

Range of Vision

By Catherine Klatzker

“Maybe it’s a little temporary nerve paralysis, from coming through the birth canal, which may be why her left eye looks smaller and doesn’t open up like the right eye,” Sam Smith, Jessica’s pediatrician, said at her newborn exam. “Let’s watch it.”

He moved his practice outside the city of Phoenix so we saw a pediatrician closer to home for her one-month exam after the New Year.

“What did Sam say?” the second MD wanted to know, when he could not pry Jessica’s eye open to examine it. He gave up trying to examine her and wrote what Dr. Smith had said in Jessica’s chart. I changed doctors again.

“Please look in her left eye; she’s never had a good exam and something is wrong,” I told her third doctor in Phoenix. The color drained from his ruddy face as he peered into Jessica’s eye. “I need to refer you to a pediatric ophthalmologist, there’s a new one in town. Let me see if he can work you in today. Nice young man, good doctor.”

Angus MacDonald, MD, in Scottsdale, Arizona demonstrated the anatomy of a normal eye with the large-scale plastic model on his desk for the third time to my husband Steve and me. When he was satisfied we understood, he explained Persistent Hyperplastic Primary Vitreous to us. It wasn’t as bad as the pediatrician feared when he saw a white signal where he should have seen red from healthy blood flowing through tissue. There was a mass in her eye; it was not cancer. Was she fussy? Did she cry a lot? *Yes*. She couldn’t tell us about pain. Would she ever see? Did she see now? *We didn’t know*. We discussed options. It began to feel urgent. She was not the healthy baby we thought we had. Jessica was in my lap; we had not lost her but we had lost *something*. We grieved a lost expectation as we searched for ways to help her. Steve’s shoulders slumped; he was pensive as we considered that we did not even know what questions to ask. I saw that Steve hurt, too, as I did.

We learned that Dr. Bill Scott in Iowa City had published promising results of a new surgery for many PHPV infants. Phone calls were placed, appointments made, I borrowed a winter coat and a sweater, Steve and I threw some belongings in a suitcase, I bundled up Jessica and we boarded our hastily ticketed commercial airliner. Our other kids, twelve-year-old Adam and two-and-a-half-year-old Sofia were in good hands at home with our friends Carol and Joe. On February 22, 1977 we departed for Iowa City Hospitals and Clinics by way of Minneapolis-St. Paul and Cedar Rapids, Iowa.

“Oh, a baby, a new baby, look!” a stewardess chirped. Steve and I glanced at each other, then looked away. There was a lump in my throat. Jessica’s head rested in the crook of my arm. I allowed my long brown hair to fall over my face as I pressed her tush closer with my hand. I clasped her intently as the airplane taxied down Sky Harbor runway in Phoenix and lifted off.

I thought about PHPV, Persistent Hyperplastic Primary Vitreous, and the secondary glaucoma our baby had; how I nursed and Steve and I took turns walking back and forth all night with her, unable to help her settle comfortably; how her eye was arrested in fetal development and a hard mass formed inside her eye; how it affected only her left eye, presumably not her right; how the previous thirty days had been an emotional roller coaster for us—the relief of ruling out retinoblastoma, cancer of the retina and a likely death sentence in 1977; then finding that she had a secondary glaucoma causing unknown pain. The surgery developed in Iowa City by Dr. Scott for PHPV babies showed gratifying results. Those facts were clear in my mind. I had tucked my feelings away where I needed them, far away, so they wouldn't interfere with what needed to be done.

The receptionist who welcomed us in Iowa City turned out to have been the college roommate of a friend of ours in Phoenix. Steve chitchatted with her and relaxed as she extended her warmth, the familiarity of almost-friends. I felt impatient, restless. I could not do chitchat well and I felt pressured to get on with it, to get moving.

I recounted the history of Jessica's left eye to the ophthalmology team. I did not speak of her right eye; that wasn't why we traveled half way across the country. Bill Scott, MD, was the PHPV expert. He was why we were there. We were shuttled among ophthalmic teams to imaging specialists with our baby. It was tedious. By afternoon we sat in a small exam room bunched together, Jessica on my lap, head on my knees, two residents holding her still. When she cried she shut her eyes tightly and wriggled against their strong hands. "I can't get any kind of image if this baby keeps squirming," the ultrasound technician complained. Our baby would have to be sedated and for that she needed an IV. Steve raised his voice. "This little baby has been poked and prodded and examined too much today to tolerate any unnecessary sticks. You get one try for an IV. Bring in your best person." A large vein protruded on the right side of Steve's forehead, his disheveled hair frizzed out of control, his button-down shirt was wilting. Everyone blanched as they turned toward Steve, then they backed off a little.

