



**The
Kristin
Book**
(1987)

by
Robert
Nichols

and

**The Kristin
Book:
Update
2013**

by
Kristin, Carol, and
Robert Nichols



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A note about this update to *The Kristin Book*

March 10, 2013

Coffee House

In the next week or so, Carol, Kristin, and I are going to e-publish this new edition of *The Kristin Book*, inclusive of the original 1987 text (with a few minor corrections) and a new section to bring this work up to date. I just finished rereading my book (the first sixteen years of my daughter's life as a person born with Down syndrome), and I truly hope that the other patrons of this establishment—the texters and web-surfers and, Face-Bookers *et al.*—don't notice that I'm crying.

Or, on second thought, let them witness the honest emotions of a fuzzy-faced old man. It might do their youthful views of this world some good. Hey, maybe someone will lend me a hankie.

The original version of this book took me over ten years to write. I mean, we're not talking *War and Peace* here. With large print and a small format, it barely inked out at a hundred pages. As I strive today to avoid shorting out the keyboard of my laptop with tears, I recall why it was such a long process and, most importantly, why our little story is still relevant over forty years after the birth of Kristin.

Committing the deeply personal truths of a life is a wrenching process of memory, emotion, and soul-felt openness. This was an important story to tell and one that had to be told with a raw edge of honesty that was sometimes hard to face. I had to talk about my Carol's brush with suicide, my Kristin's encounters with a cruel and ignorant world, and my own nearly psychotic avoidance of reality that, for the first year or so, undermined my own usefulness both as a husband and a father.

And if that were all there was to *The Kristin Book*, then it would be a nice little work of limited interest.

But, I believe it is more than a sad and sentimental tale of a small family confronting seemingly impossible obstacles to happiness. Though in places it is sad, and I make no apologies about the role of sentiment in the telling of my truths; the story I tell is one of hope and humor in the face of difficulty. It relates as much today as it did decades ago to the situations all of us encounter in a life fully lived.

This is not a book about Down syndrome, though this chromosomal abnormality is certainly the central issue at its core. Our daughter was born with a terrible stigma attached to her pretty little being. According to the experts who counseled us those early days, she wasn't supposed to amount to much. And, believe me, as her parents we didn't have a clue as to how to give her the life we had imagined for our child. From

the day after Kristin's birth, when Carol called me at work from the maternity ward of the hospital and told me, "There's something wrong with our baby," through this morning nearly forty three years later when Kristin heads out into her world, a lovely lady whose life of grace, good heart and spiritual magic blesses any who have the good fortune to encounter her, this is a tale of love, humor and compassion relevant to the humanity of us all.

Some years ago, I was having a beer at a ragged old high-mountain tavern when, in a roar of a voice, my bear-sized buddy Norm Simmons bellowed at me, "Nichols, I've got a problem with you." My initial reaction, of a sort that has served me well over these years, was to make a run for it out the back door. But I didn't. Norm was a heavy equipment operator, truck driver, and renowned barroom brawler loved and feared by many. I took a chance that my friend wasn't too likely to kill me.

I stepped down to his end of the bar and said, "So, what's up, Norm?"

The large man lithely spun around and stood up. He reached into the pocket of his coat and pulled out a worn copy of *The Kristin Book*. "Hell, Bob," he said as he put a big hand on my shoulder, "your damned book made me cry."

I just grinned. "And . . .?" I asked.

". . . and laugh, and feel a bunch of stuff like that."

Yeah.



The Kristin Book (1987)

Introduction

The power of these words originates in the power of my own rage and sorrow and joy. This book is the product of sincere, poetic perception of a life-deep situation which, at times, has been exceedingly difficult to face.

This is the story of the first sixteen years of my daughter's life and of the influence of those years upon the lives of her parents. It is also a book about compassion and the world.

Kristin is a fine and pretty young lady who, early in the moments of her precious life, was described as being a "non-human," a "vegetable."

Her congenital condition, Down syndrome, is not particularly rare. Kristin Marie Nichols, however, is an extremely rare and truly exceptional human being.

I did not write this book for a limited audience. It was my purpose to communicate to many people. I think my words will benefit parents, teachers, doctors, and especially the mass of us who normally spend our days out on the gawking edges of the whole issue of physical or mental "abnormality."

The Kristin Book is neither maudlin, nor is it bitter. It is intended to be an articulate and honest expression of an important message.

The Beginning

Kristin lost all of her hair when she was three years old. She was beginning to lose her eyebrows too when, perhaps touched by the severity of Their cruelty in the dulling of her face, the Gods relented in this minute way and allowed them to regrow. The Gods had already worked Their dark magic upon her mind and upon every cell of her body. I wrote a poem about it.

