seemed to need less oxygen at lower temperatures, which might have implications for heart surgery. After four

minutes without oxygen at normal temperature, human brain and body begin deteriorating. If Bigelow could cool a patient's body sufficiently, perhaps a surgeon could interrupt circulation and open the heart to operate quickly without damaging the patient.

Starting in 1947, Bigelow began animal experiments. He and his team discovered that, under specific anesthesia, metabolism fell steadily as the body temperature was lowered. They made their first open-heart attempt on a dog in 1949. Its body temperature was lowered below seventy degrees Fahrenheit, and the circulation stopped for fifteen minutes. Bigelow and an associate then saw a heart beating bloodlessly for the first time. The dog was warmed back up and survived. Over several years, Bigelow operated on over one hundred dogs, anesthetizing them, burying their bodies in ice, and monitoring their vital signs while he opened their chests, and sometimes their hearts. He found no damage to body or brain. Yet once his technique was perfected, Bigelow couldn't attempt it on a human. While the procedure was best suited for the smaller bodies of children, Bigelow was at an adult hospital. Meanwhile, his peer at the children's hospital in Toronto was attempting instead to use monkey lungs as a means of oxygenating blood during surgery.

Bigelow's research did excite others in the field. Building on Bigelow's technique, another University of Minnesota surgeon, John Lewis, operated in September 1952 on a five-year-old girl who had been born with an ASD. Lewis's surgical team chilled the girl's body to 81 degrees F. At this temperature, she could survive without deterioration despite a lack of oxygen to her body for ten minutes. First blocking blood flow to her heart, which emptied of blood, Lewis opened her heart and sewed up the hole between her atria. Then, the surgical team released the clamps on her veins, massaged her heart until it regained a regular beat, and immersed the girl in warm water in a watering trough that had been purchased from the Sears catalog. She went home, cured, eleven days later, and the operation was deemed the first successful open-heart surgery.

All the while, Gibbon persevered despite his initial surgical failures. In May 1953, he operated on a desperately ill eighteen-year-old woman. His pump oxygenator oxygenated and circulated her blood for almost thirty minutes, which allowed Gibbon to stop her heart, repair her ASD, then restart her heart when the repair was finished. A private man, Gibbon told only a few friends about the operation and gave a few interviews. News got out, though, and in May, *Time* featured his work in the Medicine section. According to the reporter, Gibbon was "too camera shy to pose with the apparatus." He did, however, explain that " the machine is not a cure-all for

all heart conditions. It will probably be used chiefly on patients born with a deformed heart.. . . . But now, for the first time, it is possible to look into the heart. It's sort of like drying out a well to do some work at the bottom of it.'"

Comparing the bypass machine to a well pump made it understandable to the public, yet the machine was hardly simple in theory or practice. Two subsequent surgeries Gibbon attempted that summer resulted in death. Both children were desperately ill—one with five defects to the atrial wall, the other with multiple profound cardiac defects—but after these deaths, Gibbon called for a one-year moratorium on all use of his machine. In 1954, two more attempts at the University of Minnesota using a similar machine also resulted in death. Gibbon in fact ceased work on the heart-lung machine altogether and turned to lung cancer research.

Despite the failures thus far, researcher and surgeon Walter Lillehei, who had assisted Lewis at the University of Minnesota with the successful 1952 surgery using induced hypothermia to reduce metabolism, was determined to persevere. Lillehei thought that Gibbon's machine was too complicated, requiring sixteen people for an operation. As a member of one surgical team, he had seen operator error result in death in 1951. While pursuing research with dog lungs, Lillehei and his research team began investigating if one dog could oxygenate and circulate blood for another. Working with a dairy pump that could move fluids in different directions and connecting two dogs with clear beer keg hose, Lillehei damaged the brain of their first animal, but succeeded in connecting the next sixteen test subjects without incident. To ensure that brain damage wasn't occurring, Lillehei then tested cross-circulation on some well-trained and beloved golden retrievers, loaned by a cardiologist friend who himself had heart damage.

By 1954, Lillehei was ready to attempt human cross-circulation. This surgery involved hooking a child's caval veins, which return oxygenated blood to the heart, to a parent's circulatory system. He located a family, the Gliddens, who had lost a twelve-year-old daughter to a ventral septal defect in 1950, and now were losing a new baby to a similar defect. In March, Lillehei and his team closed thirteen-month-old Gregory's VSD, with the baby's anaesthetized father oxygenating blood for them both. Though the surgery was a complete success, Gregory died of pneumonia eleven days later. Determined, Lillehei continued, with another successful surgery and patient who survived in April 1954. In the next two years, he operated on forty-five patients, virtually all infants and toddlers, seventy

percent of whom survived. In total, Lillehei performed over 60 cross circulation surgeries to repair heart defects.

Though cross-circulation worked, many hospitals and physicians balked at the procedure, which could potentially have a 200% failure rate, killing both patient and parent. By the mid 50s, a number of surgical teams started seeing more reliable surgical success with new heart-lung machine models, most notably the bubble oxygenator designed by Richard DeWall. The practice of cross circulation became a medical oddity, the heart-lung machine the norm.

Since the 1950s, the heart-lung machine has evolved considerably and is used world-wide every day. Still, use of this machine carries risks. Clots can form, which then cause strokes, heart attacks, or other organ failure. Sometimes an inflammation forms in reaction to the machine, or patients continue to bleed after surgery and need further repair. Some patients report difficulty with confusion or lost memory.

Today, reliance on the heart lung machine is waning. New technologies have enabled less invasive surgeries, such as robot-assisted surgery, and even continued beating of the heart during surgery. Unfortunately, these options were not Jonathan's, whose initial correction required a chilled body, stopped heart, and external circulation and oxygenation.

During the years in which Gibbon had collaborated with IBM, other medical researchers joined forces with industry giants to build a heart-lung machine. By the late 1940s, a partnership began between Michigan cardiologist Forest Dewey Dodrill and General Motors, whose president Charles Wilson, was also Board Chairman of the Michigan Heart Association. GM agreed to donate a research team from their laboratories to work on this project. It did not seem a stretch to the team members: as one explained in a 1952 GM publication. "We have pumped oil, gasoline, water and other fluids one way or another in our business. It seems only logical we should try to pump blood."

Between 1949 and 1952, the GM team assembled several pumps. Their most well-known version resembled a Cadillac V-12 engine. Separate pumping chambers on each side of the machine even looked like car engine cylinders. By January 1951, the team began testing this machine on dogs from the local pound. Over the next eighteen months, Dodrill performed heart surgery on nearly one hundred animals, eventually reaching a point

where eight consecutive test dogs survived surgery. Finally, in July 1952, Dodrill successfully operated on a forty-one-year-old Polish immigrant with a heart valve defect. Because Dodrill bypassed the patient's heart, but not his lungs, however, the Michigan Heart is not generally credited as being the first successful cardio-pulmonary bypass.

I mention this story because one of its details stays with me. While waiting for his operation, the forty-one-year-old patient spied something surprising from his hospital window: dogs with shaved chests playing on a nearby roof. These animals were the survivors that had helped Dodrill refine his machine. I try to imagine these dogs playing when I consider the hundreds and hundreds of animals, strays or loved family pets, that were killed or brain-damaged during the development of the heart-lung machine. I think often of the parents desperate to save dying children, willing even to attempt cross-circulation, an operation that seems almost as much science fiction as fact. And I cannot forget all the blue ghosts, the infants and children born before the heart-lung machine existed. Their hearts could not sustain their lives.

I would give almost anything to have Jonathan's heart be normal. Yet surely the families of loved ones born before open heart surgery was possible or born in situations where diagnosis or surgery are still not possible, would give anything to be as lucky as we are today. In the story that follows, I explore what this luck, the luck others have died for, has come to mean to me.

Part One
January—April 2001

Chapter One
Bang

"Can't you tell that isn't a space? Are you blind?" I engaged both clutch and brake again. The white Lincoln ahead of us had stopped and idled at the halfway point of three entire parking garage floors before turning left to snail upward another level. Now, it sat, the blue-white head of the driver barely visible above the steering wheel as she pondered whether or not to park in a spot clearly covered with yellow stripes.