"Oh Kaaaaay," the resident agreed. He exited the exam room to make arrangements, to speak to someone else.

I half expected them to bring back a supervisor to ask us to step out, that we were interfering. I closed my eyes briefly against the beginning of a headache and I realized it would not surprise me to be told to *shape up or leave*. I wondered how we were supposed to behave. I was sure we weren't *supposed* to give ultimatums, to tell them how to do their jobs. My own mother always did as she was told, by everyone in authority and by anyone wearing pants. A nurse from another department entered to start Jessica's IV. I felt embarrassed for Steve, apologetic. The doctors were just doing what was needed. No one wanted to hurt our baby. He acted like they were hurting *him*, I thought. His voice quivered. He was losing it. He had been excusing himself periodically, leaving for ten to fifteen minutes at a time. I wondered if he was sneaking cigarettes. Later I learned he was going to the men's room to cry. I allowed the oxytocin released by lactation to calm me. The rest of my feelings were tightly shackled or shunted elsewhere. *Feelings are dangerous*. I focused on the facts.

Jessica's IV was placed on the first attempt. There was a knock at the exam room door while we waited for her sedative to take effect. "There's someone here to see you. Are you the Klatzkers from Arizona?"

A young man we'd never seen entered the room. "I'm the Hillel rabbi at UI. Your friend Barton Lee called me and said I MUST find you and come see you." Our good friend Barton, the Hillel rabbi at ASU in Tempe, Arizona reached across the miles to hold us. We

spoke for a while with this proxy friend; it was like extended family had found us. For Steve, something disconsolate was mitigated. “Is it OK if we go take a walk around and leave you here with Jessica for a little bit?” he asked.

I had a moment of anxiety that something larger than possible eye surgery was going on, that my husband was becoming emotionally unhinged for reasons I had not grasped. Then I put that thought aside. I told myself if I focused on the facts and didn’t allow my feelings to cloud my perceptions I could stay in control and be more useful to both Steve and Jessica. I didn’t know how to stay with my feelings—my old habit under stress was to keep them apart from me, to dissociate. I could split off without leaving the room. Steve returned from his walk calmer, less jumpy.

By the end of the afternoon we were told there was nothing to be done for Jessica’s left eye. It could not be salvaged. The ultrasound revealed a fully detached retina. There was also a large hematoma, a blood clot, creating pressure and obstruction inside her eye.

The ophthalmology team seemed finished, like they expected us to leave.

“Can we talk to someone like an attending doctor, if not Bill Scott himself, to understand what’s next?” Steve said.

We never saw Dr. Scott. We were ushered into Dr. J’s office. When the tall white-coated Dr. J entered, he did not smile or extend his hand. He barely met our gaze. Jessica dozed, sedated, in my arms. Dr. J sat stiffly behind his desk. An imposing library lined three walls, floor to ceiling. He tapped his fingers, looked at his watch.

“What do you want to know? Your child does not qualify for Dr. Scott’s surgery.”

“What happens next?” Steve asked. “Will she have more pain?”

An expression of distaste flashed across Dr. J’s long thin face. “Of course. There is a secondary glaucoma. It will progress until, at its most extreme, the eye will simply implode on itself. There is no more pain after that happens.”

Steve and I winced. Dr. J looked at his watch.

“I don’t understand,” Steve said. “You’re saying she’ll keep having pain until her eye explodes?” His voice and his hands trembled.

“Not explode. Implode,” he corrected Steve.

I wondered if he could be more condescending as he sighed and repeated that Jessica’s retina was detached, it could not be reattached, it was a blind, useless eye with a painful mass. “No, there’s no such thing as an eye transplant.” Dr J shook his head at the ignorance of such an idea and as his impatience mounted, Steve’s frustration escalated. It would have been a bonus to find kindness in Dr J’s training; I did not expect it. He had no use for feelings. I also was more than ready to dismiss Steve’s feelings, all feelings. *Feelings are dangerous.*

I interrupted. “I understand you cannot remove the hematoma or the vitreous and do any good for Jessica because her retina is detached.” My voice was even, clinical.

Dr. J nodded.

“Yes, that’s it exactly,” he affirmed.

“We want to know what’s next. It seems cruel to let her suffer what has been described as very intense pain.”

