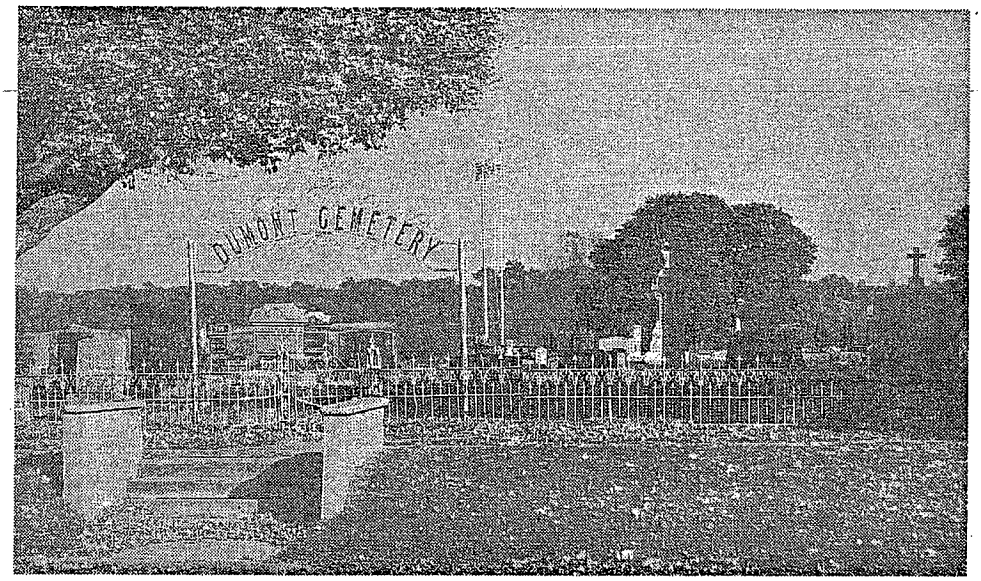


Hoping For More

— By JONNA HIGGINS-FREESE —

A few days before our son Reuben's first birthday, my husband and I took him on a walk through the cemetery in Dumont, Iowa where, for the first six weeks of his life, we feared we might have to bury him. I wore Reuben on my back and Eric carried an oxygen tank on his. A tube ran from the oxygen tank to a cannula taped to Reuben's cheeks, so that a liter of oxygen a minute blew into his nose. Reuben looked around with his usual keen interest as we walked, taking in the houses, the leaves on the trees and the shadows on the ground, all the while patting my neck and babbling.

We walked to the shaded end of the cemetery where the markers were worn and the graves frequently held the very young. Given our recent near-miss, we couldn't help imagining the tremendous grief represented by each quiet, simple stone. Two in particular caught my attention: "Magdalen Crotty, D. January 31, 1900, aged 31 years" lay next to a smaller memorial: "Joseph Emit Crotty, died May 11, 1900, aged 4 ms. 12 ds." The baby had been born in early January. Had the mother died from complications of childbirth, or did she sicken and die for reasons separate from the death of her son? Was the baby ill from the beginning, either as a cause or result of a complication of the labor? Was there no money or desire for a wet nurse, or did the baby not thrive on the homemade formulas available at the time? I tried to imagine the father standing there in the cemetery in January. Would he have known, then, that the child would die too?

I looked out from the cemetery over the fields and wondered where the Crotty's farm had been. Unlike the bare dirt with corn or bean stubble visible in every direction on this early spring day, some of their land at that time likely still would have been in prairie pasture rather than plowed. Or perhaps, since the child had been buried in this cemetery rather than a family plot on the homeplace, the Crottys had been shopkeepers, running one of the businesses on Main Street that had thrived for such

a brief few years between the arrival of the railroad and the beginning of the decline of small family farms in Iowa.

In 1900, when Magdalen and Joseph died within months of each other, the infant mortality rate in the United States, (defined as children who died before age one) was over 120 deaths per 1000 live births: every eighth baby died. By the time Reuben was born a little over 100 years later, every 166th baby dies.