"Relax, honey. We have at least ten minutes before his appointment." My husband Jeremy patted my right thigh.

I tensed my quadriceps and shifted left. "We can't be late. These specialists have tight schedules."

"Shireen, we're on time," Jeremy looked over at me, but kept his hand on the truck seat, "and we'll be out of here in an hour."

Sixty minutes later, we wish we were bickering back in the Ford F150. My son Jonathan is struggling as hard as a three-month-old can against the echocardiogram. A technician is attempting to map his heart functions, but Jonathan screams and kicks. The older child being tested in the other half of this small room, divided by a plastic curtain, begins wailing.

"Honey, shh, shh. It's okay." I stroke Jonathan and bend over to hug him, strapped down as he is on the gurney. Electrode goop smears on my chest as my dress rides up in back: Jeremy quickly pulls down the hem. *Who cares if my butt shows right now?* I furrow my brow at him; he furrows back. Dr. Russell, the senior pediatric cardiologist we met for the first time today, comes in. He's short—and I mean short, as in five feet, three inches tall—but commanding.

After glancing at the technician's read-out, he turns to us. "Can't you give him a bottle, quiet him down?"

Jeremy responds: "No, he's nursing, and we didn't think to bring a bottle. "

"Look at that heart rate! We've got to calm him down." He turns back to the technician, and they confer quietly. Jeremy stiffens. We don't look at each other.

Maybe nursing will help. I force my right breast up through my neckline, recline sideways on the gurney, and rub the nipple across the baby's lips. Jeremy starts to hold a green striped receiving blanket around me, but gives up. The technician is busy with her probes and machinery anyway. Jonathan latches on and sucks, shutting out the cold and the noise and the strangers who keep touching him. Now, as he settles, the technician resumes her measurements.

The echocardiogram screen features greens and blues and reds and yellows. Periodically, the technician freezes a frame and measures the distance between two blobs, then moves her probe on Jonathan's chest. Blue gives way to red gives way to blue again. *Is that what a heart looks like in action? Is what I'm looking at good or bad?*

Over the hills and far away

Teletubbies come to play

I snap toward the noise. A video has begun playing on a TV mounted high in the other child's corner. Purple, lime, yellow, and then a smaller red being spring out of a dome.

Time for teletubbies

Time for teletubbies

Oh, that's what they look like! Now the tubbies are introduced, each waving to the camera. *Which one's supposed to be gay?* I can't understand their speech, but watch anyway. It hurts to look at the video slumped sideways, but Jonathan seems hungry.

Another doctor, twenty years younger and even shorter than Dr. Russell, enters, and the technician asks him to look at the screen. He smiles and points. "That's good. That's really god. His valve is fine." He turns to us. "Your son has the best possible version of his defect."

Defect. As in defective. Jeremy and I nod as if we understand. We don't.

Three months earlier, Jonathan had been late, but healthy, on January 9th. Early the next morning, around 2:30 a.m., I remember sitting awkwardly on my adjustable bed, gazing at my son. I was supposed to be nursing him, but had tried without success. (The next morning, a lactation consultant will ask "Do you mind," then grab my breast, shape it into a point, and rub the nipple across Jonathan's lips repeatedly. Under such confident hands, he will latch on and have his first real meal.)

I stared at him, tiny, so alert. He gazed back, and I cried and smiled and snuggled him close. We rested in scented semi-dark—roses from Jeremy, a carnation and miniature rose arrangement in blue baby shoe vase from my in-laws, an open double-decker of Whitman's from a friend. Except for squeaky footsteps and passing med carts, the hall was quiet. *Hi sweetheart. . . I'm your mommy. Do you know me?* At Lamaze we'd learned that newborns know their mothers' voices immediately, familiar from months of muffled conversations. *Will I be a good mommy? Who will you be?* Jonathan's small face suddenly squinched, mouth opening in silent cry. *Sing a lullaby, quick.* I remembered few. "Rock-a-bye baby?" *No, that's dumb—what's a cradle doing in a tree top? And then it all falls down. Why would anyone sing* ***that*** *to a baby?* But he was still squinching.

Why do birds suddenly appear
Every time you are near?
Just like me,
They long to be
Close to you.

My teary croak parodied Karen Carpenter's effortless, doomed voice, but Jonathan's face relaxed and his eyes closed. I continued.

Twenty-five minutes later, when a nurse came to check bleeding and give me a welcome Oxycodone, I was sniffling as I held my sleeping son.

"Are you okay? Have you peed yet?" Her hand pushed firmly on my deflating balloon of a midsection. "Does this hurt?"

"I'm fine, just stiff. Numb tailbone, but I've gone to the bathroom twice.. . . . He's so sweet."

She smiled down at us. "What a pretty little boy."

Time for tubbie bye byes

Time for tubbie bye byes

This announcement sounds from a periscope that protrudes out of the teletubbie dome. At first the tubbies resist the directive.

"All done here." The technician deftly removes electrodes from Jonathan's chest, then wipes off the sticky residue. "You can pull his clothes on and go back to the examining room."

I would rather keep watching the tubbies.

Minutes later, we wait in the small examining room where we started this consultation. I hold Jonathan, now quiet in a red and yellow striped onesie and fleece Pooh pants, in my lap. Jeremy stands, cradling my sweaty, cold right hand, and we stare at the drawing of a heart on the wall. Dr. Russell enters. He leans against the examining table. He looks at us.

"Some children have heart problems that don't require surgery. Sometimes a minor defect requires no care. Other times it requires only regular observation or perhaps medication." He pauses, then speaks even more deliberately. "Your child, however, has a congenital defect that requires immediate open heart surgery and lifelong medical care."

Jeremy gasps, slumps. My right arm wraps around him tight. Silent sobs are shaking his body.

"What is his defect called?" I ask, my voice too high but clear.

"It's called Truncus Arteriosus." Dr. Russell shows us a large laminated picture of a healthy heart, then superimposes a sheet with Jonathan's defect on top of it. He talks us through the specific features of Jonathan's condition. Jeremy regains his voice and begins to ask questions. I stare and nod without grasping details. I do hear the big message. Without surgery, Jonathan would most likely die of congestive heart failure by his first birthday.

When I can focus again on what's being said, Dr. Russell's tone is lighter. "Usually this defect is diagnosed at birth. I'm amazed that your son is in such good condition for three months old. He's grown well, which is excellent news for the surgeon." (I have since learned that our hearts are the size of our fist. A three-month old baby hand balled up is the size of a golf ball or a plum.) "But he is a pale, sweaty baby because his pulmonary system is being increasingly compromised. We need to operate as soon as a suitable homograft can be found and before more damage is done."

As our session finishes, Dr. Russell gives us an American Heart Association Brochure—*If Your Child Has a Congenital Heart Defect*—and dog-ears the pages on Jonathan's "because it's helpful to have this when explaining it to relatives." We exit through the general waiting room, where beige sofas and coordinated chairs hold the cardio-impaired—balding,

white, and gray headed people and their relatives. Jonathan's stroller feels heavy on the thick carpet. No one drives in front of us on the way out of the parking garage, I think.

I manage to call my mother as Jeremy drives us toward home, but break down in the middle of a call to Jonathan's godfather. Hanging up, I gasp and gulp. Jeremy has parked and gone inside a neighborhood pharmacy to fill Jonathan's prescriptions for a diuretic and a heart medication. *How could this be? Did we miss something?* Always sleepy, initially drugged, hormonally wobbly, I remember the routines but few specifics from his early weeks. I was with him almost all the time. Lucky to have a job with flexible scheduling and a partial maternity leave with full salary, I left Jonathan only to teach a Virginia Woolf seminar on Monday afternoons and hold office hours on Thursdays. We took forty-five minute morning walks through the neighborhood, the baby in a snuggly on my chest, our two dogs straining against their leashes. I sat in a worn recliner and positioned him on my bent legs, facing me. I could read, watch him, doze.

And his pediatrician hadn't noted anything wrong at first. At his month check up on February 9th, she asked me if I had any concerns. Jonathan's measurements—height, weight, head size—were all progressing well.

"Not really. . . he's stuffy a lot, but he hasn't run a fever or anything." I held Jonathan, dressed and burritoed in his yellow Carter's blanket, and patted his back.