I heard Steve’s breathing, labored. I heard the ticking of Dr. J’s watch. Nothing moved. The baby was sleeping more soundly than we had seen since she was born; she looked very peaceful when she was sedated. Dr. J’s eyes were blue, I noticed, like ice. My own scrutiny was direct and steady. His gaze shifted from Steve to me and stayed with me, above my head.

“Some people choose to have the bad eye removed. We don’t know yet how good her right eye is—if she sees—but we know it does not have PHPV. She is already one-eyed. You can have her left eye removed—surgically enucleated. It’s your choice. It’s something you’ll talk to her doctor back home about. We’ve done all we can do here.”

He started to stand. He did not offer his hand. He had the grace to look uncomfortable. He exited his office first.

“That bastard,” Steve exhaled.

“He’s just an academic,” I excused him. I felt almost nothing. I held Jessica close in my left arm and I wrapped my right arm around Steve.

I did feel something. Protective. I felt that.

Jessica had a random, rare disorder, and by March in Phoenix when she was three months old it was evident there was something wrong in her remaining eye. For the first time the word “blind” entered my mind. *Blind?*

Her left eye, the PHPV eye, looked closed a lot of the time; it teared freely from the glaucoma; it looked opaque. Her right eye quivered and, try as I might, I could not get her to track anything in front of her face, in what should have been her field of vision. Steve and I dangled little mirrors that caught the light; we hung mobiles in sharply contrasting hues, black and white spheres. We learned that contrast was more eye-catching than flashy colors. We learned to separate sounds from visual stimulation, to not “give away” what we were testing as her hearing became progressively more acute.

I had read the baby books, taken Ashley Montagu’s *Touching* to heart; choked down nutritional brewer’s yeast daily with my prenatal vitamins; done the childbirth trainings, engaged in completely natural childbirth with no medication of any kind, and I was breastfeeding. There were simply no guarantees for happy healthy babies. Babysitters were shaken to find they could not calm Jessica’s crying spells when her pain was severe. So was I, not knowing if she was colicky or if it was worse.

The fragrance of orange blossoms drifted in the open windows of our central Phoenix sunroom. It was a balmy day. Only the yard birds could be heard. The dogs were asleep, Steve was at work, Adam at school, Sofia in pre-school. Jessica was not tracking; her right eye quivered rapidly, unable to focus. Yet again, I could not make eye contact. Gaze felt fundamental to our attachment, an intrinsic basic connection was missing. She was a cuddly baby, she felt physically connected yet psychically disconnected without eye contact, and I grieved that loss; it touched a desolation in me that had been dormant for many years. How could I really *be* with my blind baby? I couldn’t see her looking back at me. I felt utterly alone with that agony.

Of course there was a reasonable answer, I thought. I reached for the telephone extension near the couch where I held Jessica. I knew better than to expect anything at all from my mother. I could not remember turning to her for comfort ever, and I wondered when I learned that lesson. I telephoned her this time because I remembered that my mother found some resources when my youngest brother Paul was born with a cleft lip and palate. “Who did you call when Paul was born, Mom? Was it the March of Dimes or someone like that? Crippled Children? I need to know.”

“Is this for Jessica? About her bad eye?”

I flinched when she said *bad eye*.

“I think she might be b-b” my voice stopped. I forced myself. “B-blind” and I watched my self start to cry on the phone to my mother who was nothing if she was not emotionally unavailable. What came over me? Blind, blind, blind, I said in my mind, but saying it out loud about my baby was an almighty effort. My heart was on my sleeve and I felt disoriented.

“Oh, let me think,” Mom prattled. “It might have been Easter Seals; not the March of Dimes.”

Unexpectedly, it occurred to me, “Mom, you have been through something like this. Paul was your *baby*. How did you do it?”

“Oh, I don’t know. It’s not so bad.” Her voice was singsong, cheerful, false. Why couldn’t she be honest? She had no idea how to talk to me or be with me or hear me. I *did* know better than to expect anything from my mother, I thought.

I reached over the built-in shelves near the bar and I pulled out the phone book and started looking. It *was* the Easter Seals. “OK, Mom. I have a number here. That was a good suggestion. Yeah, we’re all fine, I’m good.”

