

“I’m Sorry to Tell You This...”

My Son Was Very Sick. Suddenly I Was Dealing With Brain Surgeons, an Ex-Husband, the White House Physician--and the Biggest Challenge of My Life.

By ANN COCHRAN

I’ve never been one to worry that too much happiness tempts the fates, and I’m well aware that rain falls on the just and the unjust. Still, I took notice of the stretch of contentment I’d been experiencing over the previous two years. I was happily married to Chuck, and our blended family of six had hit its stride. In addition to love and three additional grandparents, Chuck had given my two sons and me the gift of financial stability. Our house in Bethesda was surrounded by a picket fence that could be white if we ever hired someone to paint it.

On Sunday, October 22, 2000, I woke up in my cousin Silvia’s co-op in New York City, where I was visiting her and my 26-year-old son, Clayton. I called my voice mail at home, expecting messages from friends, clients, and my husband, who’d be checking in from a business trip.

“This is Dr. Castellanos from NIH,” a voice said. “I was assigned to review your son Harris’s MRI from the attention-deficit-disorder study. I’m sorry to tell you this, but it shows something of concern that needs to be addressed. It’s not a tumor. You can page me through the NIH operator.”

I called back and listened to the doctor explain my 13-year-old’s condition. Harris’s participation in the ADD clinical trial wasn’t altruistic. He was a “normal volunteer” mercenary, saving up for a PlayStation 2 video-game system.

While Dr. Castellanos talked, I strained to think up questions. Good parents ask good questions at times like this, but I was frozen.

I took notes while Dr. Castellanos explained that Harris’s brain contained an arteriovenous malformation, or AVM, a mass of abnormal blood vessels through which arteries connect directly to veins. It was bad news, he explained, because veins and arteries should

connect only through small vessels called capillaries.

“The veins and arteries normally have a bed of capillaries between them to regulate the pressure of blood flow in the brain,” he said. “AVMs can cause headaches and seizures.” Sometimes, he added, they lead to massive brain hemorrhages and death.

I heard Dr. Castellanos say, “find a good neurosurgeon.” And “Your son has probably had this all his life.” And--once more with feeling--“I’m sorry.”

I must have ended the call by thanking the man who was the bearer of bad news but also a potential life-saver. After all, we were lucky the AVM was discovered, weren’t we?

My fun, funny kid, who looked so perfect, had been walking around with a time bomb in his head.

Harris has rich brown hair and eyes to match. He’s tall and slender and is passionate about basketball and Britney Spears. A popular kid in perpetual motion, he excels at Instant Messaging and talking on the phone, often at the same time.

“All the girls’ mothers know Harris,” a woman told me at a PTA meeting. “All the girls are crazy about him.”

While I was in New York, Harris was with his dad, my ex-husband, Michael. They were staying at my house, because Chuck was away. An ex-husband in the house is an odd arrangement to some people--including my current husband--but it works for us. Harris can keep his social and sports commitments, and Michael can avoid driving back and forth between Bethesda and his Capitol Hill home.

My ex-husband and I alternately aggravate and ignore each other, but we know how to achieve a fragile

peace when important issues arise. If pressed, we can list a few characteristics we like about each other. I admire his calm demeanor in a crisis.

After I got off the phone with Dr. Castellanos, I called Michael. I said he could either tell Harris that morning or wait and we could do it together. After a couple of jabs at me for questions I'd failed to ask, he said he'd do some Internet research so he could explain an AVM to Harris. Because he'd had a medical education en route to a psychology PhD, I knew he'd do a good job.

"Okay," I sighed, "I'll be home by five."

"I've got to meet people back on the Hill before six," he said.

"Do you mean if I don't make it back by the time you have to leave, you'll just go? You'd leave Harry alone after announcing this news?" He said nothing, and I took a deep breath. I had to believe he wouldn't do that. "Good luck, Michael," I said. "Tell Harry he can call me on my cell phone or just wait till I get back--whatever he wants."