In short babies in Iowa and the rest of the United States are 20 times less likely to die than they were a century ago. Infant mortality dropped 50 percent between 1900 and 1937. Housing got less crowded and sewage treatment improved, so infections spread less easily. Clean drinking water became more widely available. Antibiotics and other medical treatments saved more babies, and neonatology emerged as an area of medical practice after World War II. The remainder of the decreased infant mortality rate is due to improved technologies and medication. It is to these that our son owes his life.

♥

After a healthy pregnancy, Reuben pooped in the 15th hour of labor. This isn't uncommon: 25 percent of babies pass their sterile feces, called meconium, while still in the womb. Sometimes this doesn't affect the baby; sometimes it causes severe illness. Since Cesarean sections don't necessarily improve the outcomes, my labor continued normally until, just as Reuben was getting close to emerging, the labor nurse no longer could find his heartbeat.

Our son was in cardiac arrest, essentially dead on arrival. Had he been born 100 years ago, or yesterday in a less developed country, he would have stayed dead. In 2006 at the University of Iowa, he was immediately resuscitated, intubated, sedated, and shipped off to the neonatal intensive care unit (NICU), where he was diagnosed with severe meconium aspiration syndrome and persistent pulmonary hypertension of the newborn. We were launched into a high-tech world of central lines and catheters, experimental gases and ventilators, nasogastric tubes, X-rays, and laboratory analysis of his blood.

I first laid eyes on him over an hour later when I finally was able to be pushed in a wheelchair from labor and delivery to the neonatal intensive care unit. We found our son at the end of a long hallway of wide glass double doors. Although his room was darkened, the doors stood open and sophisticated equipment spilled out into the hallway. Incongruously, a sign hastily written in black Sharpie marker on green office paper had been taped to one of the machines: "Please be very quiet in and around my room xoxo Reuben."

Reuben lay on his back on a small padded table with short glass edges, his arms flung above his head and his little frog legs bent. His eyes were covered by purple foam goggles and he wore hard yellow ear covers. His tiny mouth hung open slightly, a piece of white tape like a mustache across his upper lip holding two tubes in place, which we would learn later were the endotracheal tube that carried gases to his lungs and the oral-gastric tube that carried small amounts of food to his stomach. The nurses explained that the three round patches on his chest were leads for the monitors indicating his heart rate. Arterial and venous lines in his umbilical stump allowed the nurses to draw blood and administer medication and nutrition. One of his big toes glowed bright red from a pulse oximeter attached to it with more white tape. This device indicated how much oxygen was in his blood.

The nurses carefully explained each piece of equipment and each of the monitor readings and what it meant, then asked if we had any questions. I had only one, "Can I touch him?"

"That's probably not a good idea right now," the nurse said stable. Reuben breat ium which damaged l of that caused the oxygen from his lun clamp down, so he's r gen he needs. Any tir of stimulation, tho down again. The less the more likely it arteries will relax ar oxygen to flow prope So it's better if we we don't have to."

The high-touch ca nearly all mothers our extreme case be instant by a no-touc one of Reuben's bo managed intensely, b cation and equipmen oscillating ventilator of oxygen and nitric at a frequency of minute. The low, ra thump-thump-thump dryer in overdrive, track to our days. him from stress, and dition and the vari ments were manage morphine, ativan, ar 81 times stronger t blood pressure was r antibiotics fought t cropped up continuo moved his urine be sedated and his kidr whelmed to perform amounts of breast through a tube in his to his stomach in or gestive system functi of his calories came teral nutrition, a cle electrolytes, mineral bohydrates administ inserted into his uml

The doctors fully would recover with percent of babies wi

now," the nurse said, "he's still too unstable. Reuben breathed in the meconium which damaged his lungs. The stress of that caused the arteries that carry oxygen from his lungs to his heart to clamp down, so he's not getting the oxygen he needs. Any time he has any kind of stimulation, those arteries clamp down again. The less stimulation he has, the more likely it will be that those arteries will relax and allow blood and oxygen to flow properly so he can heal. So it's better if we don't touch him if we don't have to."