I nursed the baby, put her in her car seat, and left to pick up Sofia at pre-school. When Sofia ran to hug me my momentary grief and helplessness were long gone; my feelings were shut down and I was in “action mode.” It was so different to have two babies under the age of three, compared to how Sofia filled my entire day as a newborn when Adam was in school. Mothers must always feel like they’re leaving someone out, I thought, as I wondered again about my own mother. I mostly found my way by *not* doing what she did, by trying harder to engage my kids, to know them.

I appreciated how good our lives were. Adam hurried home from school to push Sofia on the swing in our backyard; he had doted on Sofia since her birth when he was nearly ten. I treasured the luxury of staying home with my kids since my marriage to Steve six years ago. I did not take that time for granted. Every baby-moment with the girls was a reminder of baby-days I missed with Adam when his birth father died; they intensified my decision to wait as long as possible before returning to work. I did not want to miss anything.

By the time Steve came home from the independent Claims Adjuster office he managed, I had followed a chain of referrals from the Easter Seals number and found the Foundation for Blind Children in Phoenix.

Elaine from the Foundation visited us during the week and she was disarmingly normal, calming our fears. We became friends with blind children who showed us they were kids first. They normalized blindness for us. We learned to know Jessica, who saw in other ways. She amazed us when she reached for objects by sound, Adam’s old wooden block with the bell inside. We moved it, she found it, enormously pleased with herself, pounding it on the table, and we cheered.

Two months later at a party near Encanto Park Golf Course in the home of our friends Jim and Rita, our first pediatrician, “Call me Sam” Smith happened to ask after Jessica. He remembered her, even though I changed doctors when he moved his practice outside the city.

“Oh, Sam, you don’t know!” I said. I sipped my wine. “So much has happened.”

He raised his dark eyebrows. His facial expression was blank.

I talked quickly. “Her left eye has PHPV; it has glaucoma and the retina is detached. Her right eye has nystagmus and she does not fix-and-follow. They say she should see, but she doesn’t. She doesn’t track anything.”

“Does she have pain?”

Steve answered. He was drinking Jimmy’s twelve-year-old scotch. “Yes. She can’t tell us diddly, but she definitely has pain. She is five months old and she has never smiled.”

Sam’s expression was grim around his dark beard. The party was loud around us. He gestured for us to move in close to him. “Closer, come closer.” We crowded in.

“Get her left eye removed,” he said clearly and distinctly. “Get it removed NOW.”

Steve and I stared at Sam.

“I don’t even know if Dr. MacDonald has hospital privileges at St. Joe’s yet,” I said, “or how long it will take to get them.”

“I don’t care. Any first year resident can remove an eye. Work it out with his group. The sooner that left eye is removed the sooner she *might* start to use her right eye. It’s her only chance.” Sam was no longer partying and neither were we. His brown eyes were kind and he was dead serious.

Steve and I took turns at the hospital with Jessica, and he stayed with her the night before her early morning surgery to enucleate her left eye. I fed her and left for home with Sofia and Adam overnight, so I could see them off with their carpools before returning to Jessica pre-op. The night was endless, sleep did not find me and sounds from the back alley behind our house grew more disturbing as I restlessly tried to stop my mind from spinning my fears into physical pain. I imagined my baby unconscious, I imagined the scalpel lifting her eye and then I cringed and kept cringing. The sounds from the backyard continued and when I noticed a flash of light through the window, my heart rate quickened. My mind was already spiraling out of control and it continued its course—*someone is out there and will break in through the French doors and then what?* Heart pounding and hyper-alert, I tiptoed into the sunroom and peeked out. Through the oleander I saw flashlights going back and forth. I realized I could call the police. There were intruders and I should call for help. Adam and Sofia were in opposite ends of our U shaped house, sound asleep. The phone was in the other room. Could I dial in the dark? If I turned on a light “they” would see me. My heart raced, my pulse pounded, my breathing was wrong. If I could, I would scream. I froze.

I didn’t know how many moments later I heard water gurgling outside and I understood it was the irrigation system. The men were from the Salt River Project and this was the new scheduled irrigation time for our neighborhood. They were doing their jobs. When I let down my guard and allowed my feelings, my panic was right there, a membrane away. I felt foolish. I was shivering as I returned to bed, folded myself into a fetal position and found brief, vigilant sleep.

Jessica was five-and-a-half-months old when her left eye was removed. When she woke up post-op in her hospital crib, we saw her first smiles and we knew she was pain-free for the first time. We could not get enough of her smiles, of seeing her comfortable. We noticed other children in her pediatric ward who did not have parents with them and we found ourselves untangling their IV tubing, patting and comforting them when they cried, calling the nurses for them. They were from six months to two years old; they could not call the nurses for themselves. We saw much sicker children than Jessica and we appreciated what we had. So many wounded and sick children, I thought, tucking the scene away in my heart.