"Don't worry, Annie."

I hung up and looked toward heaven.

My cousin Silvia came down the hall with a cigarette and ashtray. "Something's wrong with Harry," I squeaked out. Then I cried for the first time that morning.

"Oh, God--tell me everything," she said. "Here's a cigarette."

I smoke only in New York. My cousin and my son Clayton both smoke, and they like the company.

Clayton arrived, and I started crying again. After he heard as much as I knew about his brother, he was sad but calm.

"Mom, don't worry," he said. "It may turn out to be much less threatening than you think. Wait till you know more before you jump to conclusions."

Hadn't he heard what I'd said?

"I'll drive you home and take a train back," Clayton said. "I need to be at a meeting in the morning, but at least I can see Harry for a little while."

I tried to refuse. "That's silly. I'm all right to drive."

"Of course he's driving you home!" Silvia said. "Don't be ridiculous--you can't drive."

When people describe navigating a crisis by saying, "I just put one foot in front of the other," I now know what they mean. In what felt like slow motion, I handed Silvia our theater tickets along with a phone number to cancel brunch reservations. I put one foot in front of the other, tying up loose ends.

I packed my clothes and jewelry and kissed my favorite cousin goodbye.

On this one day, I was glad my son smoked. I smoked, too, all the way home--with the Starbucks we got before we left Manhattan and with the Diet Cokes we drank on the New Jersey Turnpike. As we approached the Beltway, we broke out the Altoids. Harris tolerated knowing his brother smoked, but he had no clue I did.

When we walked into the house, Harris was smiling. "Clayton!" he shrieked.

I thought Michael had decided to hold off so we could break the news together, but Harris gave me a hug that told me he knew. Then he challenged Clayton to a video game.

Michael told me Harris had cried about the diagnosis but quickly moved on to more immediate teenage concerns.

After our brief talk, Michael left. It must be tough, even in normal circumstances, to leave the home of a son he loves. On this day, it must have been unbearable.

I shut the door behind him and glanced downstairs. Harris and Clayton were consumed by flashing lights and beeping. I dragged my bags upstairs and unpacked. Then I remembered a stash of Valium in the bathroom. Finally something to smile about.

It was dusk when Harris and I drove back after dropping Clayton off at Union Station. I was afraid to talk about the AVM--I still didn't know much. I started to say a few things in the car, but my effort to be reassuring while I was so shaken made the moment halting and uncomfortable.

Later, as Harris sat in bed, I told him I knew God had a plan for his life.

"Mom, what if this is it? What if this is God's plan for me--that I die now?"

"Impossible, Harry." Impossible for me, I thought selfishly.

The two of us prayed that God would heal him, and if that wasn't the plan, that he would guide us every step of the way. I ended as I always do when we pray: "Angels watching over you."

That phrase comes from an Amy Grant song and from the 91st Psalm, the most comforting in the Bible. I read it to Harris that night: For he will command his angels concerning you to guard you in all your ways. They will lift you up in their hands, so that you will not strike your foot against a stone.

On Monday, October 23--when I wasn't hanging onto door frames crying--I got down to business.

I began by calling Harris's pediatrician and our internist. Then I put out an e-mail to friends and family. E-mail became an instant support group, family reunion, and advisory board. Friends of friends, relatives of friends, and friends of relatives wrote back:

"We have friends at Mayo."

"You have to see Cogen at Children's."

"We're bringing dinner over on Friday night. What's Harry's favorite dessert?"

I was inept at group e-mail and found myself re-creating the expanding list every time I wrote an update. A friend suggested a Web site called CaringBridge.com, designed to track births, deaths, adoptions, and illnesses. I created Harry's page with a few clicks.

Great advice came from the sister of a friend who'd died of ovarian cancer: "Get a big fat notebook and write down everything. Keep a chronology. Bring someone with you to appointments. You can't listen, ask questions, and take good notes all by yourself."