The Manila Folder

*They had your future in a manila folder labeled "Kristin Nichols."
We saw it on a Denver summer afternoon.*

*It was deep in the thousand-celled, honeycomb clinic,
where people in white robes work
and people in street clothes wait.
“You see,” said the man of medicine
(kind and with eyes deep into the pathos
of helpless knowledge),
“on the twenty-first set there are three chromosomes instead of two.”
And we saw the blotches—carefully patterned by nature;
sorted, magnified
and printed by man.
“You see,” he said
“all of the pairs and one triplet—
she’ll never be
a computer programmer,
or a secretary,
or a lady taxi cab driver.”
and then we left, you were so small—
a dozen days or so at most—
and already we knew you’d never like
James Joyce.*

She was four months old and I was attempting seclusion in a corner of a teachers’ lounge. It was her first autumn and I was just starting to realize how much she was affecting me. (We have known many autumns since then, and the realization is still growing.) A bone-faced, blond-haired lady came over to me and, with practiced smile and tone of voice, leaned into my space and said, “Mr. Nichols, it was God’s Will.”

“Oh . . .” I said.

“Yes, and it’s wonderful, I’m sure. Sometimes it is not for us to understand His Wonderful Ways,” she said, almost in whispered song.

“I understand His ways,” I said in an even voice while staring through her joy-dulled eyes and directly into her empty head.

“You really think that you understand Him?” she asked with one of those pious, near smirks so common to those who have deemed themselves the bearers of the only truth.

“Yes,” I assured her, “I thoroughly understand Him and His Wonderful Ways.”

“Oh, please, Mr. Nichols, enlighten me.”

“It’s quite simple. Your God is heartless.”

That was a long time ago. Long before the afternoons when Kristin would get home from school with tears dried on her cheeks and tell me, for maybe the third time that week, the mean kids had pulled her wig off. A long time before I had laughed at her

funny words and cried with her pretty heart. Long ago—and I meant exactly what I had said. I was young and Kristin was just a soft, warm little being who had been terribly abused by fate. I loved her because she was my baby girl. It's years later now and I still love her as my little girl; but, I also love her because she is my friend and companion. I don't think a lot about Him, of Them, or any of the other What-Have-Yous that supposedly create and then piece-by-piece destroy us in Wonderful Ways. I think about her, and when I do, I forget about Causes and rejoice in the effects. I am constantly filled with dichotomous feelings of joy and sorrow and Kristin's very being which, when truly appreciated, mocks and, for the most part, negates the sorrow.

And, still, there is no denying the fact that she got a rotten deal. I haven't begun to get over it; she never will. It would be quite easy to become lost in such obsessions—very easy—were it not for the fact that; with such limitations, such hindrances to human accomplishment; she is yet a wonderful human being. One of the best I've ever known.

Sometimes when the ever-present rage asserts itself within me and I am shaking and whispering the fervent oaths, Kristin places her hand on my shoulder and says, "It's okay, Dad."

And sometimes it really is.

The Crib

I drove seventy miles per hour, ran stoplights, slid around corners, and cursed the seconds, which sped on ahead of me—impossible to catch. We didn't have a lawn. The front yard was dirt and gravel with large cottonwood trees. The little house was white and sat by itself a mile from town, with acres of green alfalfa fields and distant red cliffs surrounding it. The screen door was locked. I knew it would be locked. It was logical she would have locked the screen door. I ripped the door open, leaving the hook dangling from the eyelet screwed into the doorframe. I burst into the living room and saw my wife, Carol, sitting calmly at the kitchen table. The room was silent, except for the tingling of a tiny bell from the bedroom as Kristin pulled the red satin ribbon that moved the tiny hammer and struck the bell, which hung from the railing of her bright red-and-white crib.

Carol was still talking on the telephone to John. I had stopped at John's apartment for a beer and had called her, and then realized that she was probably trying to kill herself. John had known, too, and kept talking to her as I had rushed home. I was in time, but somehow, it seemed so hopeless that I just stood there for a moment

staring at the pieces of broken glass lying on the table and the dried, dark trickles of blood staining her pretty arm as she joked with John and avoided looking at me.

We hadn't brought Kristin directly home from the hospital. It is wise not to be embittered by the unintentioned malice of the ignorant, but it is difficult to arrive at an objective viewpoint concerning a human life and love. The doctor had said to think about having other children. The doctor had said this child was imperfect and should be institutionalized as soon as it was old enough. The doctor used words like "severely," and "institution," and "it." I think a nurse was the first who used the word "vegetable."

The doctor talked to Carol and said the words that haunted her pretty being for years and whispered death wishes and insanity throughout her conscious and subconscious existence. He said, "Think of *it* as being dead." He said to Carol, and with only the best of misguided intentions, "Think of *it* as being dead . . . a *non-human* . . . put *it* in the State Home and have another baby as soon as possible." (Visions of monsters; nightmares of hideous inhuman creatures; a non-human baby borne of her flesh.)

