

Chapter Three:
A Crash Course in Medicine



"Which end is up?" (Catie through a kaleidoscope.)

Photo: Jay Newman

HIGH PRESSURE PARENTING

A Change of Plans

Most of us tend to live in a world full of assumptions. We might make plans for tomorrow and assume our alarm will go off, the car will start, and the destination will be there in the morning. The reality is, a thousand and one things could happen to change those plans, but that doesn't occur to us most of the time.

When I first became a parent, I didn't know about all the things that could go wrong. I knew my kids would get sick, and I thought my job was to nurse them back to health. By the time Marley was 15 years old, he had taught me that sometimes kids can be sick and doctors don't always know what's wrong and there isn't always a cure.

On "switch" day, I went to the middle school to pick Marley up and his stepsister, Laura, told me to meet Drew and Marley at the doctor's office. I didn't think much of it. I picked Catie up and headed for Marley. When I got to the doctor's, Drew said they thought Marley might have pneumonia. I just figured I was going to start my two-week shift with the kids being a nursemaid.

It was Friday afternoon, and it was dark by the time the doctor had done an exam and told us we needed X-rays at our small local hospital. Drew left Marley and Catie in my care. Because it was after hours, we couldn't *just* get X-rays, we had to go through the whole emergency room procedure. After waiting forever and getting yet another physical exam, the X-rays were taken and the official diagnosis was delivered. It was all there in black and white. Marley had pneumonia. I thought, "No big deal. I can handle this." We were given antibiotics and discharged. On our way out, we were handed a computer printout, defining pneumonia.

"Pneumonia is an inflammation of the lung(s). It is an infection caused by inhaling one of three types of irritants: viral, bacterial, or fungal. This disease is treated with antibiotics, plenty of fluids, and bed rest."

We dutifully went home and propped him in a recliner in the living room with plenty of fluids. On Sunday, I started to worry. His

symptoms had changed for the worse. The antibiotics weren't doing the trick. I watched Marley's eyes roll white with an intense "I'm-going-to-suffocate" fear because his lungs simply couldn't take in enough air. It was very scary when I realized he might be in serious trouble. I called Drew.

Leaping into the Unknown

It was leap day, February 29th, 2000. Our friend Dee was in labor with her firstborn, and I was supposed to notify everyone when baby Kellar was born. I called the first person on the phone list and passed the responsibility on. I had to get my boy to the hospital. It was late, and Catie was asleep. Our friend Liz agreed to stay with her and keep the wood stove stoked. Drew and Cindy were going to meet me at the ER in Medford, 40 minutes north. We had decided that if Marley needed emergency care, we were going to a larger hospital with better equipment and more experienced doctors. (From then on, Medford symbolized bad experiences, so henceforth, I refer to it as "Dreadford.")

The infection in Marley's lung landed him in the Intensive Care Unit (ICU) for almost two weeks. Marley's case of pneumonia escalated so quickly we had a hard time keeping up with what the doctors were saying. It was one emergency situation after another. It felt like a nightmare that I couldn't wake up from.

During those 12 days in the hospital, I felt lost and queasy most of the time. At first I thought it was a normal nervous response, but then I noticed that whenever I walked outside, the feeling disappeared. I figured it must have been a combination of fluorescent lighting, heavy-duty cleaning fluids, and using the elevators. Regardless of the discomfort I felt, I knew I couldn't leave my son alone.

After many gruesome procedures, Marley started recovering and we were able to bring him home.

I wasn't prepared for how strong we would all have to be. I wasn't prepared for having to be in a relationship with Drew and Cindy again. I felt dizzy and scared like I was on the roller coaster from hell.

FLUID FACTS

Catie's Report

During the visits with her brother in ICU, Catie spent her time drawing diagrams of all the tubes and machines attached to Marley. She, like her three parents, needed to be able to wrap her brain around a situation to make it less scary and unfamiliar.