There was no chance Harris and I were going to be by ourselves in a doctor's office during this ordeal. Harry's dad had a right to be present. If Michael came, I'd need my husband at my side. Chuck is a calm Midwesterner and an effective buffer between Michael and me. Last but not least, my father was coming up from South Carolina. On Halloween morning, we all went to the first consultation--with Dr. Lalgam Sekhar, a brain surgeon in Fairfax.

Brain surgeons are highly specialized, and Dr. Sekhar is recognized as one of the three best for AVMs in the country. TV's Chicago Hope based an episode on one of his operations.

The five of us looked so comical jamming all of our chairs into Sekhar's examining room. We didn't learn much, but it wasn't the doctor's fault.

Sekhar asked if Harris had any symptoms. I would have to repeat to doctor after doctor in the months ahead that he had none. With only an MRI to look at, Sekhar didn't have enough information. Harris needed to get a more definitive test, an angiogram.

Sekhar explained the two options for treating an AVM. The first, brain surgery, was drastic, but the AVM would be gone. The second was stereotactic radiosurgery with gamma-knife equipment--also known as gamma radiation. It amounts to one session of high-powered radiation. It's less invasive than surgery, but the cure stretches over one to three years as scar tissue forms around the AVM and cuts off the abnormal blood flow.

As soon as I got home, I set up an appointment to have Harris's head examined at Inova Fairfax Hospital.

The angiogram was frightening. Under local anesthesia, an artery is opened for a catheter that travels from the groin to the brain for a sophisticated x-ray. Harris did great, but he didn't like having to lie flat for hours after the surgery so that the opening in his groin would seal.

“What if it bleeds?” I asked a nurse.

“You don’t want that to happen. He could bleed to death.”

The nurse must have had a teenager, because she gave Harris a phone to distract him. As soon as one friend knew the number, the calls never stopped. I was afraid Harris’s laugh would bother other patients, but I couldn’t ask him to stifle it.

The angiogram displayed a surface malformation. That was the good news--it should be easy to reach and remove. The bad news was its location near the brain’s speech center, making the surgery more delicate, with significant risk.

When we arrived home that afternoon, Harris’s friends started coming over. Teenagers love drama. Girls cry, hug, bake, and write long notes on sweet cards. Boys joke and play video games.

All of the boys and some of the girls couldn’t get enough of Harris’s PlayStation 2. It had been released four days after we learned of the AVM--a miracle of sorts. We hosted frequent video-game marathons with pizza. It was noisy, but good noise.

While Harris was at school, I made phone calls; working on a solution held me together. Timing was a concern. How long was too long to make a decision? No one could say. How many opinions did I need? Enough to feel confident.

I continued my corporate communications work for two understanding clients. In every area of my life, I said no whenever I wanted to with no questions asked. It was a bittersweet freedom.

One frivolous thing I kept on my calendar was my volunteer job in the White House social office. At the White House, I had support, distraction, and holiday sparkle. I also had Betty Currie.

Betty and I had met years before, across the fence between my brother’s house and hers in Arlington. I decided to check in with her to make sure I got the names of the best doctors.

I didn’t need such a highly placed connection--the

same names pop up repeatedly once you start looking--but I was leaving no stone unturned. With my voice cracking, I summarized Harry’s condition.

“Where would the Clintons send Chelsea?” I asked.

Betty referred me to Dr. Connie Mariano, director of the White House Medical Unit, who spent time consoling and educating me. I was surprised until I remembered that unless she was traveling with the President and his entourage, she had only seven patients: three Clintons and four Gores. She’s also a mother.

“The Mayo Clinic is it,” Dr. Mariano said. “Let me call one of my colleagues.”

When we spoke the next day, I told Mariano I thought I should see specialists closer to home first and keep Mayo in reserve if I needed a tiebreaker. She agreed.

I called our insurance company to find out if we could even go to the Mayo Clinic. To my relief, the answer was yes.