"I don't hear any respiratory problems," she smiled, stroked his head. "Winter babies are often stuffy. What have you been doing to treat it?" I mentioned suctioning his nose and running a vaporizer. If he seemed really congested, she suggested that we could also elevate the head of his cradle.

We had been cautious parents, never leaving him with a sitter, staying home for the first five weeks. He was so little, my tailbone so sore, that even a brief car trip seemed beyond us. Finally, in mid-February, we spent a long weekend with Jeremy's family in Charleston. Jonathan needed to meet his great-grandparents, we agreed, and Jeremy hoped to persuade me to go out for dinner without the baby. On Saturday, I said I'd try.

As Jeremy merged onto the freeway about five minutes from his parents' house, I checked my little golden watch (a new Christmas present

that I hadn't yet lost). *7:00 and he'll need to nurse again by 9:15 at the latest. Should we go somewhere closer?* Jeremy sighted my wrist turn and smiled.

"Honey, he'll be okay. My parents raised three kids successfully, well, two if you don't count me."

I smiled at the familiar joke and started a CD. Cold winter rain drizzled us to downtown Charleston. One hour and two sakes later, I was dipping a spider roll in wasabi soy mix, and we'd begun to succeed in talking about something besides the baby. For the first half-hour of our date, we'd gloated about Jonathan, so much so that my milk let down. This sushi bar was dark, though, and I was wearing black. The wet spots dried as we ate. After supper, we walked down damp streets to a local coffee shop for pastry.

We got back to Jeremy's parents at 9:40. Jonathan was sleeping soundly.

Looking back, I guess the first big clue came at Jonathan's two-month check up on March 9th, when Dr. Sherman lingered as she listened to his chest.

"I think I hear a murmur. Yup, there it is." She smiled and told me that many people have heart murmurs and it means nothing. "He's fine. I'm sure he'll be able to play sports and everything. But just to be safe, why don't you come back in a month, and I'll listen to it again?"

Jeremy loves gadgets: I do not. But he had convinced me to get a cell phone about mid-way through the pregnancy "so you can call me in case." I acceded, but my subsequent track record—two lost cell phones in a little over three years—suggested resistance. The moment I left Providence Pediatrics, however, I was dialing his office.

"Hey, Shireen, how was the check up?"

"Bad. . . . Well, I mean, Jonathan's 50th percentile for weight and 75th for height, and he handled his shots fine, that's all good, but Dr. Sherman heard a heart murmur. We have to take him back in a month so she can recheck it."

"Did she seem worried?"

"Well, I don't know." I braked hard to avoid rear-ending a dented hatch back that swerved in front of me, then stopped at the red light. "Watch it, you ass. . . jerk!" Since Jonathan's birth, I'd been trying not to swear in traffic.

"Huh?"

"Sorry, somebody just cut in front of us." The light turned green, and I shifted from first to second, tailgating the offender. "Anyway, Dr. Sherman didn't seem worried, but then she's not going to scare parents unless she has to. She did say that heart murmurs are common and often don't limit activity." I heard Jeremy typing. He was probably writing code for some web page even as he talked.

"Well, there you go. That's true. I think my mom might have a murmur, or maybe one of my other relatives."

"Jeremy, this is serious. Can't you call your mom and find out?"

He did so that night. She did not have a murmur, but Jeremy asked around and found a number of mutual acquaintances who either had one or knew someone who did.

Should we have pressed for more testing then? Jeremy did some web surfing and reported that heart murmurs in infants are fairly common. We continued to suction thick yellow mucus out of his nose, but elevating the cradle head did ease his night breathing.

Then, the past distracted me from the present.

A week after Jonathan's two-month check-up, I was at home, trying to finish class prep on Woolf's *The Waves*. It was already after eleven, and I hadn't figured out which student reading journal entries to use in discussion. The phone rang. I stared at it, unmoving. It rang again. *Damn— I've got to get ready for class, but Jeremy will be pissed if I don't pick up.*

"Hello?"

"Hi Sweetie, how are you?" It wasn't Jeremy, but an old friend, Evan. I love catching up with him, but our phone conversations always surpass sixty minutes.

"Hi, Evan! I'm fine, just trying to get ready for class this afternoon."

"Honey, I've got some bad news." He paused, inhaled, exhaled Camel Light. "Um. . . have you heard anything about Ron lately?"

Ron? Ron was my ex-husband, and we hadn't spoken for over five years. I knew that Ron's business had gone under a couple of years after the divorce. Once, a process server looking for him had come to my house in Charlotte, but I had neither current address nor phone number.

"No, what about him?"

"Well. . . he's got cancer. He's in hospice."

"What! What kind?" Jonathan began crying from his nap basket in the corner. "Hang on, Evan, I have to get the baby." I scooped him up, sniffed his bottom, and returned to the phone. "He's in hospice? That means he's dying."

Evan confirmed this. The cancer was widespread: lungs, liver, brain. Ron had little time, maybe a week, maybe two.

"I just found out myself from Robbie," Evan explained. (Robbie was Ron's former business partner.) "I asked him if he'd told you, and he said no. He figured you wouldn't care, with the new baby and all."

"Wouldn't care!" Jonathan started; I patted him calm.

"That's what I said. 'Jesus Christ, Robbie,' I said, 'She was married to the guy for eight years and with him longer than that. Of course she wants to know.'"

Evan explained that he was going to try to visit Ron; he gave me Robbie's phone number, and we agreed to speak that night. I hung up. Now it was twelve. I had to finish nursing, then drive thirty minutes to school, hand the baby off to Jeremy at his office, and make my class.

In 1984, I had been waiting tables at a diner in Ft. Lauderdale, Florida. Twenty, I was saving money to return to college, frightened by the life possibilities ahead if I didn't finish my degree. Ron was thirty-seven, a well-traveled marine diesel mechanic on the brink of opening his own engine sales and service office. He ordered the same breakfast—the Port, with one scrambled egg, two bacon strips, one slice of wheat toast, coffee—every morning and flirted with me. As someone who varied her large breakfast orders, I admired his dietary consistency and restraint.

Once we started dating, he respected my autonomy (not the strong suit of previous boyfriends). He encouraged me and helped support me financially as I returned to college. We married on New Year's Eve, 1986, after I'd started a doctoral program in English, during which we lived apart for eight months of every year for four years.

One Christmas, he gave me a leather-bound *Encyclopedia Britannica* and Great Books collection.

"Honey," I held up A-Al; the blue leather, gilt-lettered volume was heavy. "I don't know what to say. This is nice, but where did you get the money?"

"I financed it." He spoke quickly. "This will help you with research, won't it?"

I blinked. Ron hated holidays, Christmas especially, and he had made a big effort with this gift. But it wouldn't help me, and we couldn't afford it.

After finishing my doctoral exams, I returned to Florida. I taught classes at a nearby university and wrote my dissertation, while he struggled to keep his business solvent in an increasingly difficult market for high-end sports fishing engines.

Entering the job market in 1992, I looked for positions at schools within the southeastern U.S., where Ron's company held an engine distributorship. When I was hired at a liberal arts college in North Carolina, we thought this was our fresh start. We'd now have two real incomes. Our plan: Ron would commute between North Carolina and Florida for the first year, then relocate with me.

The marriage finally broke late that fall. I called it off, but Ron knew before I spoke. We didn't fight, splitting up our little stuff and substantial debt evenly. Throughout the divorce process, we tried to stay friends, but old tensions and the ghosts of emotion once present interfered, and we lost touch.

Ron had been slated for bad health before we split. Years of heavy smoking, work around diesel fuel and engine paint, and intense sun exposure all taxed him. But now he wasn't ill. He was dying.

Tuesday morning, early, I called my brother Eric. After Eric graduated from high school, he had moved from Minnesota to Florida and worked for Ron's business. Over the years, he had trained as a marine diesel technician, then eventually left Marine Mechanical Systems. One of Ron's many protégés, he needed to know. I told Eric the bad news in a rush.

"I heard." He spoke quietly.

"What?" *How could he have heard? Why hadn't he told me?*

"I ran into a guy at a boat show last November, and he told me Ron was sick. Then I talked to Dad about it and," he paused, "we decided not to tell you because I wasn't sure how good the information was and you were about to have a baby. Dad—we—figured you'd moved on and didn't need this."