The high-touch care that is best for nearly all mothers and babies had in our extreme case been replaced in an instant by a no-touch policy. Yet every one of Reuben's bodily functions was managed intensely by machines, medication and equipment. A high-frequency oscillating ventilator vibrated a mixture of oxygen and nitric oxide into his lungs at a frequency of 300-900 cycles per minute. The low, rapid "thump-thump-thump-thump-thump" of the vent, like a dryer in overdrive, became the sound track to our days. Sedatives protected him from stress, and the pain of his condition and the various invasive treatments were managed by a cocktail of morphine, ativan, and fentanyl, a drug 81 times stronger than morphine. His blood pressure was regulated by Viagra, antibiotics fought the infections that cropped up continuously; a catheter removed his urine because he was too sedated and his kidneys were too overwhelmed to perform this task. Small amounts of breast milk were dripped through a tube in his mouth directly into his stomach in order to keep his digestive system functioning, but the bulk of his calories came from total parenteral nutrition, a clear fluid mixture of electrolytes, minerals, proteins and carbohydrates administered through a line inserted into his umbilical stump.

The doctors fully expected Reuben would recover with this treatment; 95 percent of babies with his condition improve within seven to 14 days. "The goal," they told us, "is to keep him alive until he recovers." I had not realized that a surprising amount of intensive care is not designed to heal, but to keep people alive long enough for their bodies to heal themselves.

Reuben did not improve. Then on Day of Life 21, at about 11 on a rainy Sunday morning, his right lung collapsed. His blood oxygen levels fell from the mid-90's to low 80's, where they usually hovered, past 70, 60, 55. Air was leaking from a hole in his lung into his chest cavity, where it compressed the lung further, preventing it from reinflating. Dr. George, dapper even on a Sunday morning in jeans that looked as though they had been ironed, inserted a needle into Reuben's chest to drain the air, but couldn't penetrate through the fluid-swollen tissue. He called for larger needles as Reuben's heart rate began to drop: the air in his chest also was compressing his heart.

All we knew was that Reuben's oxygen levels were creeping lower and lower. We didn't know if he was dying before our eyes. All the nurses and doctors were too busy to talk to us. My prayers were compressed into one word: please. Please, God, let him live.

"I was scared, too," Dr. George told us later. "But finally I called for a spinal needle and I was able to release the air in his chest cavity. His heart rate came back up and I thought then we would be able to stabilize him enough to put him on ECMO. I already had made the calls to start the initiation process."

When Dr. George had stabilized Reuben, he came to speak to us in his quiet, kind voice. "He's stable now, and heavily sedated. We'll tell you when we think it's hopeless. But for now there's reason to hope for recovery, so I'm recommending that we place Reuben on ECMO. A pneumothorax—a lung collapse like he just had—is an indicator that the child usually will not continue to do well on the ventilator alone."

"Worse, we would live beyond his death. Whatever ceremonies or coffins or resting place we chose, eventually we would have to place him in the box in the ground, end the ceremony and walk away from the baby we wanted only to hold tightly in our arms and love forever, and for whom we could now do nothing further."

He explained that ECMO stood for extra corporeal membrane oxygenation, a technology that runs the patient's blood through a machine that functions as heart (pumping the blood), lungs (adding oxygen and removing carbon dioxide), and kidneys (removing toxins and fluids). The technique was very effective at giving the patient's body a complete rest to allow for healing, but carried significant risks of infection and stroke due to the invasive nature of the treatment and the large doses of blood thinner that prevent the blood from clogging the tubes outside the patient's body. He told us that in general the success rate with the treatment was about 80 percent.

"And what do you think Reuben's chances are?"

He paused. "I would say above 50 percent."

"And without ECMO?"

He didn't hesitate. "Much less than that."

The resident held out a clipboard with a permission form and began to explain the risks of the procedure. I cut him off. "Where do I sign?"