When I married Chuck, I’d gained good health insurance, and I never stopped being thankful. As a single parent, I’d been to my share of lackluster doctors and psychiatrists who paid more attention to the clock than to my struggles with depression. I know health insurance causes anxiety for many, but in our case it was a stress-free zone.

On November 13, Chuck, Michael, Harris, and I drove to Johns Hopkins. Our first appointment was with radiosurgery expert Dr. Jeffery Williams, who told us that Harris’s AVM wasn’t a good bet for gamma radiation. At almost three centimeters, it was too big.

From there we met with Dr. Rafael Tamargo, director of cerebrovascular neurosurgery. He advised against brain surgery in favor of embolization followed by gamma radiation. Embolization is a procedure like an angiogram in which a catheter is threaded from groin to brain but with surgical glue then injected into the AVM to block off blood flow--reducing the risk of bleeding, often shrinking the AVM, and making surgery or radiation easier.

As we were eating lunch in the cafeteria, my cell phone rang. Dr. Kieran Murphy, the embolization doctor--interventional neuroradiologist, to be precise--could squeeze us in right then. I was glad I'd asked.

Dr. Murphy, a friendly type from Ireland, explained the benefits and risks of embolization. If something goes wrong, the patient can have a stroke, but Murphy said he'd never had any problem.

"You know type-A people?" he said. "Well, in this department, we're type-before-A. We are beyond careful. We cannot make a mistake."

He kept Harry's angiogram and MRI slides and said he'd discuss the case with the neurology team.

Walking to the car, Harris looked depressed. It was a lot to take in.

"I thought we wanted the surgery," he said. "I want to get it over with."

"We can't go with surgery if it could hurt you, Harry. I have to get some more opinions. It's time to send everything to the Mayo Clinic. You'll get the best care, I promise."

I rarely allowed myself to imagine the worst-case scenario. It was too much to bear. If Harris died, my soul would rip open and bleed for the rest of my life. I wondered if I'd fill his empty room with an adopted child from Romania or leave it a shrine to him and Britney Spears. Would I spearhead the Harris T. Clarke AVM Research Foundation and lobby to get every baby's brain scanned?

At my core, under all the layers of fear, I believed Harris and I would be together again someday. No one knows how much time we have on earth. It was strangely comforting to take the worst-case scenario all the way out, beyond death, to heaven.

As I collected names of brain surgeons, my big fat notebook was filling up. Tabs included three hospitals, 11 doctors, individuals who had neurological problems, parents of children with neurological problems, Walt Whitman High School, and a master phone list.

I needed someone to translate the medical lingo. I

enlisted the help of Dr. Frank Young, a former head of the Food and Drug Administration whom I knew through his role as director of adult education at Bethesda's Fourth Presbyterian Church. That church is close to my heart for many reasons; Harris is a member of its vibrant youth group.

On Thursday, November 16, I heard from both the Hopkins team and Dr. Sekhar, with different recommendations. Twenty Hopkins neurologists had reached a unanimous opinion: embolization followed by gamma radiation. Because the AVM was near Harry's speech center, they felt surgery was too risky.

Sekhar was equally definite: embolization followed by brain surgery.

They agreed on one thing besides embolization: a consultation with Dr. Ladislau Steiner, the grand master of gamma radiation. Steiner, a co-inventor of the treatment, practices at the University of Virginia.

Soon another doctor weighed in. Dr. John "Buddy" Connors, then head of interventional neuroradiology at Inova Fairfax, reviewed Harris's angiogram and said Steiner might have what it would take to radiate the AVM without embolization. One less procedure would be a good thing.

Fairfax sent its slides to Steiner, and Hopkins FedExed the other set to Mayo.

I was living on tiptoe, startled every time the phone rang. My Valium supply was low.

On December 18, Dr. Corey Raffel, a neurosurgeon and our Mayo point man, called with his recommendation: gamma radiation, no embolization. He scheduled our case to be studied at the next Mayo Clinic neurovascular conference.