"Didn't need this! Eric, he was my husband. We were together for ten years." My reply was so loud that it startled Jonathan, napping in his little basket near my feet.

"I know. But like Dad said, you have a new husband and life. . .."

"Eric, just because I'm remarried doesn't mean I don't care about what happens to Ron." My voice was shaky, and I tried to steel it. "I had a

right to that information. I have a right to say goodbye. You took that from me."

I slammed the phone, then spent the morning holding Jonathan, nursing him, changing him, and crying for Ron—the Ron I knew, the Ron leaving now. He would be stoic, but scared, too, and scared to show his fear. If I could visit, we could remember. But Evan had learned that the frequent flyer plan wouldn't work. Maybe I could drive the ten hours, though that would be tricky with breastfeeding. And I'd have to bring Jonathan even to hospice. Ron never ever wanted children, so would that be too odd, seeing his former wife with her baby? *But he's dying. He's scared. I can help.*

Ron died two days later. According to Robbie, the visit I could not organize would have been too late, for Ron had no longer been lucid.

"And Shireen, he'd lost his hair. He would have hated for you to see that. He was always vain, you know." Turning more serious, Robbie promised me that he'd told Ron what I had asked him to earlier in the week—that I loved him and wanted him to know he was a good man, a man who mattered.

"I don't know if he knew me during my last visit, Pooh Bear, but I told him everything you wanted me to say."

Hearing Ron's old nickname for me brought tears again, and I cut the conversation short. *Did that confusion mean that his end came easy?* I could never know: I didn't see him, didn't help him, didn't say goodbye.

In seminar on the afternoon I learned that Ron was sick, I had fought with a student over the ending of Virginia Woolf's *The Waves*. In the final section, the main narrator, Bernard, is old, a self-described "heavy man with grey hair." His attitude wavers between indifference and despondency, but then he elects to end in defiant hope:

> And in me too the wave rises. It swells; it arches its back. I am aware once more of a new desire, something rising beneath me like a proud horse whose rider first spurs and then pulls him back. What enemy do we now perceive advancing against us. . . It is death. Death is the enemy. It is death against whom I ride with my spear couched and my hair flying back like a young man's. . . . I strike spurs into my horse. Against you I will fling myself, unvanquished and unyielding, O Death!

After Woolf's suicide during World War Two, her husband Leonard selected the closing line as her epitaph. I cry almost every time I read Bernard's final words.

In class that afternoon, one student referenced this passage as particularly poignant. Another class member rejected her point, arguing that Bernard's words reflected Woolf's obsession with death rather than the way "real people think about this stuff." I maintained, sharply, that people do think of death, to say nothing of the fact that literature would "be out of business if we omitted characters thinking about their own mortality."

"It isn't <u>that</u> we die, but <u>how</u> we face it." I looked around as I spoke, hoping that my eyes weren't tearing too noticeably.

"But dead is dead," the student replied.

"Well, that's simplistic," I snapped, pleased to see "good" students frown at him.

Yet as my student had said, dead is dead. Now Ron was dead.

For the next two weeks, I thought of Ron and cried for him. Preoccupied, I worried little about Jonathan until April 9th, the day of the appointment. Dr. Sherman listened intently.

"The murmur's still there. . . and I think it's louder." She pulled down Jonathan's blue fleece shirt—too warm for the weather—and turned to me. "Just to rule out anything serious, Mrs. Campbell, let's check with a specialist. Let me see if I can get you an appointment."

She left the exam room. I held a fussing baby, patting his back in the light, rapid way he liked. He burped, relaxed. A child was shrieking nearby. *A toddler getting shots. At least Jonathan hasn't had any shots today.*

"Good news," Dr. Sherman smiled as she re-entered the room. "The Corman Clinic had a cancellation, so I was able to get Jonathan in tomorrow." Slim, blonde, she bent over the exam table to date and sign a referral.

"They're great—the best in the area. Again, I don't think anything is seriously wrong, but we'll all feel better when we know more about this little one's heart."

Today, we know. Once home from the clinic, we make and receive endless phone calls and visit with Jeremy's two business partners, who bring

us sympathy and ready-to-cook orzo and couscous from a nearby organic grocery. We show them the AHA diagram in *If Your Child has a Congenital Heart Defect*. After they leave, we cry and hold Jonathan. That evening, Jeremy collects information about truncus arteriosus. Preferring ignorance, I cannot look at what he uncovers.

Instead, I look at pictures from our three months with Jonathan.

Shortly after the Charleston trip, a winter storm had hit Charlotte. Because our street crews don't plow, don't even have plows, any accumulation shuts roads down, and any snowstorm means playtime. In the morning after the storm ended, Jeremy and I bundled Jonathan in a fleece one piece, extra pants, coat, red hat, and mittens, then loaded him in our jog stroller and went to explore the white world. We walked to Monroe Road, a four-lane road one block from our house. It was smooth, undriven.

"Whoa." Jeremy slipped a little, but caught himself. A step ahead, I turned to smile, then thudded on the Oakhurst Baptist Church lawn.

"You okay?" Jeremy was trying to hold the stroller, to help me, and to avoid falling himself. Toto, our big black mutt, nosed me.

"Yes, it's soft in the grass." I made a snow angel before getting up. We crept two more cautious blocks down Monroe, then turned right to loop back through our neighborhood. By the Lakeview Apartments pond, ice crisped willows and cloaked the large, usually stinky green dumpsters. We asked a man scraping his windshield with a spatula to take our picture, in which we beam and Jonathan stares. Snow falls diagonally, upper left to lower right, and loads the glossy green leaves of the large magnolia tree behind us.

My family is big on snapshots. These track our holiday selves and other irregularities, such as when toddler Eric danced in the mud. My in-laws tend toward a more formal visual history through framed studio shots of coifed, well-dressed children. Jeremy and I try to bridge the gap. So, one Saturday near the end of March, we had taken Jonathan to "sit" at a kid's photography store. The adolescent photographer had propped him up against various colored bean bags.

"Jonathan. . . Jonathan! Hi sweetie!"

"Little buddy, look at Daddy!"

He stared at the photographer's bright toys, at our goofy faces. What did he see? How far could he see? None of the five poses was great, but we bought two anyway: one a full-length shot that emphasizes his baby body, the other a head shot in which he gazes at the camera, an earnest Gerber baby with red wisped hair and deep brown eyes, skin pale, slightly

blue around the bridge of his nose. Until his diagnosis today, I had not seen that blue.

Small, but insistent, Jonathan's come-get-me-feed-me cry rouses me into early sunlight. I stretch, then stop. Yesterday returns. Rising, I bring Jonathan from his nursery to our bed. Today, he looks frail: rapid shallow breaths, delicate blue about his lips. Jeremy rests on his side, back to us.

"Honey, are you awake?"

"Yes" –voice muffled and wet. He turns over, and we lie there and cry, the little buddy quiet between us.

Chapter Two
Frogheart

The town where I spent most of my childhood, Grey Eagle, Minnesota, has about three-hundred twenty residents. I graduated in a class of forty from a K-12 school. With limited course offerings, little money, and old equipment, my science education was poor despite our teacher's best efforts. I remember enjoying physics and disliking chemistry, but nothing about biology. This gap, not remediated during my one required college science course, didn't bother me until Jonathan's diagnosis, when I struggled to understand the drawings of hearts—normal or abnormal—that I was shown. Reading reference books, studying medical websites, and trying to write about Jonathan's defect have helped me to an improved, still quite limited, understanding.

Basically, the heart pumps blood to the lungs for oxygenation, then distributes it out to the body. It has four chambers: the top two are called atria, the bottom two ventricles. Four interior valves keep the blood flowing in the right directions. In normal hearts, de-oxygenated blood returns to the heart's right atrium through a network of veins, then travels through the tricuspid valve down to the right ventricle. The right ventricle sends this depleted "blue" blood through the pulmonary valve into the pulmonary trunk, which disperses it through the pulmonary arteries to the lungs. Freshly-oxygenated and now bright red, the blood returns to the heart via the left atrium, then passes through the mitral valve to the left ventricle. From the left ventricle, it flows through the aortic valve into the aorta and out to the body.