With Marley as our teacher, we learned a new fact about pneumonia. Catie used the information to write a school report, adding another cause omitted on the hospital's original handout.

Pneumonia by Catie Pratt (age 10)

Pneumonia is when you have fluid in the lung caused by an infection. Pneumonia is usually caused by one of four things.

The first is bacteria, which is an organism that is so small you can only see it under a microscope. It can also be caused by a virus, which is even smaller than bacteria. Common diseases that a virus can cause are: the common cold, flu, strep throat, smallpox, and mumps. Another cause is a fungal infection. Fungi can also cause Ringworm, Candida, or Athlete's Foot. The last possible cause is aspirating foreign material like chemicals, a peanut, or, in my brother's case, a piece of chicken.

Before the development of antibiotic drugs in the 1940's, pneumonia killed about a third of its victims. Today, with the proper medical treatments, 95 percent recover. But pneumonia is still a leading cause of death.

RECEIVING THE NEWS

Marley's Western Rest Home

Marley's horrific health drama had faded away with the cold winter months. We were all recovering, delighted that spring was fast approaching—a time for new beginnings. Just when we thought the stormy weather was over, Marley's energy started to dwindle. He no longer wanted to play, complaining that his back hurt and he was again having trouble taking big breaths. We took him back to the doctor for another round of tests. When the doctor summoned us for a meeting, we knew bad news was brewing.

*“What if you slept,
and what if in your sleep you dreamed,
and what if in your dream you went to heaven
and there you plucked a strange and beautiful flower,
and what if when you awoke you had
the flower in your hand? Oh, what then?”*

—Samuel Taylor Coleridge

There's something simply rude about the design of most medical examining rooms. The one we were sitting in was a square 12-foot box, painted a horrible shade of green. It was barren of any wall art or window covering. The contents of this room consisted of a gray metal desk, a chair, a stool, a trash can, and an examining table covered with slick, white paper.

We were patiently waiting for the doctor to tell us the results of the most recent tests. I sat at the desk, tapping my fingers on the arm of the chair. Marley was spinning on the stool a few feet away. After a few excruciatingly silent minutes, Marley rolled the stool next to me, leaving a small trail of dried mud clods from his boots behind him. Marley leaned forward and said he had an idea. He wanted to start a new business. My mouth dropped open as I stared at him. He rarely talked of future plans except for how high he planned to jump his bike or what kind of all-terrain vehicle (ATV) he wanted. Until this moment, his dreams were always simple and very immediate.

Marley was serious about his plan, which he called his “Western Rest Home.” The plan was to give crippled cowboys and elderly ranchers a comfortable place to spend their last days, doing the things that had made their lives worth living. He described his idea in detail—from the width of the wraparound porch to the dimensions of the greenhouse.

He described the layout of the bedrooms, which would come equipped with refrigerators for whiskey and beer. The beds could be hospital beds, but they would have colorful flannel sheets instead of thin white ones. To add color and comfort, the blankets would be down or woven wool. Native American style tapestries and “really cool art” would hang on the walls throughout this enormous log structure.

The guests could relax on the front porch and smoke their fat cigars and shoot at targets. If they wanted to go hunting, an ATV with a flatbed trailer would take them into the woods. He even designed the flatbed to have hooks to secure their wheelchairs to. If they wanted to go horseback riding, he had an idea of how to design the saddles to accommodate IV hookups. For the gardeners, the large greenhouse would have plant beds at the right height and angle to be wheelchair accessible.

He thought of every detail. He described what the staff would wear and what they would look like; all young, strong, and beautiful. He made my mouth water as he went over the daily menus and explained how, in case the old rancher women wanted to help cook, the kitchen would be modified for their convenience. Every room would have a view of the Cascade Mountains or the gardens in the courtyard. The hayfield would be visible from the porch so that during the hay season the old ranchers could feel like they were a part of the process, even if they couldn’t help.