Raffel explained everything he and his colleagues had observed from the slides. The AVM was small and superficial, with a well-defined core, but it was in a bad location. He said it wasn't only near the primary speech cortex--it was inside it.

How could such eminent physicians look at the same image and make such divergent comments? I never got a good answer to that.

I heard from Dr. Steiner that same day. He'd reviewed the slides and reports, concluding that his guidelines fit Harry's case.

"If a person has had no symptoms or problems, radiation is the way to go," he said. He thought a skilled neurosurgeon like Sekhar could remove it surgically and we'd never have to think about it again. "But," he added, "at what risk?"

A few days before Christmas, the pieces all fell into place. At the Mayo Clinic, the vascular conference, with "unanimity of decision," recommended radiation. Again, no embolization.

I felt calm. Presidents and kings go to the Mayo Clinic--why not Harry?

In what was typical of the proactive style of the Mayo Clinic, Dr. Raffel called Harris one day after school to make sure he understood its recommendation. Harris took the phone and strode off to his room. I had to hold onto a kitchen chair to keep from following him. I knew he had never changed his mind about wanting surgery, but when he came back to the kitchen he looked completely comfortable.

On January 23, Harris, Michael, Chuck, and I flew to Minnesota. Chuck told Harry his role was to be a peacemaker, just in case.

On Wednesday and Thursday, a multitude of meetings, appointments, and tests led to treatment day, Friday, January 26. When we met Dr. Bruce Pollock, Mayo's head stereotactic radiosurgeon, he told us everything about the treatment. The scariest part was the head frame they'd screw into the skull before starting the radiation. Pollock explained how they had tried hundreds of ways to make it easier, but it wasn't an easy process.

"Once it's done," he reassured us, "the rest of the day is boring."

Harry had one question: "Are you going to shave my head?"

"No," Pollock said, "but you might end up with a bald spot the size of a quarter from the radiation."

"Uh-oh, I have to make a call," Harry said. "A bunch of my friends are planning to shave their heads."

Gamma radiation is a high-tech affair that involves three specialists. Pollock, along with a radiation oncologist and a nuclear physicist, would plan the dose and pattern of the radiation with a 3-D computer model based on an MRI and angiogram they do after the head frame is on.

Harris started the treatment day at 5:30 AM. He had a Valium--just like Mommy!--and a nurse put in the intravenous port. That nurse told us he'd be with Harris every step of the way. Harris remained in good spirits until he was wheeled away from his room.

"Angels watching over you," I whispered into his ear.

The minute the elevator doors closed, I found it difficult to breathe. I remembered signs to the hospital chapel and hurried in that direction. Chuck caught up with me while Michael wandered off the other way. I regret that I didn't have it in me to be kinder to my child's father at that moment, but I just needed to get myself to a quiet place.

We turned a corner and entered a spacious Catholic cathedral with marble columns and stained glass.

"Protect my son," I prayed. "Keep him safe."

I appreciated being able to pray in such a jewel of a sanctuary. It fit the Mayo Clinic to have something like this. Mayo is made up of many buildings spread out over the town of Rochester. We were in St. Mary's Hospital, thus the Catholic chapel. In the Mary Brigh Building, I'd seen a beautiful prayer and meditation suite that had a modern stained-glass window, a fountain, and prayer rugs. Something for everyone was appropriate in a place that's a medical mecca to people all over the globe.

Harris returned to his room at 1 o'clock, awake and cheerful. It was all over but the urinating. Harris had to continue to lie flat until 2:30 because of the potential to bleed from the angiogram's entry point. Chuck and Michael returned in time to hear him begging the nurse to let him walk to the bathroom. She handed him a plastic container.

Harris ignored the bottle; he had a phone card to play with. He launched into a long series of calls to buddies, girls, grandparents, and Dr. Mariano. A few minutes later, the nurse stuck her head in and said, "If he can't urinate, we can use a catheter."

Between calls, Harris asked, "What's going on?"