Heart defects can be congenital, meaning they formed while the baby was in the womb and are present at birth, or acquired, meaning contracted after birth through specific diseases. According to the American

Heart Association, an estimated nine of every thousand children in the United States (an estimated thirty six thousand yearly) are born with congenital heart defects. What can be wrong? Arteries can originate in the wrong place. The heart can have a hole in the wall between the atria (called an atrial septal defect, or ASD) or between the ventricles (called a ventricle septal defect, or VSD). Blood vessels can be too narrow, valves malformed. Parts of the heart can be underdeveloped, sometimes radically. In complex defects, such as Tetralogy of Fallot or Transposition of the Great Arteries, more than one of these problems exists. Overall, an estimated twenty-five percent of infants who die because of a birth defect have a heart defect.

Jonathan's condition, Truncus Arteriosus, is rare, not even described in books such as *The Parent's Guide to Children's Congenital Heart Defects*. Statistics vary by study. The most recent American Heart Association statistics indicate that 1.3% of children born with congenital heart defects each year have some type of truncus arteriosus. To put this in the context of total births, 4,025,933 children were born in the United States in 2001, according to the National Center for Health Statistics. An estimated 460-475 had truncus arteriosus. What leads to this rare problem? In early fetal development, blood moves from the ventricles to the atria through a single blood vessel—called the truncal vessel. Normally, as the fetus develops in the first eight weeks, a wall forms between the two ventricles and divides this trunk into the aorta and the pulmonary artery. Jonathan's heart didn't undergo this development, however, and he was born with a hole between the two ventricles (a VSD) and an undivided truncal vessel.

According to a friend in the Biology Department, when our news reached my campus, her colleagues conceptualized the defect readily. "Oh," one said, "he has a frog's heart." To someone who had dissected a frog in high school or college biology, this may clarify the defect. When she mentioned this to me, I had no idea what she meant but nodded as if I did. Only recently, as I scanned web pages devoted to frog lab exercises, did I begin to understand.

Unlike humans, frogs have three chambered hearts—one ventricle and two atria. Depleted blood drains into the right atrium; oxygenated

blood drains into the left atrium, after which both atria empty into the ventricle. Small sub-chambers in this ventricle reduce the mixing of the depleted and oxygenated blood. When the ventricle contracts, it sends the fairly well oxygenated blood back to the head and brain, the depleted blood to the lungs and skin. So, in a sense, Jonathan was born with a frog's heart. And for a baby, this is bad. Frogs oxygenate through their skin as well as their lungs. Humans do not.

While he was inside me, Jonathan experienced no difficulty because the placenta re-oxygenized his blood and removed carbon dioxide for him. After birth, however, Jonathan, like all babies with truncus, started having difficulties. Because the large blood vessel is undivided, oxygenated and depleted blood mixed. This results in insufficient oxygen to the body and excessive blood flow through the circulatory system. Often truncus babies struggle for sufficient oxygenation from the beginning, their extremities a tell-tale blue. Once the defect is diagnosed, surgery occurs promptly, in many cases only days after birth. Without surgical correction, truncus babies start showing symptoms of congestive heart failure, including difficult, rapid breathing, problems eating, and increased sweating. If left untreated, they will fail to thrive and 75% die of congestive heart failure by their first birthday.

Jonathan was fortunate: his truncal valve, which is often malformed, was correctly formed and functioning well. (This was what the doctor referred to during that first echocardiogram.) Because the valve was good and newborn pulmonary arteries are strong, he did thrive at first, with good weight gain. The symptoms of his condition came on only gradually. His heart murmur alone was an insufficient indication, though once our pediatrician noticed that it was getting louder, she sent us to a specialist.

Though Jonathan's truncal valve worked well, his blood vessel was still supposed to have become separated into the aorta and pulmonary artery during fetal development, and his ventricles were not supposed to connect. To correct a truncus arteriosus case like Jonathan's, the surgeons must lop off the branch that incorrectly connects the truncus to the pulmonary arteries and graft in a blood vessel to connect from the bottom right region of the heart to the existing pulmonary arteries, which transport deoxygenated blood to the lungs. The remainder of the truncus is patched where the branch was cut off and directed toward the bottom left region of the heart to become the aorta which carries oxygenated blood to the body. The hole between the ventricles gets patched as well.

Through the life of a truncus patient, the graft connecting the right ventricle to the pulmonary arteries must be replaced as it becomes too small

and degrades with time. This requires multiple open chest surgeries (called sternotomies) that are more frequent during childhood and adolescent growth and every ten to fifteen years during adulthood.

I did not understand my colleague's comment about frog hearts at first, but did not want to admit this and instead looked up information on frogs. While looking, I found not only scientific websites devoted to dissection exercises but also commercial sites offering various stuffed and ceramic frogs somehow combined with hearts. I do not know who buys "BRIGHT GREEN FROG WITH HEARTS 11 INCHES TALL," but the range of merchandise suggests considerable public interest in frog collectables. This interest in frogs has deep historic roots. Across eons and cultures, frogs have been symbolically important. Sometimes, the connotations are negative: early Christian church fathers considered frogs as related to the devil or to heretical beliefs. More often, their symbolism is positive and powerful, representing fertility, metamorphosis, even a link between the living and the dead.

Positive connotations show up as well in children's stories. In the fairy tale I remember from childhood, a witch turns a proud prince into a frog. He can become a prince again only when kissed or loved by a beautiful princess. Once returned to human form, he marries the princess, and they live happily ever after. A more recent twist on this plot is offered by Disney's *The Princess and the Frog*. In the movie, a prince named Naveen who hopes to marry for money is transformed into a frog by an evil magician. The frog prince mistakes a girl named Tiana for a princess and convinced her kiss him to break the spell. (Both characters know the classic children's story.) The kiss does not break the spell, but instead turns Tiana into a frog as well. To reverse the spell, the two of them must travel to a good voodoo queen deep in the Louisiana Bayou. In classic Disney style, they make good friends and learn valuable lessons during the journey. After internal transformation and sacrifice, the two marry in frog form; because the marriage technically turns Tiana into a princess, the evil magician's spell is broken, and both return to human form, facing a life of happiness and love.

The frogs of commerce, symbol, and children's story (whether classic or contemporary) seem luckier than frogs in reality. Their populations have been dwindling world-wide for several decades. Some species have disappeared, presumably extinct. At times, research isolates a

specific local cause. But even frog populations in protected habitats are declining. Researchers continue to try and determine what is causing their decline. Meanwhile, fewer frogs are seen or heard.

In this sense, being born with a frog heart is not necessarily lucky for the frog. The few babies born with truncus each year seem unlucky as well. Yet, if such a baby's heart can be made normal or near normal, his or her life extended and improved through medical magic, that child and family are lucky indeed.

Chapter Three
Hours of Lead

Whenever I teach the introductory course to the English major, I often draw on Emily Dickinson's poem, "After Great Pain," to introduce poetic meter. The first line knits meter (the rhythm of stressed and unstressed syllables) to meaning beautifully. The poem begins with a claim: "After great pain, a formal feeling comes." Most lines of this poem follow a regular rhythm of iambic pentameter, the meter most common to poetry in English, in which unstressed and stressed syllables alternate. While the first three words of Dickinson's poem are irregularly stressed (**Af** ter/**great pain**), the rest of the line is regular iambic pentameter (a **for**/mal **feel**/ ing **comes**). The shift from irregularity to regularity parallels Dickinson's claim: a shock is followed by numbness.

In the days between Jonathan's diagnosis and his surgery, I kept thinking about this poem, particularly its last stanza

> This is the Hour of Lead—
> Remembered, if outlived,
> As Freezing persons recollect the Snow—
> First—Chill—then Stupor—then the letting go—

Now, rather than teaching students how the poem's meter worked with its meaning, I felt taught by the poem. Whereas I used to translate the "formal feeling" as numb regularity, I now felt it as relentless, heavy dread, capable of taking me beyond comfort or connection.

