

# Prologue



Craig William Sampson, weighing a mere five and a half pounds, made his entrance into the world three weeks ahead of schedule on September 23, 1966, in Lima, Ohio. A few days later, I, his mother and the narrator of this story, and my husband, Bill, were given a tentative diagnosis of his condition, called Mongolism at that time (a term which has, mercifully, been replaced by Down syndrome). Down syndrome is a congenital disorder caused by the presence of an extra chromosome in which the affected person has mild to moderate mental retardation. In Craig's case his condition was diagnosed as translocation, a chromosomal problem in which an extra chromosome is attached to another chromosome in each of the cells in his body. This occurs in only 2-3% of children born with Down syndrome.

I immediately began to search for literature and support groups that would both enlighten and encourage us regarding this disorder. Dale Evans Roger's delightful little book, *Angel Unaware*, was the only reading source available other than technical books. Parental support groups, unfortunately, were all too often a pooling of negative emotions regarding their children.

As time went on I began to sense a need to share the story of Craig's journey in this life with others with the thought that some parent, relative or friend of a special needs person may either relate to or be encouraged by our experiences. My purpose in writing these memoirs is not only to uplift others, but also to illustrate the sustenance and support that we have received from our families, our friends, our neighbors, and especially from God. Our faith is the guiding force and strength of our lives, and it is inseparable from who we are. We make no apology for that; we want to share the love we have enjoyed. The sadness that enveloped our lives on September 23, 1966, has disappeared. You will feel the transformation as you read along. In place of sadness we have come to realize that God gave us a special gift. Craig brings love and humor to our home on a daily basis. We are forever changed because of him.

## *Chapter 1*

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# The Arrival



The morning was overcast and gloomy, and as the two doctors approached my hospital bedside, I sensed a foreboding. When the general practitioner and the pediatrician gently broke the news that our three-day-old baby, for whom we had waited seven years, displayed many signs of Down syndrome, my mind seemed to freeze, unwilling to accept what was said, or to give up our hopes and dreams of a healthy child. A panorama of those dreams flashed through my mind—our son growing, speaking, achieving, attending college, and getting married. Somehow I had to accept the fact that these milestones might never be reached.

Yet our loving God, who promised never to forsake us, had carefully prepared my husband, Bill, and me for the special son He was placing in our home. Both of us had been raised in Christian homes and as children had come to believe in Christ. My personal goals in life had always been clear-cut: first, to seek the partner who was *the one* for me; second, to establish a home based upon Godly precepts and service; and third, to train our children “in the way they should go” (1). Our faith was, still is, and always will be an integral part of our lives. God allowed

many tests and Master-instructed us before He was satisfied that this home was prepared for one of His more precious gifts.

In the spring prior to graduation from high school, Bill and I began dating. After graduating and starting our careers, we became aware the two of us shared similar priorities and purposes in life. On a cold, crisp Valentine's Day in 1960, we were married in the presence of many friends and family in a church wedding in Ohio.

Nearly seven years passed before the Lord began to fulfill the third aspect of my goals. After dealing with infertility issues, correcting minor medical problems and experiencing the disappointment of several miscarriages, the news came once again that we were to become parents. Elated beyond measure Bill and I began preparing for the child that was to bless our home. Then at the first trimester of my pregnancy, fear struck as I was rushed to the hospital in an effort to avoid another dreaded miscarriage. I shall never forget the comfort and gentle understanding of our doctor as he bent over me and explained that the chances of carrying this baby full-term were now only twenty-five percent. Even in the turmoil of those moments, however, God's promise that with Him "all things are possible" (2) filtered through the confusion of my emotions and filled me with His peace.

Wondrously, the crisis passed and I was discharged from the hospital. The succeeding weeks were a beautiful interlude of peaceful rest in anticipation of the birth of our child. How nice it would be if all mothers-to-be could experience such an interval before the arrival of their children—a time to prepare for the truly awesome tasks ahead.

On a beautiful fall morning in September we made the momentous trip to the hospital. By evening we were parents of Craig, a sweet 5-1/2 pound boy, born three weeks prematurely. Family and friends who had been praying faithfully for several months shared these happy first days with us. It seemed like a culmination—an end-of-the-journey experience. Little did we

realize that it was only the beginning of an uncharted trip! Being a brand new mother, how was I to know that my tiny baby's constant, deep sleeping, his inability to take nourishment, his limpness, and general lethargy were warning signs to the doctors and nurses?