There were friends with awkward good intentions and acquaintances with careful greetings. And from unexpected corners of our world came the closeted parents of children who had been institutionalized or had been taken in by grandparents. Their eyes told us that their hearts were torn when they spoke to us, and yet, they knew it was right for them to speak. Some of them were near strangers; some were longtime friends—people at work, people who barely knew us. Many spoke to us and they all said the same thing: Put her into the State Home.

If we had only been watching them closely. If only we had not been quite so willing to accept their words. If only my mind had not been so ready to run—I would have seen in their faces that they were lying to us and, of course, to themselves.

In Grand Junction, Colorado, there is the State Home and Training School where people like Kristin spend their entire lives under the supervision of underpaid personnel and the watchful eye of closely budgeted care. The doctor had said Kristin should go there. I talked to the people at the Home on the afternoon of Kristin's second day and they told me she would have to be at least two years old before they could take her. The man to whom I spoke recommended that we contact the Department of Social Services to arrange for foster parents until she was old enough to be placed in the institution for the rest of her life.

"Sure," I said.

"Carol, they say we probably ought to give Kristin up," I said.

She knew. She had heard the whispers of nurses, seen the eyes of those who avoided her. When she asked her doctor what was wrong with Kristin he had, with all of his well-meaning medicine, turned in silence and left the hospital room.

Already they had given Carol a shot which prevented her breasts from producing milk.

* * * *

Carol stayed up all night making curtains for our old Dodge station wagon. I went to Grand Mattress the next day and bought a large piece of scrap foam. It was July. Kristin was a month old and living with foster parents across the valley from the white house and us. We were getting out of town in an attempt to make everything feel better. We would stay at campgrounds and sleep in the car. It would be just as it had been for the previous four and a half years of our marriage. We rafted on the Green River in Utah; we canoed on the Flaming Gorge Reservoir in Wyoming; we camped by Bear Lake in Idaho; we wandered through the International Food Bazaar in Seattle and rode to the top of the Space Needle; we rented a one-room cabin on the Olympic Peninsula where the Pacific Ocean ceaselessly explodes upon the rocky shoreline, and where eerie inland valleys are ever grey and pale-green in rain forest mist.

"I can't sleep with the light on," I had said as we lay in the back of the station wagon on the foam mattress with the curtains pulled shut. It was the first night of the trip and she had our six-volt lantern burning.

"I can't be in the dark," she said.

Later by the ocean in a seven-dollar cabin with the one light hanging from a wire in the middle of the room burning all night as we continued a week-long rummy game into the tens of thousands of points. Of course, we knew something was terribly wrong. We never spoke of Kristin. I seldom consciously thought of her; Carol seldom thought of anything else.

A few weeks were expended and we returned home. I was a teacher and still had another month before I had to go back to work. My parents came from Virginia to visit us. We sat out under the huge cottonwood trees in the front yard at night watching for falling stars and drinking beer. One afternoon, Carol and I went to the foster home and picked up Kristin so her grandparents could see her and hold her for a while. We still have pictures of that afternoon and our faces are tight with sorrow and loss. My father's gentle, honest eyes speaking from within the stoic exterior of his strong being. My mother's magical, loving hands; the glow of her glad face; the inference of her life-long heart upon the moment of the visiting granddaughter.

I took Carol to a dentist the last week of August. She went into the office while I stretched out on the foam pad which we had left in the back of the car and drifted off to sleep. Sometime later, I was startled by frantic tapping on the window. A lady from the dentist's office told me that something was wrong with my wife. I found her in a semi-conscious state, lying in the reclined dental chair, muttering the name of our child.

We still laugh about how ridiculous it was for an intelligent, well-educated participant in the Twentieth Century to hyperventilate while having a tooth filled. The

unfortunate dentist had been in practice for only a few weeks at the time and seemed to be on the verge of taking in a little extra oxygen himself.

It's strange what things can become the catalysts of truth. If Carol hadn't had a toothache, it's hard to speculate about how long we would have continued the farce of our separation from Kristin. Sometimes I think about myself and what an empty life I would have had if it were not for Carol's toothache, Carol's heartache, Carol's honesty. If it weren't for her obsession that kept us up nights with lights burning and cards shuffling, and that finally put her into dental-hysteria; I could have spent my whole life apart from my child—and also apart from my own truth.

There are so many mistakes to be made in a lifetime. Fortunately, some can be rectified.

The next day we began repurchasing baby equipment and made arrangements for bringing Kristin home. We stayed up all night painting the used crib I had found at Goodwill—neither of us could sleep.