His eyes sparkled as he told me every last detail. I could smell the scents, imagined seeing spittoons being cleaned daily, and could hear the extraordinary stories of these old folks. I wanted to hear more, but...the door opened. I had been so wrapped up in Marley’s story that I had completely forgotten why we were there.

Foul Weather Ahead

The girls played outside the doctor's office, while Drew and Cindy waited in the lobby and I waited with Marley in the examining room. I had been thoroughly entertained by Marley's plan to create his Western Rest Home until the doctor walked in with Drew and Cindy on his heels.

Unbelievable words spilled from the doctor's mouth. He kept going over the same details, coming up with the same conclusion. He explained there was a fifth cause for pneumonia. He said that Marley didn't inhale a piece of chicken taco into his lungs as we first suspected; it was caused by a tumor growing in his left lung. For a few seconds I felt like I was lifting out of my body; I could see everyone in the room, but my ears were ringing and I didn't feel connected at all...to anything. Marley had lung cancer.

When there was nothing more the doctor could say, we walked out of the prison-like cubicle. I'm sure I looked calm, fortified with that supernatural kind of strength mothers can muster when their family is under fire. Internally, it felt as though I was staggering, as if I'd been told that a hurricane was speeding straight toward us and all exits were blocked. In the back of my frozen brain I could find only one thought, "Leave it to Marley to come up with something like this."

We left the doctor's office to join the rest of the family outside. It was a beautiful, sun-filled April morning and Cindy's two daughters, Laura and Vanessa, had been playing tag with Catie in the sea of fresh cut green grass. In the middle of this manicured lawn was one stone bench. That's where we gathered to relay the news to the girls. Drew and Catie sat on the bench as Marley, Cindy, Vanessa, Laura, and I formed a circle before them on the grass.

Drew slumped slightly forward and sighed. His head was bowed low as he took off his cap, squeezed it in his free hand, and slapped it against his thigh as if to brush off the dust after a long horseback ride. It didn't take too many words before the tears began to drop onto his jeans. His voice quivered only slightly as the three girls listened intently. Catie instinctively moved in to

nuzzle closer to her dad. She knew something was terribly wrong as she watched Drew.

Batten Down the Hatches

Drew took a deep breath and said, “Well, it turns out that Marley didn’t aspirate on that piece of chicken at school after all. Instead, he got pneumonia because there’s a tumor in his lung. Marley has lung cancer. He’s got a kind of cancer they call “squamous,” and they did all those tests to make absolutely sure. I guess they’ve never seen this kind of cancer in a kid.”

Vanessa, the oldest of the girls, was shaken but curious and asked, “Are they *really* sure?”

It was a good question, but there was only one short answer, “Yup.”

Laura calmly asked, “What happens now? What are we going to do?” I had known Laura since she was a wee babe and always marveled that nothing seemed to rock her off balance.

Cindy sighed and explained, “Well, the two doctors we have now said from here on, this is out of their league. I guess now we need to find a new doctor while we learn as much about this as possible on our own.”

Catie was crying. She looked up at her dad and quietly asked, “Is Marley going to be okay?”

Drew put his arm around Catie and almost whispered, “We sure hope so. There’s a lot we don’t know yet.”

Marley was quietly sitting on the grass, leaning back on his outstretched arms, chewing on a long blade of grass. Our stomachs were in knots and an uncomfortable silence swept over us. When there were no more answers, we wandered over to Drew’s truck, not really wanting to separate.

It was switch day. I’d had the kids for two busy weeks of juggling work, school, and a sick boy. All of a sudden, the kids drove away with Drew and Cindy, and I found myself standing in the parking lot alone. I was numb. I couldn’t believe this was really happening.

I had to drive 20 minutes back to Ashland to go to work. I

thought about going home to recover, but it dawned on me that life wasn't going to stop because my son was sick. The tasks required both at work and at home couldn't be ignored just because I was scared.