The clock reads 6:15 a.m.. Waking up with the diagnosis in mind, I feel too sad to move. But Jonathan's hungry, and I have to stop sobbing in order to nurse well. I help the baby latch on. Jeremy spoons behind Jonathan and puts his arm across us both. Above the baby's industrious head, we stare at each other.

Afterward, I shuffle to the kitchen in my cotton nursing nightie. Jeremy follows, though he actually took time to dress. We fall into normal morning routine. He holds the baby, while I start coffee and get the *Observer* off the lawn. Dogs Toto and Thor pee repeatedly on our bushes.

Jonathan sways in his mechanical swing while we eat cereal, slurp black coffee, read the paper. In the past year, I'd started giving Jeremy the front section each morning, while I took the Living pages. I do this even though some days I want the first section, mostly the front page and the letters to the editor, and even though Jeremy would certainly read another section until I finished. Worse, I sometimes resent giving him the news, but I never say anything. Today, it wouldn't matter what section I pick. I can only figure out one of the four Jumble words: **thigew = weight.**

Abandoning soggy Cheerios, I extract Jonathan from the swing and slump on our already slumped futon. Thor has been rolling on its maroon cover again. We lust for better furniture, but financial baggage from my failed first marriage and our years in graduate school (and out of paying jobs) stints have kept discretionary income below upholstery level. I'm picking off white clumps when tears start, quiet, then wracking. Pressing my nose against the baby's fuzzy head, I inhale him. *Think of nothing. Think of nothing. Breathe.*

Jeremy's suddenly there, hugging us and sobbing.

Minutes later, he pulls away. "Honey, I can't.. . . I can't." He withdraws to the cramped study and sits at our computer. I suspect he hopes that a client has reported a programming or networking glitch he can fix.

Gradually, and as Jonathan wiggles, I become conscious of my own performance of grief. I've been crying since yesterday. Now the sounds embarrass me—too much snorting, too nasally. In made-for-TV movies, moms whose children are imperiled cry attractively. (They also always have tissues or even a handkerchief nearby. I have neither.)

Jonathan's stomach clenches, then releases in diminutive explosion. *Good.* I have something to do. We walk back to his room and consider the options—cloth or disposable diaper, sleeper or daytime clothes. I want to swaddle this suddenly fragile body, but it's supposed to be warm today—high 70s at least. Putting Jonathan on his changing table, I opt for cloth, then select an outfit, a onesie and shorts in white with tiny blue spots. Reading the small mustardy clumps in his soiled diaper, I infer only the known: Jonathan is breast-fed.

His room is ten by twelve, classic spare bedroom size. Obsessive hours watching *A Baby Story* last December exposed me to parents who

spent thousands on original nursery murals or familial quilts; others ordered custom birth-to-college furniture suites. Both broke and intermittently frugal, we instead relied on donations: a carved wooden crib that Jeremy used as a baby, a changing table from friends, a simple wooden rocking chair from my parents. Just before Jonathan's birth, we had painted the room in a goldenrod semi-gloss and installed a wallpaper border in blues, purples, greens, and yellows. Realistic cartoon elephants, giraffes, tigers, gazelles, and toucans march perpetually right around the nursery.

Today, the room glows. Jonathan's striped curtains and animal patterned sheers, which Jeremy's mother made, frame a blue sky.

Pretty day. We should go outside. One of Jonathan's stuffed animals, his big Piglet, has fallen off the shelf, but I can't put it back until I get the baby off the changing table. *So much stuff.*

What would we do with it all?

Unbidden, this question asks itself. The room blurs. *Can't think about this now. Finish and get out.* The question sits, unanswered, resistant, but I push it away and continue dressing him.

Jonathan's passed that baby burrito stage in which he kept arms and legs close, hunkered as he had been in noisy, wet dark for months. He likes to stretch and be tickled. Before snapping the crotch on his onesie, I blow raspberries on his tummy. He smiles and wiggles.

After a family walk, we're home and crying again. It's only 9:05 a.m..

"Jeremy, we've got to do something." I speak toward him but avoid eye contact.

"We aren't supposed to take him around people." Jeremy shrugs and paces two steps across the living room, then turns and paces back to the picture window. He's right. The baby's never had more than a slight cold. The doctor told us that one now could delay surgery or even worse.

"How about a family portrait?" Jeremy blinks. I blow my nose and continue talking. "We could call Janice Miller and see if she'd come over. I mean, the azaleas and dogwood are blooming and it's going to be really nice today."

"Do we want company?" Jeremy gestures at himself and at me.

"We don't have a family picture. . . . I'd like to get one now." This time I do look at Jeremy, which is a mistake. *He hears what I'm not saying, too.*

When Janice arrives, Jonathan's napping, so we chat. A mother of three young ones, Janice took our wedding photos sixteen months ago. She asks about diagnosis and treatment, and Jeremy begins giving the technical info. *She looks at us like it is hard to look. No one wants to be us.*

"Well, they have to repair the hole between the chambers of his heart, which apparently they do with Gortex." We'd fixated on this detail yesterday. Reportedly waterproof, Gortex-lined boots have let me down sometimes on backpacking trips, but its use as heart wall makes the surgery more comprehensible. "The surgeon cuts off the misformed blood vessel and connects a homograft, that's a replacement blood vessel, to connect his heart to his lungs." Jeremy is now pointing to the diagram in *Your Child's Heart Defect.*

Janice nods, pauses, then asks, "Do you have to wait. . . for a donor?"

"No, the homografts are harvested from cadavers and freeze-dried until. . . ."

"You know," I interrupt, "we don't have a family picture. We need to take one in case. . . . " My throat clenches.

"Oh, Shireen." Janice's voice sounds constrained. Jeremy exhales sharply, his breath shifting the dust motes visible in a sunbeam that streaks the floor.

I deliberately finish the sentence: "you know, in case Jonathan doesn't make it."

Whenever I face a difficult situation, I begin by imagining the worst. I wallow in the moment until my self-pity becomes a joke. Sometimes, though, the worst is worse than at others. Sometimes it seems unthinkable. Yet saying what could happen turns the answer into a story. Telling the story lets me control the information. And this morning, telling the story makes me feel a little control over listeners.

While Jonathan dozes, we dress: Jeremy picks a blue blazer, white dress shirt, slacks. I chose a rose sundress with tiny white and black flowers. After the baby wakes up and nurses, we pose over and over and over—in front of huge white azaleas in the front yard, both seated and standing; in front of hot pink azaleas, smaller, in the back yard, from different angles. It's a sun-dappled spring day.

A gifted photographer of the familial, Janice will seem unhappy when she drops the pictures off a few days later. She has been thwarted by

her subjects. In no single image do we all look okay. Swollen eyes, distant gazes, and reddened noses mark our faces. We smile without smiling. Jonathan is alert, but looks limp, his skull bare under translucent skin.

We huddle on the loveseat in the study. Light from one lamp barely illuminates the paneled room, with twilight fading beyond the picture window. Jonathan is deeply asleep in his father's arms: Jeremy's shoulders heave as he cries. His tears have soaked the giraffes and monkeys on the powder-blue receiving blanket covering the baby.

"Jeremy, shh, shh." I stroke his hair, swallow, stop my own sob from welling. "Honey, it's **way** past his bedtime. We have to put him to bed."

"But Dr. Russell said if his catheterization tomorrow has bad results, they could just keep him in the hospital until surgery. I want the little buddy with us. He might not come home . . . . " Jeremy chokes and cannot finish.

He might not come home. We'd sit, quiet, flat, in the house. It would always feel late on a cold wet afternoon.

Stop. Jonathan needs sleep.

"Sweetie," I swallow. "I know. But he needs rest for tomorrow. He can sleep with us if you want." I help Jeremy to rise, walk back to the bedroom, and lie down with our son. I let the dogs out to pee, lock up, brush my teeth, then join my family. Jeremy snores lightly in the dark. Jonathan's breath, a little raspy with phlegm, barely registers above the snoring. I kiss his head lightly. *Please stay with us. Please stay with us if you can.* His rasping continues, and I try to relax, pacing my breaths with Jeremy's snores.