While Reuben was in surgery, we sat in the seventh floor family lounge in the John Pappajohn Pavilion at the University of Iowa. Watching the rain streak the tall glass windows and fall on the playground in the courtyard below, I thought that if he died we would bury Reuben in the cemetery at Dumont. Eric's grandparents, in their practical way, once told us that when they purchased their own grave plots in the Dumont cemetery, they also bought a few extras, just in case anyone needed them.

As for a coffin, I imagined the satin and varnish offerings at the funeral home. No. Our friend Rich was a carpenter. With his help we could build something simple and beautiful. I imagined how it would be to leave the hospital world of hallways and stale indoor air, the relentless gray carpeting and studiously cheerful blue-and-yellow curtains, the constant adrenaline and the particular NICU smell of hand sanitizer and cleaners and medicine, and go out again into the summer to Rich's shop amongst corn fields and pastures near the English River. I could see us choosing the wood, hear the rising whir of the saw blades, and smell the sweet, clean tang of the sawdust. I could imagine the three of us there together, after the end of our world, building and staining and varnishing the box, while Eric and I began to try to sense what shape our lives might take now that Reuben's had ended.

I saw all of this in my mind in just a few moments and then I returned to my conviction that Reuben must live. The prospect of his death, though I had made these few contingent plans for it, was a possibility too terrible even to hold in my mind for more than a few seconds. Worse, we would live beyond

his death. Whatever
fins or resting place v
we would have to pl
in the ground, end
walk away from th
only to hold tightl
love forever, and f
now do nothing furt

* *

Nothing could pr
the first sight of a ch
ben had been surrou
before; now he wa
To get to him, we h
ECMO cart and th
cannisters of oxyge
A piece of yellow ta
crime scenes, ran f
tanks blocking acce
carried his blood.
one false step I
child's blood vessel
heightened alertne
known before. Turn
tilator, we edged t
by the closet and th
see Reuben's tiny,
eyes were covered
cloth, his head to
the left, revealing a
edged in slightly
the insertion point
disappeared into h
pool of blood on h
place where Dr. Ge
able to bleed off t
collapse; because h
to clot, we could n
He never had beer
washed after birth
swollen with fluic
treatment that his
peeling.

The doctors us
to put oxygen d
blood, allowing his
A pump assisted F
ing the extra volu
both his body an
Meanwhile, the
of the circuit assis

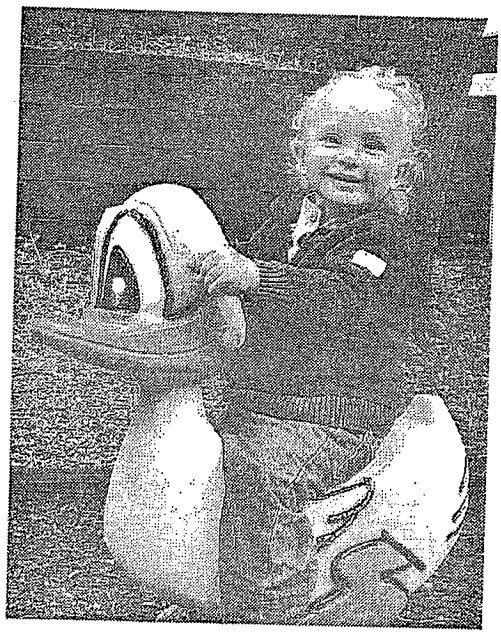
his death. Whatever ceremonies or coffins or resting place we chose, eventually we would have to place him in the box in the ground, end the ceremony and walk away from the baby we wanted only to hold tightly in our arms and love forever, and for whom we could now do nothing further.

* * * *

Nothing could prepare a parent for the first sight of a child on ECMO. Reuben had been surrounded by equipment before; now he was hidden behind it. To get to him, we had to walk past the ECMO cart and the ventilator with its cannisters of oxygen and nitric oxide. A piece of yellow tape, like that used at crime scenes, ran from the cart to the tanks blocking access to the tubes that carried his blood. Knowing that with one false step I could trip over my child's blood vessels caused a state of heightened alertness unlike any I'd known before. Turning right at the ventilator, we edged back into the corner by the closet and there, at last we could see Reuben's tiny, battered body. His eyes were covered with a soft white cloth, his head torqued awkwardly to the left, revealing a line of black sutures edged in slightly congealed blood and the insertion points where the cannulas disappeared into his body. A half-inch pool of blood on his chest marked the place where Dr. George finally had been able to bleed off the air from his lung collapse; because his blood took so long to clot, we could not risk wiping it away. He never had been stable enough to be washed after birth, and his body was so swollen with fluid from the weeks of treatment that his skin was cracked and peeling.