Shocked by the proportions of the storm we were facing, I drove back to the office to the folks I worked with—they were the closest thing to family I had locally. As awful as this situation was, after I finished telling the news to my clan at work, I knew someone could and would make me laugh. Sure enough, Jay, the jester of the crew, broke the tension and sadness that was filling the office. He did a perfect imitation of my desire to deny the diagnosis with the following quote from one of Marley's favorite movies:

“It's NOT a 'tuma.”

**—John Kimble (Arnold Schwarzenegger)
*Kindergarten Cop***

Communicating with the Clan

The last thing I felt like doing was talking to my family on the phone for the next few hours. Just the process of contacting my five sisters and three brothers would have taken forever. I realized I needed to create a new way of communicating this news to other family members and friends. Too many people knew and loved Marley, and they all needed to be kept in the loop. I stayed late at the office to use the computer and started drafting a letter. I started at the beginning and tried to explain everything. I sent the e-mail update to everyone who knew Marley.

From that day forward, Marley's Network was officially formed. I had no idea how incredibly important this communication technique would become. Every time information needed to be updated, I just sent another e-mail. I also didn't expect how comforting it would be to write about what we were experiencing. At the time, it simply seemed like a logical solution. The process of communicating kept me focused, connected, and relatively clearheaded for the duration of Marley's journey.

Wednesday, April 12, 2000

Subject: "MARLEY NETWORK UPDATE – #1"

Dear Ones,

This is the first of many e-mails designed to invite all the people in my life to join forces. I'm up against the most important event in my life, and I have a very strong feeling that it's critically important we go through this together. It's an unusual story, and it's going to affect many of us for the rest of our lives. Sit down and prepare yourselves.

My son Marley is very sick and is facing choices few of us will ever know. As his mother and advocate, I call on all of you to form a well-oiled machine that's prepared to handle *anything* we're faced with.

I do my best to manage Bathroom Readers' Press, a publishing company that is currently for sale. I work with an exceptional team of people. I'm good at what I do; communicate, organize, and delegate. It occurred to me that I need to use my professional skills in my personal life so I can have the time and energy to care for my son and daughter, continue to run a business, and still have time and energy to care for myself. To pull this off, I need your help. If we unite and stay informed, we can make a difference to a unique and worthy young warrior.

I want to describe the players and recap the recent history of events. Soon I will send a list of possible needs and "job descriptions" for those of you who'd like to help but don't know how. It's time to get organized.

The Star: Marley Jacob Pratt (15 years old), born Feb. 6, 1985.

The Lead Characters: Drew (father), Cindy (stepmother), Catie (sister, 10 years old), Vanessa (stepsister, 14 years old), Laura (stepsister, 11 years old), and me (Marley's mother).

The Supporting Cast: You.

The Plot: Marley is a unique and well-loved individual whose special spirit has wiggled into the hearts of many. Trying to define Marley is like trying to make sense of chaos. He's had a radical history of undiagnosed irregularities throughout his short stay on Earth. In spite of his life hurdles, he's a tall, strong teenager who has a remarkable sense of self and the rare ability to express love.

On Leap Day, Marley went to the emergency room with pneumonia, which escalated beyond the expected. The first two weeks in March consisted of one procedure after another, and he has the war wounds to prove it! At first, the emergency room doctors tried to suck the fluid from his lung with a long syringe (didn't work).

Next, a lung specialist put three half-inch drain tubes into his side because the fluid had escaped into the *pleural cavity* around the lung (didn't work). A surgeon was called in to do a *thoracotomy*, an incision from his nipple to the top of his shoulder blade, designed to clear out all the *empaema* (thick fluid) from the cavity around his lung. At the same time, the surgeon elected to do a procedure called a *bronchoscopy* (several tubes up a nostril lead-



Wonder Boy in ICU

ing down into his lung). A “foreign body” was identified, looking like a piece of meat. This explained why the antibiotics didn’t do the trick and why the infection persisted. Marley recalled choking on a chicken taco at school. The way he eats...no wonder! It was nice to have a reason for this drama.