My head rests on Jeremy's shoulder as we stare at Jerry Springer's abusive guests. This Thursday late morning show features "Moms who dress too sexy" and the families they embarrass. The guests and audience all seem loud, fleshly. *But these mothers have kids with good hearts.* I hate them. Two hours earlier, in this room on the pediatric floor of Carolinas Medical Center, Jonathan was sedated. We walked with his roller crib to the catheterization lab, then saw him whisked behind heavy metal swinging doors. After a greasy cafeteria breakfast—scrambled eggs (a little too soft),

crispy hash browns, sausage patties, toast—we returned to his room and now snuggle on a bed that Jonathan is too young to use.

Footsteps. We sit up and shut off the show just as a nurse enters, towing the crib. Unconscious, Jonathan is swaddled in a little hospital blanket.

"He came through just fine." She parks the crib and sets its brakes. "Now, let the floor nurse know when he wakes up and eats."

Jonathan does wake and nurse around eleven thirty. A phlebotomist and Dr. James—the pediatric cardiologist who performed the catheterization—arrive as I am re-buttoning my blouse. Dr. James shakes our hands. Although we have never met him, he has fed a tiny line all the way from Jonathan's femoral artery deeply into his heart.

After introductions, Dr. James explains: "The defect is, as the other tests indicated, simple truncus arteriosus. We also found a fairly common minor malformation, what is known as a vascular ring." Basically, Jonathan has an extra blood vessel growing from his aortic arch, which wraps around and constricts his trachea. "We'll fix that during his surgery. We did confirm that his truncal valve is competent." (Competent, in this case, is good, not faint praise.)

As he talks, the phlebotomist makes her first stick, but the vein collapses before she hits blood. Jonathan jerks out of his milk-belly doze and protests.

Dr. James explains that they are collecting blood now to see if Jonathan has a genetic disorder, DiGeorges Syndrome, that accounts for a little over twenty-five percent of truncus cases and has serious developmental implications. I think Jeremy had mentioned this when he tried to share his research with me.

Jeremy nods knowledgably. "Dr. James, do you think he has DiGeorges?"

"He doesn't display the craniofacial characteristics consistent with such a diagnosis, but you should have the results back in a couple of weeks on that. Any questions?"

Meanwhile, the lab tech has poked Jonathan again, but failed. Jonathan is screaming as loudly as a three-month old with poor blood oxygenation can. Moving to help the phlebotomist, Jeremy holds Jonathan's arm still for another try. Dr. James starts answering a question Jeremy has asked, but the room starts feeling fuzzy. *Gotta get out of here.*

In the hall, I lean against solid, cool wall. A nurse wheels a cart full of bright pills in Dixie cups past me. The slightly squeaky wheels sound familiar. During college, I had been a phlebotomist for a year or so. I began

in the hospital lab as a technical assistant, entering blood work results into a database and sending them through the hospital's pneumatic tube system. Then, I became a blood runner. I can't remember why I wound up switching to this, one in a string of for-the-money jobs. On my first full day, I struggled to draw samples from dozens of nursing school students. You would not know it from my initial bungling, but getting blood from a healthy adult is simple. The feel of the vein, not the appearance, predicted how quickly I'd find blood. Resistant sponginess meant a good vein. A ropey feeling might signal a vein that would roll from the needle. The chronically or acutely ill and junkies were especially tough subjects. Sometimes a syringe in a foot or hand vein could coax blood from the former, but junkie veins ran away: a tough exterior, hard to puncture, hid an elusive rope of blood. Once I had to get a twenty-three-year-old in shackles (he had tried to rob a pharmacy) to draw his own blood. But for me, children were always the worst—newborns pained by the mandatory heel sticks, toddlers with tiny veins and fierce resistance.

"I want to talk to you." Dr. James has followed me out and stands in front of me. Unlike his office counterparts, he is tall. "Why'd you leave? There's going to be a lot more difficult things to see after surgery." He speaks directly down at me.

"I just don't like seeing him stuck repeatedly." I push off the wall, straighten, and inhale. *Get this over with.* "So, I want to be sure I understand. This surgery is the only thing that will save Jonathan's life, but it is also his greatest danger."

Dr. James makes eye contact, looks down, then up again. I think I've surprised him.

"That is correct." He reviews what we've already been told, that Jonathan's odds for surviving surgery are good—approximately nine out of ten. What happens in those ten percent of cases? For one thing, during the corrective surgery, the infant's heart is stopped, and a heart/lung machine takes on the work of heart and lungs. Sometimes, after the repair is complete, the patient's heart won't restart.

As Jonathan's screams stop, we return to the room. The phlebotomist has gotten her sample, and Jeremy cradles Jonathan on his shoulder.

"Dr. Tate, our pediatric surgeon, will meet with you before we send you home," Dr. James explains. He shakes Jeremy's hand again, then leaves. I sit down on the bed, offer the baby a comfort breast and sing.

About two hours later, we're cuddling on the bed and Jonathan's napping when a tap at the door stirs us. Jeremy stands and faces the

opening door while I straighten my clothes and smooth my hair. A slender man in navy shorts and gray polo shirt enters.

Jeremy smiles and they shake hands. "Hi James, nice to see you. Honey, this is the minister at Davidson United Methodist Church." James explains that he's been visiting ill parishioners and thought he'd drop by. As Jeremy begins describing Jonathan's defect and what has been happening today, I excuse myself to use the bathroom. It is large enough for a wheelchair, with a toilet flanked by large support bars. The bare wall holds a call button. I sit and prop my head on fisted hands. *Why is that minister here?* Jeremy is a cradle Presbyterian, while I'm a cradle Unitarian Universalist. Maybe he's not here to evangelize. Jeremy does provide information technology support for DUMC. Still I am suspicious.

In early 1983, I lived for several weeks with my grandmother and her new husband Roy, whom she married recently after decades of widowhood. Grandma Elsie had undergone surgery for a brain tumor the previous year, but it had re-grown rapidly. After discussing her options with her doctor, Grandma chose not to pursue aggressive and statistically unpromising medical treatments, deciding instead to stay and die at home. Because I was between jobs and had previous medical experience (six months as a nursing assistant between high school and college as well as the phlebotomist gig), my dad and his sisters hired me to provide afternoon and evening comfort care. Days, I commuted from her house in Little Falls down to my classes at St. Cloud State.

Grandma eased into a coma shortly after I moved in. Her care was simple—giving her juice through a straw, changing her diapers, sponge bathing her, and changing her bed linens. In the early evening, Roy and I watched the local news and the Lawrence Welk show in her room, and I'd rub her chilled hands and feet with cherry-scented Jergens. During the weeks I was there, the minister of her beloved Baptist church and his two assistants visited several times. They'd go in her room, yell "hello, Mrs. Larsen," and pray briefly, then repair to the living room to drink coffee, eat cookies, and chat with Roy.

She died in mid February in the early afternoon. After a night and morning of loud, rough respiration, her breath had quieted that afternoon, then slowed, then stopped. Her transition seemed easy. Afterward, I stroked her face, worn and soft, and closed her brown eyes. Aunt Shirley, Roy, and I kissed her goodbye.

Three days later, at her funeral, the minister reminded her family—a mix of Protestants, Catholics, agnostics, and atheists—that Elsie was in heaven now. She should be at peace, but was uneasy because those of her

family still on earth who weren't saved would never see her again. We'd burn in the fiery pit, forever damned. I stared at the man, padded with congregational cookies. Nearby in our pew, my grieving, agnostic father sat, slowly twisting his mother's memorial program.

Maybe this guy is going to tell us Jonathan is in god's hands. I can handle that. But if he says that it's a blessing if god calls him home, I don't know what I'll do. But I can't just strand Jeremy with this conversation. Flushing the empty toilet, I wash clean hands and rejoin them by the crib. Judging from what Jeremy is saying, James has asked him about long-term prognosis and is listening quietly to his answer. Within a minute, the minister offers a few words of support, shakes our hands, and leaves.

"Honey, he didn't say anything preachy!" I pause. "Sorry I left you here alone."

"No problem. I like James. He's a cool guy. I mean, we don't attend his church, so he's not going to assume anything about our faith. He just wanted to check in." Jeremy stretches, yawns. It's almost mid-afternoon.