Jessica’s care was easy in the early post-op period. Her eye socket had a space holder in it and no one tried to fit artificial eyes in and out of it against her will while it healed. She

showed us her happier disposition as we continued to dangle shiny objects in front of her that she ignored, preferring sounds and tactile stimulation. Then Jessica very slowly began to learn to see from her low-vision right eye, which had sympathetically not functioned until the left eye was surgically removed. The exact mechanism of this was unknown, and I never found a satisfactory explanation, except that her pain might have inhibited the vision center in her brain. We would never know that, or why her remaining eye was low-vision.

She was partially sighted. Now that I accepted blindness, I was grateful she was free of pain and I was wonderstruck as she revealed piecemeal how she filled in the gaps of sound, touch, smell, memory, and partial vision.

One year after her trip to the Iowa City Hospitals and Clinics, she was walking on her own. She fell down and got back up, she tried everything. We applauded and cheered. I kept her barefoot most of the time, to feel the texture of tile, carpeting, concrete, wood planking, linoleum, wet mud and pokey grass. She memorized her environment. She didn't know what she could not see, so she couldn't tell us. We guessed, and we kept her out of harm's way as well as we could. At about eighteen months, secure in Steve's arms outdoors one day, she asked, "What's dat?" We looked around us.

"Tree?"

"No! What's dat?" Jessica repeated.

There were no large red and white Coca Cola trucks nearby—we knew she could see those.

"Flower?" There wasn't much else around.

She began to scream. "No, no, no!"

Finally she gathered herself, she had our attention, her right eye was bouncing back and forth and she screamed, "What's dat I HEAR?"

Steve and I both looked up, our mouths fell open and "Oh-Ho!" we laughed together, "That's a helicopter!" Her vision was still secondary.

We were the slow learners. Adam, Sofia, Steve and I were all stunned by Jessica's explosive nature, her impatience with our misunderstanding of how she experienced the world.

Jessica was eight months old. She was ten months; one year; two; and each time it took all my strength at home alone with her to hold her down, to care for the eye socket that housed her prosthesis, her false eye. False eyes are like custom-fitted and color-matched marbles with hollowed out backs. The medication was an ophthalmic antibiotic. In her early years Jessica was prone to frequent bacterial infections because of putting her hands, and later, her toys, food, sand, and whatnot in her eye.

My knee was on her kicking legs, my left arm pinned her arms and hands against her chest, she screamed, my right hand struggled against the moving target of her thrashing head and I needed a third hand to pry open her left eyelid, a two-handed job at best, even without having to restrain her. I needed to remove her prosthesis, her false eye, instill medication, clean and return it to her left socket. She fought with all her might, still screaming. *This felt like abuse.* Sickening feelings arose in my abdomen and throat. I felt ill, nauseated, and then numb. I only knew I had to do it, to care for Jessica, to keep her safe and well. Another well-defined feeling began to take shape: anger. "Just hold still!" I commanded between clenched teeth.

"Don't move!" I yelled. She cried harder and twisted to her left, obscuring her face.

I had the sensations, stomach pain and nausea, without any clear memory of where

they came from. I felt amorphous grief with no story, no beginning or end. I felt crazy. There was something dangerous going on as I dipped into my own priority to keep Jessica safe. I did not associate having unpleasant things done against her will to her by the one person who loved and protected her with anything personal in my own life yet. My own childhood was well and truly hidden, only now coming out in my body.

My grip tightened. *I can't do this*, I needed to stop but she needed the medicine. I wanted to force her somehow to be still, to not move, so I could just get this done. I felt a dark impulse to strike her. I had no free hands. I buried the impulse. I took a deep breath.

“Please, baby, please,” I softened my voice. I breathed deeply again. “Let’s do it quick so we can have a story.” I loosened my right hand; I stroked her forehead, her wispy, sweaty hair. She was still crying. This was going to take a while, and I had so much to do. I still felt sick. Horrified and sick. Those feelings were dangerous. The moment, the impulse, had left me shaking. The perfect storm of grief and guilt associated with Jessica’s medical diagnosis, and the struggle to protect her, triggered something old and forgotten in my own childhood. I saw myself in my child, helpless to me as perpetrator, and I knew that I was both.

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