

Tears of Hippocrates/Go Gently

John M Briley Jr MD*

Kim Bode**

I encouraged Kim Bode to allow me to include the piece she wrote for Hospice. It follows immediately after this article. Any of you who have lost a child would understand, once you've read her story, why it should be shared.

Tears of Hippocrates*

As little Khris' pediatrician I considered it a privilege to work with him and his family, but it was equally heart-rending to lose him and watch his parents work slowly through their loss. It hasn't been easy for them. But then, you readers already know that or you wouldn't be reading this publication.

I remember Khristopher Bode as never complaining about all the procedures I had to perform. Of course, he would look at me apprehensively, but never with dislike. And every now and again he would look at me with the merest hint of distrust, but never with distaste. While grateful for this gentle reception and forgiveness, my task was made all the harder.

I remember Kim, his mother, facing her problems alone while her husband frantically begged the Army for a transfer from Boston. I remember trying to be supportive, but as Khris' pediatrician I was more often than not the relayer of bad news. But like her son Khris, Kim never complained. I remember my own sense of frustration. I could do nothing more for little Khris, of course, but guilt can gnaw at a doctor's ego like a demon. Emotion—even unreasoning emotion—given half a chance, will always overcome logic.

Which brings me to the subject of guilt. Specifically, parental guilt.

As Oliver Goldsmith observed: "What art can wash guilt away?" Indeed, once guilt has been inflicted it cannot be taken away. Picture taking a feather pillow to a high mountain on a windy day. Imagine ripping the pillow open and scattering the feathers to the wind. Now, gather every single feather in the valley below and far beyond, and then stuff it with all its fellows back into the pillow. The ability to accomplish such a feat would be roughly equivalent to what it would require to remove a guilt which has been set in motion.

Unfortunately, Khris' parents had guilt laid on them, and, I am sorry to say, by my brethren in the medical profession. Hippocrates said, "At least do no harm." We doctors—and nurses—would do well to heed that sage piece of advice. If Hippocrates were alive today, he would shed tears.

What happened? Though we had decided to keep Khris comfortable in every sense, we had also decided, after much discussion, to allow Khris a peaceful and dignified death. If he fell asleep peacefully and didn't breathe, we would not resuscitate him. We agreed that our only caveat was that if he

was struggling for air we would suction him and give oxygen; if he was hungry we would feed him; and if he was thirsty we would give him fluids. And at all times, of course, he would be cuddled and loved. And he was. A lot.

Well, Khris did start to die peacefully in his sleep, but the nurse on duty pushed the "code blue" button. The emergency room crew crashed into the room and resuscitated Khris. Unfortunately, I was at the office at the time and couldn't stop them, and they didn't heed the pleas of Khris's parents. Khris, though weaker than ever, was now thoroughly frightened. And the parents were thoroughly upset. I was phoned and, along with the parents, told the emergency room crew to back off. I also delivered the message to the floor nurse.

Then, unbelievably, the head emergency room doctor told the parents: "You realize, of course, that your child will die?"

Although this was in no way true, the terrible words had been hurled, the underlying cruel and unfair accusation had been leveled, and the road to guilt had been paved. This is why Kim says, and says with great restraint: "Certain comments were made that only increased our feelings of guilt and horror." I marvel she can put it so mildly—but then, she is a lady.

To top it off, after Khris did die (peacefully) the nurses would not allow the mother to stay with her dead infant, even for a short while. She charitably refers to this as having "met with resistance from some of the hospital personnel," because she believes the nurses truly meant well. But for a long while after Khris's death Kim felt she had never had the chance to say goodbye to her son. More guilt due to our insensitivity. Fortunately, we now know that parents should have time with a dead child; just as we know that, like an adult, a child deserves a comfortable and dignified death. Any ridiculous and emotionally counterproductive medical-legal aspects to the contrary notwithstanding.

I can only hope all of us in the medical profession have also learned to "let go"—to remember that though we are expected to save lives, that how we handle death is as least as important as how we handle life.

Go Gently**

As though it were only yesterday, I can vividly recall the events surrounding the birth of our son Khristopher. After many long and hard hours, he was delivered safely it seemed.

I remember the absolute joy in knowing I had a son, but he was whisked away rather quickly because of the complications of birth. All I knew while lying in the recovery room was that I had to go down the hallway and count fingers and toes. The nurses would not allow me up—or so they instructed me. Hugging my i.v. pole for support, I took the long walk to see my son. Nothing was going to stop me.

Khristopher, a handsome, smiley little baby with deep blue eyes, had the temperament of an angel. So for months I

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** The bereaved mother

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thought his inactiveness was due to his gentle temperament. But when he reached 4 months of age I felt something was very wrong. It was.

After many terrible tests, including a muscle biopsy, Khris was diagnosed as having spinal muscular atrophy, a form of muscular dystrophy. The physician was straightforward with us; we would be lucky to have little Khristopher for 6 months. A year would be a miracle. It seemed from that day on his health went downhill.

Khris and I came to Hawaii to escape cold weather. My husband, who had obligations to the Army, was to follow later. So the early period for me was a time of extreme loneliness. Because of all of Khris' problems, complications, and the general stress of his illness, I felt alienated from the world around me. Who could possibly understand my problems or relate to my aloneness? My mother-in-law did the best for me she could: she called Hospice. Until my husband came from Europe, and beyond his coming, they gave me the support I needed.

At the age of 10 months Khris went into the hospital for the second time. He was getting weaker and this time we were told he could no longer eat; we had to learn to tube feed him 4 times a day. It was also becoming more difficult to perform the chest compressions so necessary to prevent mucous accumulation in his windpipe and lungs. But these maneuvers were essential for his life, so we took turns doing them. I believe it was at this point we realized that no matter how hard we fought we couldn't prevent the inevitable. We finally tried to accept reality.

We had thoroughly discussed the use of a respirator, but we decided it was neither for our son nor for us. So upon his third

admission to the hospital, just before his first birthday, we knew our remaining time with Khris was limited.

Khris was resuscitated once, and the procedure was unpleasant for him and the sight was unbearable for us. With the help of our pediatrician, we made the decision to keep Khris comfortable—no respirator, no heroics. We met with resistance from some of the hospital personnel; certain comments were made which only increased our feelings of guilt and horror. But we stayed firm.

Unfortunately, the bitter memory of the confrontation described by Dr Briley will stay with us the rest of our lives. Just 3 days short of his first birthday—Khristopher died. But he died peacefully, with my husband and me and our family by his side. My husband and I believe nothing in the rest of our lives will ever be so hard on us. Yet we would not have managed Khristopher and his illness in any other way.

Khristopher taught us a lot: love, courage, humor, gentleness, and he gave us strength. We were not ready for Khris to leave, but Khris was ready.

On the day of his birth, when I walked down that long hallway to see him, I never realized how long that hallway was going to be.

▲Time has laid his hand

Upon my heart, gently, not smiting it,
But as a harper lays his open palm
Upon his harp to deaden its vibrations.

—Longfellow

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