A little after three, we're in the truck, heading home. We have just finished meeting with the surgeon, Dr. Tate, who sketched Jonathan's heart defect on a piece of paper, then showed us the basic repairs he'd be making. Contrary to the stereotype of the cold, mechanical surgeon who fixes bodies and dislikes conscious patients, he had been warm, friendly, and reassuring.

"Honey, do you think Jonathan has DiGeorges?" I hadn't listened when Jeremy was describing the information he collected on this syndrome Tuesday night, and I'm sorry now.

Jeremy turns quickly left onto our street in order to beat bunched up traffic coming toward us. I grab the handle above the door to stop myself from falling over.

"No, I don't. Like Dr. James said, Jonathan doesn't have the facial distortions that come with DiGeorges, and I think they would have noticed something wrong before now." He sounds confident.

Once inside, I put sleeping Jonathan in his crib and start poking around on the web. I learn that DiGeorges is a genetic defect, one of the so-called Catch 22s because it is caused by a deletion on the 22nd chromosome. As Jeremy said, Jonathan doesn't fit the overall description. But because DiGeorges often comes with truncus, I guess the pediatric cardiologists need to check. *But if not that, what did cause his defect? Is it my*

fault? Once we started trying to get pregnant, I didn't drink and followed all the suggestions. I had waited to have a baby until I was married to a man who clearly wanted children, too. That's good, but I got pregnant at thirty-seven. *Maybe my eggs were too old or damaged.* Anything I ate, drank, breathed, ingested—on purpose or by accident—could have led to this. *Had I done this to Jonathan?*

A hand gently shakes my shoulder as I sit, still at the keyboard, crying and shaking. The web browser displays a list of potential causes of congenital heart defects—environmental pollutants, alcohol, medicines, and the like.

"Honey, sshh." Jeremy holds a wide awake, hungry baby out to me, and my arms grab him. "I have looked at all of this already, and there isn't much known about causes of truncus except in DiGeorges cases, so don't make yourself crazy."

I retreat to the bedroom to lie down and nurse. My left breast is hard and aches because I've used the right one too much today. Jonathan latches crookedly on the left nipple. It hurts. I reset his mouth and begin again. *Jeremy's right. It doesn't matter what caused this. Jonathan has to cope with it. And I have to help him.* This minute, he is helping himself pretty well, even though the congestion, which we now know signals the beginning of eventual heart failure, makes nursing difficult.

That night, my dad calls. My parents have a good friend, Jim Hammersten, who retired after a distinguished career as a pulmonary specialist and now lives near them for several months each year. Dad has shared our news with Jim, and he invited them for lunch on Catheterization Day.

After food, Jim hauled out a large, recent medical textbook. He talked them through Jonathan's defect. He had investigated our surgeon's training (at an acclaimed pediatric hospital in Toronto) and "success rate" (excellent). He had gotten the scoop on the Corman Clinic. And, he'd tapped into his network of former medical students and managed to get Jonathan's confidential Corman file faxed to a friend and then to him.

"Apparently," Dad explains, "the examining physician was impressed with Jonathan's condition. He was surprised by Jonathan's weight and overall health. The doctor also thought he had, I think Jim said, a 'good' family situation. But, Rini, if you want another opinion or have doubts, Jim can get his case immediately transferred to the Mayo Clinic."

My father's voice strengthens as he mentions the transfer idea. The Mayo Clinic in Rochester, Minnesota, is only a few hours from their house, and to Midwesterners, it is the place where serious medical problems get solved.

"No, we're okay where we are, Dad. I don't want to take Jonathan on a plane trip or car trip right now. And, the Corman has a good reputation. They're thinking surgery might be next Wednesday—we'll know for sure Friday—and the hospital is only four miles away from here." My voice cracks a little. "You're going to be here before then, right?"

On Friday, the 13th, Jeremy returns to work. I write emails, tend the baby, and even call people. I hate the phone. I rarely call even good friends to chat. Yet all that week, I checked our voice mail regularly and returned calls quickly. In a typical call, the friend would ask about the upcoming surgery and offer support—with teaching, with advising, with food or errands. I would thank him or her, then launch into medical specifics, particularly the gruesome ones.

"They have to chill his body to sixty degrees and stop his heart altogether; he'll be kept alive by a heart lung machine." Or "There's roughly a ten percent chance he won't make it through surgery."

The caller would listen, murmur sympathetically, and then ask, voice lifting, "but then he'll be fine, right? This will all be over?"

Anticipating this question, I would respond quickly: "No, he won't. The graft has to be replaced periodically as he grows and then throughout his lifetime." The conversation would dribble to a close shortly thereafter. The more I told these details, the less I thought I felt them; the more I told them, the more separate I felt from other people. How could a caller not get off the phone and think "thank god I'm not them"?

By mid-afternoon, I've returned all our calls. Jonathan is napping. I've caught up on laundry and even tried to watch *Days of Our Lives*, a soap opera I've had a sporadic and intermittent interest in for twenty years. The writers are trying to bring the teenage children of principal characters into the plot, but they all just seem whiny to me. I shut the TV off. It's quiet. *Maybe it's time to think. What will. . . no, would we do with his stuff?*

We could just shut the room up for a time. That would never work. Our short hallway ends at the nursery door, with our bedroom door just to the left. Whenever I went to our bedroom, I'd look at the closed door. *We could hire somebody to empty the room. Moving companies pack as well as move.* But then a

stranger would just box up all his stuff. I would want to keep some of it. *We would make ourselves pack for a few minutes a day.* No. Tears end my speculation.

When my parents arrive on Saturday after two long days of driving from Minnesota today, the day before Easter, Jeremy's parents and younger sister Caroline are also visiting. We chat around a picnic table in the back yard. Pictures show smiling faces—Campbells, singular and plural, Rylanders, Rylanders and Campbells. Jonathan's red fuzz and bright eyes shine over grandfatherly shoulders. In one sequence, he models Mr. Campbell's glasses, then tries to gum them. In her journal written that day, Mom noted that "Little J looks just terrific. Nobody would know, looking at him, that he has a major heart defect." When I look at the pictures now, I see only fear on our faces, a possible hint of blue—the sign of cyanosis (insufficient oxygenation)—on Jonathan's.

On Tuesday morning, the day before surgery, Dad and Jeremy go shopping. They return with a large microwave Dad declares we need. (My parents only got a microwave when my great-aunt Linea passed away in the early 90s. Hers, a top model circa 1980, still heats their left-overs and warms beverages "just fine.") That afternoon, Jeremy and I take Jonathan for pre-surgical tests—chest x-rays, weight, height, and blood work for blood typing—and a meeting with the anesthesiologist to review tomorrow's procedures. Between the x-ray visit (which involves holding him, screaming, in an upright clamp, called a Pigg-O-Stat, used to get chest x-rays from infants) and the anesthesiologist meeting, we tour the Carolinas Heart Institute, a separate area of the hospital for the families of patients undergoing catheterization, bypass surgery, or more complicated heart work. The large waiting room holds several conversational areas. It is presided over by kind, efficient, and well-dressed women, who make coffee, communicate with families, and try to ease the waiting. We will be here tomorrow, and we cannot explain anything to Jonathan.

After our briefing with the anesthesiologist, who reviews how they'll chill Jonathan's body, we watch a phlebotomist stick and re-stick

Jonathan. The baby's circulation is pretty poor, and he's cold, which makes the job harder. I again flee the room, cursing my own cowardice but incapable of staying. The phlebotomist continues to miss, then gives up. Finally, the pre-op staffer assigned to us flags down a doctor passing through, and he retrieves some blood from Jonathan's thigh. We get home around 5 p.m..

After supper, we bathe Jonathan, then dry him on our bed. As I rub in Johnson's baby lotion, Jeremy tickles his thighs.

Jonathan giggles—his first clear laugh. I exclaim. Drawn by the noise, my parents crowd in the room.

I smile. "Don't worry—it isn't bad. Listen."

Jeremy tickles him thoroughly. Jonathan giggles again, loud, gurgly, full-bodied. He gapes and shows his gums. We smile and cheer him and tickle him repeatedly until he tires of the game.

After he's asleep on our bed, we stare at the TV until 10:00 p.m., then, join Jonathan. There is nothing we can do to stop tomorrow, nothing we can do but snuggle with our son and hope to sleep.