The doctors used the ECMO circuit to put oxygen directly into Reuben's blood, allowing his lungs a complete rest. A pump assisted Reuben's heart in moving the extra volume of blood through both his body and the ECMO circuit. Meanwhile, the hemofiltration portion of the circuit assisted his kidneys by removing fluid directly from his blood. During the weeks of treatment on the ventilator, Reuben had required large amounts of fluid to maintain his blood pressure. His kidneys simply had not been able to keep up. Now the ECMO circuit removed a bit more fluid each day—over eight pounds in all for a baby whose birth weight had been nine pounds, seven ounces. Reuben visibly shrank. One morning at rounds I teased Dr. Acarregui that he was turning Reuben into a raisin. He nodded. "I want him thirsty," he said, only half joking. "That way when he comes off ECMO, if he gains back a little water weight, it won't be so hard on his lungs."

Dr. George had explained that most newborns with Reuben's condition remained on ECMO for 10 to 14 days. We knew the risk of fatal complications increased dramatically as time went on. By the morning of ECMO Day 14, Reuben had developed a hematoma, a sac of blood caused by internal bleeding at the cannulation site. At rounds, Dr. Segar wasn't happy with the look of Reuben's X-rays, but he felt that it was time to



— A recent photo of Mr. Reuben at play —

clamp off the circuit and see if Reuben could fly on his own. "We could spend a lot of time trying to get his X-ray to look a certain way," he explained. "But the important question is—do his lungs work as they're supposed to? Let's find out." They did.

Slowly Reuben reclaimed the work of his own body. He began to breathe, urinate, move and digest food on his own. On Day of Life 80, we brought Reuben home.

He continued to heal. We protected him from colds and germs by keeping him at home and washing our own hands thoroughly when we returned. His lungs grew well and after 18 months he no longer needed extra oxygen through the nasal cannula. He has no intellectual or developmental disabilities, and the feeding difficulties that are a common result of his difficult medical treatment are expected to resolve themselves within a few years.

♥

Two months before Reuben's second birthday, on a sunny March day that was not warm enough to melt the layers of ice and snow from a long winter, we stood again in the cemetery where Magdalen and Joseph Crotty lay. We were there to bury Grandpa Freese, Reuben's namesake. Bundled in his bright red coat, little Reuben insisted on walking by himself.

People said what they always say at funerals: that Grandpa had a good, long life. He was a good farmer, a man of faith, who loved his family and served his community. Though he had tried to accept his impending death with grace and humility, declining treatment for pancreatic cancer and choosing instead to die at home surrounded by his family, he still loved his life. He visibly cherished Reuben as he held him for the last time, and days before his death he roused from sleep to caress Reuben's hair.

Michael Cunningham, in *The Hours*, writes of life that "we hope, more than anything, for more." At some point around the Biblically suggested number of years, we begin to believe that although we might hope for more, we at least got our fair share. Unlike Joseph Crotty in 1900 and the thousands of babies who still die around the world today for lack of access to basic—let alone advanced — medical care, Reuben got more. He is alive today by the unearned blessing of being born in Iowa City in May 2006. The doctors assure us that he should experience no long-term ill effects—that he should live his allotted years and die full of days.

We never would wish what we and Reuben went through on anyone. Or rather, we never would wish on anyone that their child become critically ill. But for those whose children do become ill, we would wish for them that they *could* go through what we went through: that their child's life be saved. In that sense we never forget for a moment how lucky we are to have Reuben with us. His smiles, his laughter, his devotion to construction equipment and the blues song "Walkin' the Dog," are all gifts of his unique being that we almost didn't get to experience.