Two more bronchoscopies were performed to get all of whatever was in there out—piece by piece—with microscopic pinchers. These samples were also used to biopsy both his lung tissue and the “foreign body.” The results came back “abnormal,” indicating a tumor; but *that* couldn’t be right, so it was agreed we’d let the lung heal a bit before testing it again.

During those two weeks, an incredible network of people showed their love for Marley by sending pebbles as a symbol of their healing prayers. I am still amazed at the showing of community. Marley built an incredible water fountain using the many stones and gems sent (although the container proved to be way too small!). We also did a 5 P.M. meditation daily to focus healing energy—many have continued this practice to date.

The Plot Thickens

After 12 days in the hospital, we spent one additional, truly ghastly week of Marley suffering from “spinal headaches.” During surgery, a morphine IV had been inserted directly into his spine. This is called an *epidural injection* and is standard operating procedure. These incredibly painful headaches were created when the epidural needle was removed from his spine. The hole didn’t properly close, and spinal fluid was slowly leaking out, causing excruciating headaches whenever he lifted his head above heart level.

This unfortunate side effect happens rarely, so no one thought it was a big deal. They suggested we wait it out—the ol’ “take two aspirins and rest” medicine. Enough was enough, and we demanded attention. Seven days later, all was solved with a

“blood patch.” They extracted some of Marley’s spinal fluid with a very long needle and injected it into the hole that was leaking. It was a fast but horrible procedure. Less than an hour later, the pain was completely gone. He leapt off the gurney, slapped his baseball cap on his head and defiantly strode out of ER, wanting nothing to do with hospitals ever again.

Drew, Cindy, and I were beside ourselves. We were outraged that the anesthesiologist hadn’t told us about this cure in the beginning and instead left Marley to writhe in agony for a whole week, after two previous weeks of torture. This whole situation was intolerable. The worst part was, apparently it was a risk that we agreed to when we signed the initial paperwork, so this jerk was able to charge us an astronomical fee to perform this unusual procedure to cure a rare problem that *he* created in the first place! When he fixed the mistake in just a few minutes...well, we thought his death would have been a punishment too kind.

Meanwhile, back at the ranch...Marley made me dye anything that was white except his hospital gown—he wanted to burn that one! We had a coming-home party around a bonfire, and his wish came true. He was healing fast and was back at school in no time. He was thrilled to be reunited with his beloved bike. But alas, a few weeks ago a shift happened: his energy began to decrease and the pain in his chest started to increase.

The Climax

The lung specialist was fast to react and scheduled another round of X-rays and yet *another* bronchoscopy. Poor Marley was scared to death and threw up all the way to the hospital (a 40-minute drive), hanging out of the passenger window of Drew’s truck. After an out-patient procedure, the lab results were quickly diagnosed. Our worst fear became a reality. In the superior lobe of Marley’s left lung, a cancerous tumor exists. Marley has lung cancer. Gulp.

What we know, so far, is that this type of cancer is called *squamous*, a common and slow-growing cancer found in older folks. None of the general rules of this type of cancer apply because of Marley's young age. Cancer tends to be more aggressive in youth. It looks like the tumor may have already *metastasized* (spread to other areas) because apparently, some of his lymph nodes may be suspect. We need more info and a new doctor.

We have an appointment with an *oncologist* (cancer specialist) on Thursday. We're looking into finding the best teaching hospital with the most experienced and knowledgeable multidisciplinary oncology team available in the country. No one on the West coast has dealt with squamous in a 15-year-old. We're not even clear whether we're looking at pediatrics or not. (Marley is young, but with an old person's disease.) We've been told radiation and chemotherapy are the standard operating procedures. We need more information and we need it fast! Marley's life is at stake.

Epilogue

This is where you come in. We need your help because, as you know, time never seems to stand still. Our lives are full to the brim right now even without this new scenario. There's no way we can deal with this on our own.