We told him the nurse had offered us the assistance of a catheter team. Suddenly he was peeing into the bottle like a pro.

After Harris was released, we packed and said goodbye to the family we were staying with, Minnesota friends of friends back home. At Dulles we were greeted by Clayton and his girlfriend, Diane. It was so wonderful to see their young, beautiful faces smiling big love at Harry. Diane was startled by the small holes in his forehead from the head frame. She turned away so he wouldn't see her tears.

In the months after our return from the Mayo Clinic in January 2001, I was called to Suburban Hospital's emergency room twice. Harris had accidents that disoriented him and terrified the school staff and kids who were there. The first time, he was hit in the head during a basketball game; the second time, he fell while horsing around with a buddy in the cafeteria.

I recalled that as we left the Mayo Clinic, Dr. Pollock told us not to restrict Harris's activities. "He can't be made a prisoner to this thing," he insisted. Easy for him to say.

During our first visit to the ER, we were told it might be nice to have a local neurosurgeon. I added another tab to the big fat notebook: Dr. Zachary Levine. When we met him at Suburban, Harry and I both liked his youth and his bedside manner. His convenient office was a bonus.

At the end of ER visit number two, Dr. Levine looked at me and then at Harry. He scolded him: "You have got to slow down for your mother's sake."

During a follow-up, Dr. Levine said he suspected Harris might be having "absence seizures"--short lapses in consciousness in which the person appears to be staring into space for several seconds. If he was having seizures, medication might be necessary to

prevent them from feeding on themselves and multiplying.

In a quiet voice, Harry said, "Just tell my mom everything is okay."

The doctor said he couldn't: "You are here because you have an AVM, after all, but I can tell her--and you--that everything will be okay."

I realized the scar tissue from the radiation would take time to obliterate the AVM; I just didn't know there might be more to this marathon. I'd thought we were coasting toward the finish line. What did Dr. Levine mean? Everything will be okay after we journey through new medical territory? Seizures? More specialists?

Exactly. Our new territory was Washington Hospital Center; our new expert, Dr. Marc Schlosberg. The 48-hour electroencephalogram, or EEG, he ordered showed no unusual activity, which didn't prove anything one way or the other. With no proof, we'd simply plan for regular followups.

Harris spent that summer as a golf caddie at Camp Sankaty Head on Nantucket, in Massachusetts. On July 27, I got a call from an ER doctor at the island's only hospital. The doctor told me Harris had had a seizure but had reported never losing consciousness. A CAT scan showed no damage. Still, the doctor wanted to consult with our neurosurgeon because Harris confessed that he'd had one of these seizures before and hadn't told anyone.

Dr. Schlosberg prescribed an antiseizure medication, Tegretol, which Harris would have to take twice a day for at least two years. I was in denial. I didn't want him to have to take it, but I quickly learned that the choice was medication or the risk of additional, and possibly more serious, seizures.

I was scheduled to go to Nantucket the next morning for a midsummer visit, so I asked Harris to wait to take the first dose when we were together.

On Sunday night, Harris stayed with me at the luxurious White Elephant Hotel. The only bed in the room was enormous. It still seemed creepy to sleep with my teenage son, so I put a wall of overstuffed pillows

between us. Harris went right to sleep. I held his hand over the pillow wall. Tears kept rolling down my face. My poor kid. One more thing, one more thing.

After two sleepy days, Harris adjusted to the medication and returned to camp. A typical teenager, he often forgets to take a pill and has to be reminded. That's what mothers are for, right? Mothers also fly across the country at a moment's notice--I did when Harris had a football collision at camp last June.

Because I need to be available for ER calls, my must-have accessory is a tiny cell phone. I charge it with religious fervor and carry it wherever I go.

Someday I won't need to be connected at all times. A good report from Harris's January MRI lessened my anxiety. After the angiogram he'll have next January to bookend the Mayo Clinic treatment, we hope to learn that the AVM is no longer a threat.

Life will be normal again, someday.

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