Many of us who love Iowa are concerned about the negative impacts technology and globalization have had on the state. We realize that the pesticides and fertilizers on which corporate agriculture depends also sicken us, that our farming methods wash away precious topsoil, that cities designed for cars and not people make us vulnerable to unstable politics and a changing climate.

But when Reuben was ill I had to face the benefits of technology and the University of Iowa's preeminent position in global medicine. I had been an activist on peace and environmental issues, quick to have and give opinions on how the world should be arranged. For many reasons, Reuben's illness changed that, and I am less certain about many things, more focused on the world within my home. I am now more skeptical of the

technophobic et
been immersed
ist. Sometimes
technologies are

I think often
families like the
phisticated med
or, worse, those
that such techno
not to them. S
quired the fruit
years of educa
search by thous
fessionals, not t
our insurance
million. A part o
der how many cl
country with th
ily rate in the w
been saved with
for anything ha
life, but the basi
and those famil
mind. Once I n
thought to my
works on health
ate Appropriatio
mediately said, '
—it's a false ch
enough money f
and widespread
and critical care
The wealth cre
economies is er
primarily for m
poses. The sca
health care is an
made."

When we fin
in Reuben'
aloud so he cou
though he still w
day I came ac
Light that caus
down. I watched
then I looked o
NICU across the
2 to Kinnick St
the green haze o

technophobic ethos I had for so long been immersed in as an environmentalist. Sometimes radical and invasive technologies are life giving.

I think often of the Crottys and other families like them who lived before sophisticated medical care was invented or, worse, those who live today knowing that such technologies are available, but not to them. Saving Reuben's life required the fruits of millions of person-years of education, training and research by thousands of health care professionals, not to mention an outlay by our insurance company of over $1.4 million. A part of my mind used to wonder how many children in the Sudan, the country with the highest infant mortality rate in the world today, could have been saved with that money. I would not for anything have given up Reuben's life, but the basic unfairness of our luck and those families' loss came often to mind. Once I mentioned this train of thought to my friend Adrienne who works on health care issues for the Senate Appropriations Committee. She immediately said, "Don't think about that —it's a false choice. There's *more* than enough money for both preventive care and widespread public health measures *and* critical care for those who need it. The wealth created by our industrial economies is enormous, but it's used primarily for military and other purposes. The scarcity of resources for health care is an illusion, a choice we've made."

♥

When we finally were able to speak in Reuben's room, I started to read aloud so he could hear my voice, although he still was heavily sedated. One day I came across a poem by Kate Light that causd me to put the book down. I watched Reuben breathe, and then I looked out the window of the NICU across the roof of Parking Ramp 2 to Kinnick Stadium and beyond, to the green haze of the trees of Coralville shading off into the distance of fields and the enormous blue sky of Iowa's summer. Under the green fields is the soil, and the soil runs in deep rich folds across the land. The rivers cut through it to bedrock, and the towns grow over it under the sky, and in every direction it cradles the delicate bodies and bones of the children who died too young, those we did not know how to help, like Joseph Crotty, and those born in Haiti or the Sudan today whom we simply didn't help.

I looked back to the book and re-read the words that finally gave voice to my experience: "There comes the strangest moment in your life, when everything you thought before breaks free—/what you relied upon, as ground-rule and as rite/looks upside down from how it used to be./ . . . /How many people thought you'd never change?/But here you have. It's beautiful. It's strange." □

— Jonna would like to thank Dr. Jill Endres, Dr. Jonathan Klein, Shanna Siegel, RRT, CHT, and Dr. Nancy Tsai for assistance with medical information in the essay.

Former Lives

The first time I went to Jim Mulac's
place,
his dog loved me, recognized me,
from another life. Maybe he had
been my dog
in Switzerland when we rescued
travelers
trapped in snow slides,
or in Scotland where we kept sheep
on the cool heather hills.
Maybe he was my dog when we
drove cattle
from Amarillo to Dodge,
or maybe he was an old lover
come back for one more embrace.

— ANN STRUTHERS