Drew and Cindy have been working their butts off. They've just bought a ranch in the Colestin Valley and are building their dream home. They are also busy maintaining two full time careers—Drew is a farrier (horseshoer) and Cindy is an electrical contractor. My career is a dream come true and is at a critical stage. My beloved boss/friend has just sold the Bathroom Readers' Press to a San Diego corporation. My co-workers and I have been sold as a part of the package. We've been given substantial raises, but our responsibilities have increased twofold. In short, Drew, Cindy, and I are under incredible stress and need all the help we can get, not only to obtain our dreams, but

to maintain our health and sanity.

Marley's little sister, Catie, needs some special attention too. She FEELS more deeply than anyone I know. When she doesn't have a safe arena to express, she tends to go into the labyrinth of Within. Unfortunately for her three parents, sometimes it's hard to be in two places at once, and some traveling may be on the horizon.

Drew and I split the custody of the children equally. Cindy and her X-husband have the same arrangement—two weeks on and two weeks off. This has been working great for many years. Both of our families live in the country and have gardens, land, and animals to tend. Neither family has a nest egg to fall back on. Thanks to my beloved boss, John, if all goes well, we'll be able to maintain and, hopefully, avoid falling into the black hole of debt. (John gave me the birthday gift of health insurance precisely one month before Marley got pneumonia.) As always, John's timing is impeccable and his gift...invaluable! Just imagine our woes if we had no insurance coverage.

Ta da!!!! Done!!!!

I love you all and can't thank you enough for your support,
Jennifer

*“The fearless are merely fearless.
People who act in spite of their fear
are truly brave.”*

—James A. LaFond-Lewis

LUNG CANCER 101

Know Thine Enemy

Taking a crash course in medicine felt much like dealing with the educational system. Drew, Cindy, and I had to quickly learn how to be effective advocates for Marley. We needed to understand the reasoning and methods of any procedure or prescription advised. We discovered that unless we asked questions, sometimes the professionals forgot to share critical information. The first step was to grasp how our bodies work and translate that information so even our kids could understand it.

In our bodies, we have trillions of cells, each cell containing approximately 140,000 *genes*, threads of chemicals known as *DNA*. It only takes a defect in one gene to cause cancer. One job of a gene is to organize the process of regenerating new healthy cells by replicating itself. Sounds simple enough—but when a malfunction happens, a copying error can occur. When the DNA mutates, the abnormal cells can multiply, which causes cancer.

It takes many genetic generations of mutation before cancer occurs. Once a cancer cell is born, it can take ten years of multiplying and grouping together to form a tumor that can be recognized by our current technology. This meant Marley may have been five years old when this disease took hold.

Lung Cancer

There are four types of lung cancer, each with their own set of characteristics. My father died from *small-cell carcinoma*. This is the rarest and nastiest of the four kinds, but it responds the best to chemotherapy and radiation. Marley had *squamous*, a *non-small cell carcinoma*. It usually affects people over 45 years old whose bodies have been abused by heavy smoking or carcinogenic chemicals. Generally this cancer grows slowly. In children, however, it can grow rapidly because a child's cells (healthy or not) multiply much faster than an adult's. (Ironic that my father—a long term smoker—contracted a non-smoker's cancer while Marley, with his virgin lungs, contracted squamous.)

FAITH IN DOCTORS

Who's on First?

While learning what the medical profession knows about cancer, we also found out how much they *don't* know; and their techniques of covering that up. We needed to learn their language so we could understand them. One thing we learned is that the more unsure doctors are about something, the more complex their words become.

When researching the method doctors use of “staging” cancer, we found clear confusion. This is supposed to be a way to identify the severity of the risk caused by a cancerous growth. The problem is, different kinds of cancers have specific staging systems, so it's like using three alphabets for one language. A brief explanation of this professional disorganization was found in *The Complete Cancer Survival Guide* (a must-read for anyone dealing with cancer). “The need for a standardized classification system has been addressed but not yet rectified.”

I'm not implying that all doctors are bad, but once we started to experience some of the holes in the medical system, like how easy it was to lose our X-rays or how difficult it was for them to admit their mistakes, we knew it was imperative to question what we were told and to research everything. We realized it could be a matter of our son's survival to take responsibility and make sure we understood what was going on.

The benefit of educating ourselves was not being at the mercy of doctors' sometimes antiquated knowledge, conflicting opinions, and limited communication skills. The problem with educating ourselves was losing respect for that which, at first, seemed so powerfully magical.

*“Those who are held wise among men,
and who search for the reason of things,
are those who bring the most sorrow on themselves.”*

—Euripides

UPDATING INFORMATION

High Speed

With every new day, people stopped me on the street corner or e-mailed me to say they wanted to be kept informed about Marley's health. Marley's Network was growing. Our lives had just been flipped upside down, and knowing what I was communicating to whom was a mystery.

In the beginning, when I wrote an Update Letter I had to assume the reader knew nothing of past events. This ended up working pretty well because, in reality, none of us really knew what was happening. Repeating some of the basic information helped me battle the stupor of shock and enabled me to comprehend the facts (or lack thereof).

*“If you can keep your head
when all about you are losing theirs,
it's just possible you haven't grasped the situation.”*

—Jean Kerr

Tuesday, March 16, 2000

Subject: “THE SCOOP ON MARLEY”

Dear Family,

As most of you know, it turns out Marley didn't aspirate on food after all. Rather, he has lung cancer—squamous, by name. Apparently the tumor reached a size great enough to irritate the lung, which caused the pneumonia. When the surgeon found the tumor, it was assumed it was a foreign object until the biopsy was tested and retested. The pros couldn't believe the initial results, so they waited several weeks for the swollen tissue to calm down enough to retest for accuracy. Last week,

he had his fourth bronchoscopy to grab another chunk of the lung to make absolutely sure it was indeed what they feared—lung cancer.

Cancer is rated by stages (with numbers; 1 – 4 and letters; A – D: the lower, the better.) Our local doctors think Marley’s cancer is pretty far advanced, but it’s hard to tell at this stage of the game. Their guess is 3A or B. It seems the tumor in the lung has already metastasized; in other words, has gone beyond the confines of the left lung. This makes it questionable as to whether or not it’s even operable. The only way for them to know whether major surgery can eliminate the tumor is to do “minor” surgery to investigate. The surgical procedure would be another thoracotomy. This is problematic, since they just did this massive procedure and his muscles and nerves haven’t had enough time to heal.

Our next step is to find out which hospital has the experience and technology to deal with a teenager with this kind of cancer. We don’t want to have three operations if they’re not all necessary. The suggested surgery and recovery will require a couple of weeks in whatever hospital is most suitable, and then follow-up therapy. We’re assured the recommended radiation and/or chemotherapy can take place locally. We’re swimming in conflicting professional opinions, and we’re not sure what river we’re in.

**Late breaking news! The doctor just called. Now they think they want to do the chemo and radiation *before* surgery. Hmmmm. Sure fills me with confidence that they know what they’re talking about. Not! Must hit the books and ask intelligent questions and find a doctor with experience.

Anyway, as we know more, we’ll let you know.

As my niece Selene once told me, “I love you up to God,”
Jennifer

PREPARATION

Questioning Everything

In the beginning stages of learning about cancer, the amount of research done on our behalf was extraordinary. We were learning everything from medical definitions to organizations that fund special needs. It felt useless to read most of the medical research because nothing seemed to quite describe Marley's case. The information about squamous lung cancer primarily related to older people who spent a lifetime abusing their bodies or being abused by environmental hazards.

I was swimming in statistics, questioning everything I had done that could have caused cancer to grow in my son's body. I had been handed hundreds of leads, and I was feeling completely overwhelmed by the amount of work required to follow up on just a few of them. I didn't know if I could deal. I wanted to run away. I wanted to wake up from this nightmare. I wanted to hide under the covers but knew my only course of action was to study hard, think like a detective, and be brave.

While reading reams of research, Drew and I came to the conclusion that none of the existing "rules" applied. Before us was a country-bred 15-year-old who didn't smoke anything and who ate mostly healthy food, prepared in healthy, loving homes. And yet, Marley had squamous lung cancer that from the get-go had metastasized to the lymph system. According to the books, Marley faced a wicked case of terminal high-class cancer, which meant he had about six months to live (give or take). But none of these books took into consideration that he was a headstrong teenager.

Marley's Way

Marley had an amazing way of looking at life. He seemed to fully understand what was going on, yet cared about only the facts—he didn't ask why, or what could go wrong—he just wanted answers to "what" and "when." All he cared about was the bottom line. I would have been scared shitless facing this kind of crisis, but he took it all in stride.

During the time we were scurrying around gathering information and making plans, Marley was basking in the attention. Everyone was being so nice to him! Marley hadn't been exactly easy to live with that year. He spent most of his time butting heads with everyone in authority. For Marley, the relationship that changed most beneficially was with his stepmother, Cindy, and he was glad of it. He was also excited about the possibility of traveling to a big city hospital, alone with me and Drew. From Marley's perspective, maybe having cancer wasn't so bad: Great things were happening because of it.

*“When written in Chinese, the word “crisis”
is composed of two characters. One represents danger
and the other represents opportunity.”*

—John F. Kennedy

I worried about this “childlike” view and tried to play psychologist, communicating in a way I knew he'd understand. Without beating around the bush, I found opportune moments to ask digging questions like, “So do you get that this disease is trying to kill you?” He'd shrug as I continued to push the “reality” river. “The doctors worry you have...like...’til Christmas to be alive.”

He'd flick a chunk of mud off his boot and matter-of-factly reply, “They don't know shit.”

My knee jerk motherly response was, “Watch your mouth, boy.”

Turning toward me with a straight face he'd respond with, “I can't watch it, when I can't see it!”

I'd roll my eyes, amazed that I'd walked right into his classic diversionary volley. He'd just smile and distract me by pointing out a red-tailed hawk and we'd both nod, appreciating its grace. After ten thousand such psychological inquisitions, I learned that Marley was very aware of his situation, but he chose to live in his own world, with its own rules of reality, and he had little time for anything else.

DECLARING PEACE

Forgive and Forget

My life was changing direction so fast that I was forced to use every skill I had, and needed to learn new ones as quickly as possible. Our 15-year-old had cancer, and it felt like we were on the front lines of a war. We knew what we were fighting, but we had no idea what weapons we could use, or how to wield them.

During the six years prior to Marley's diagnosis, relating with Drew and Cindy was respectful and cordial but a bit chilly. We basically stayed out of each other's way, respecting our individuality as two separate parental teams. When Laura and Catie were babies and Vanessa and Marley were in preschool together, it was as though Cindy and I shared all four kids. When Drew and I split up, my relationships with both Cindy and the girls had ended.

When Marley got pneumonia and we ended up spending 12 days in ICU together, there were some tense times. We were face to face, dealing with one gruesome procedure after another, in a very small space, under extreme emotional stress. It could've been ugly.

I bow down before the gods of grace in thanks that Drew, Cindy, and I were able to keep our past personal grievances and our present level of discomfort in perspective. Drew and Cindy respected my role as mother and I honored their roles as father and stepmother. We were thrown into leaning on each other for survival. At first it was like we were all wearing our clothes backwards—a little strained and uncomfortable—but we knew we were all in this equally and together. The only war to be fought was the one to help Marley live. We were all on the same side.

There were four children and three parents. Each clan had their clan and supporting network of friends. Leave it to Marley to unite us through extreme circumstances. I know it made all the difference in the world to Marley, having all three of his parents right there to catch him, and all three of his sisters there to discover their courage with him.